It sounds really easy, but putting it into practice is hard: design implications for developing a DBT Mindfulness digital health intervention for people with Borderline Personality Disorder

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August 2019

Abstract

Mental health disorders (MHDs) are the main cause of disability worldwide. Improvements in MHDs are possible with correct treatment, but retention is challenging. Therefore, inexpensive, accessible treatments which aid adherence are critical. One approach is to use a Digital Mental Health Intervention (DMHI). However, sustained use of DMHIs and clinical results have been less positive than hoped. Lack of retention may result from insufficient attention to end-user needs, leading to poor usability. One answer is to include patients with a MHD in a user-centred design (UCD) process. UCD aspires to deliver DMHIs fitting user needs, with the intent of improving engagement, potentially increasing retention and effectiveness.

This research uses UCD to create a User Requirements Document (URD) for a DMHI delivering Dialectical Behaviour Therapy (DBT) Mindfulness skills, investigating how UCD should be modified for this vulnerable user group. It comprises four studies: a scoping study with non-clinical secondary proxies; a qualitative study of DBT clients' and clinicians' experience of DBT skills training; detailed creation of the URD; and, a Delphi-type study validating the URD with DBT clinicians.

The qualitative study mapped skills training as a journey with five stages; the URD formalised this, and included personas and scenarios. In the validation study, the UX map/scenarios were unproblematic, but personas were polarising. Some clinicians found them representative of clients, others considered mindfulness acquisition portrayal was unrealistic. Following amendments, consensus was reached after two rounds.

This research contributes to knowledge of UCD with users with a life-threatening MHD. Key contributions include analysing the extensive methodological work needed in this challenging context, documenting the necessary UCD amendments, and presenting the benefits and value of such in-depth, demanding work. It provides an important resource for future UCD in difficult, challenging contexts, significantly allowing vulnerable users a voice in the design process.

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Acknowledgements

Many people have been drawn into this undertaking and I cannot express enough gratitude for all the help I've received along the way. It's been a long and very difficult journey at times, and few people write a thesis in a vacuum, but I know that without the wonderful, kind, generous help and support of friends, family and others, I wouldn't be writing this today. It's a long list of people I have to thank and I feel very blessed as I write this to have and have had such wonderful people around me.

There are a few people who started the journey with me who are sadly no longer here: my sister Vicky who died in 2015; my dear friends, Simon Poulding who died in 2016, and Jo Pugh, in 2023, all died much too young and are very much missed. Without Simon's help and support this journey might not have been started, without Jo, the EngD would have been a lot less fun; my Uncle Mike, who died in 2022, who with my parents made some of the last 5 years possible with financial support, love and everything else, thank you so much for your help and generosity in making the last part possible.

To all my York friends, who have made this journey bearable in so many ways, with kind words, food, wine, beers, honesty, tech help, laughter, patient ears and so much more, I hope you know how much you're appreciated: I was (and still am) very blessed to have such fantastic people around me (special mention to Lucy, Rob, Fi, Ian G. and the Johnson-Sharps).

Thank you to my supervisor, Professor Paul Cairns for his helpful insights and encouraging words, I couldn't have done the last part without all of his help. Thank you to my examiners, Dr Connor Linehan and Dr Jo Iacovides, for their helpful words and advice. A big thank you is also due to Dr Jeremy Jacob for his help, encouragement and optimism over many years. A huge thank you to the Computer Science support staff, both technical and administration, who have always answered questions and helped me as much as possible. You are the backbone of the department, and without you we'd be lost.

I'm grateful to the Retreat York, for sponsoring the EngD and to my supervisors from the Tuke Centre, Dr Julia Coakes and Dr Mark McFetridge, for all their help and passing on of knowledge. To all my participants who generously helped me out with my three studies, thank you all again for your time and expertise.

To Gianni for his patience and kindness, for looking after me so well in the last months, for all the wonderful food, calm words and endless love; and to my dog, Scooby, for bringing delight and chaos into my life in equal amounts.

Finally to my beloved son Joe, who gives everything meaning: thank you for being a sympathetic ear, a wonderful travelling companion, a calm voice of reason and a daily inspiration. Love you to the end of the universe, which as we know...

Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

Glossary

ACT	Acceptance and Commitment Therapy
APA	American Psychological Society
BACP	British Association for Counselling and Psychotherapy
BPD	Borderline Personality Disorder
CBT	Cognitive Behavioural Therapy
CFT	Compassion Focused Therapy
DA	Discourse Analysis
DBS	Disclosure and Barring Service check for a criminal record
DBT	Dialectical Behaviour Therapy
D(M)HI	Digital (Mental) Health Intervention
DEAR MAN	DBT acronym for one of the Interpersonal Effectiveness skills (used for gaining one's objectives in a respectful way). **D** – Describe, **E** – Express, **A** – Assert, **R** – Reinforce, **M** – (be) Mindful, **A** – Appear Confident, **N** – Negotiate.
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
GIVE	DBT acronym for Interpersonal Effectiveness skill (used for initiating and maintaining personal relationships) **G** - (be) Gentle **I** - (act) Interested **V** - Validate **E** - (use an) Easy manner
HCI	Human Computer Interaction
Health	Health Sciences (literature)
IPA	Interpretative Phenomenological Analysis.
IRAS	NHS Integrated Research Application System
MBCT	Mindfulness-based Cognitive Therapy
MBI	Mindfulness-based Intervention
MBSR	Mindfulness-based Stress Reduction
MBT	Mentalisation-Based Treatment
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence
NREC	NHS Research Ethics Committee
PD	Participatory design

Glossary cont.

RCT	Randomised controlled trial - a methodology widely used in clinical research
SFT	Schema Focused Therapy
SMI	Serious Mental Illness
STEPPS	Systems Training for Emotional Predictability and Problem Solving
TA	Thematic Analysis
TAU	Treatment as usual
TFP	Transference Focused Therapy
UCD	User-centred Design
URD	User Requirements Document
UX	User Experience
WHO	World Health Organisation
Note:	Depending on the perspective, the literature refers to people with a diagnosis of BPD who are undergoing therapy as clients or patients. Clients and patients is used interchangably throughout this thesis. The Retreat used the terminology *client*.

Chapter 1

Introduction

You can't stop the waves, but you can learn to surf – Jon Kabat-Zinn, 1994

A mental health disorder causes thoughts, emotions and mood to be disrupted, leading to problems in coping with daily life, work and relationships. Mental illness has a devastating effect on individuals and society. Mental illness and substance abuse are the main cause of disability worldwide (WHO, 2019), with around 800,000 people every year dying from suicide. Great improvements in mental health disorders are possible with the correct treatment, including pharmaceutical interventions, as well as different psychotherapies and psychological approaches. However, it can be challenging to retain people with a mental health disorder in ongoing treatment (Dixon et al., 2016). Post-financial crisis austerity politics have put additional pressure on UK mental health services financing (Cummins, 2018). Therefore, as awareness and diagnosis of mental health disorders increases, and health budgets stagnate or decrease, it is important to find treatments that are widely accessible, suitable for the task and inexpensive.

Digital health interventions (DHIs) aimed at improving mental health (DMHIs) have become increasingly common in the last decade, with the widespread use of mobile phones and other internet-enabled technologies (Murray et al., 2016). DMHIs can be used for self-training and supplementing existing therapies, using applications (apps) to help eating disorders, post-traumatic stress disorder, anxiety and depression, to name only a few. Using DMHIs in the treatment of disorders allows those with a mental illness to cheaply and easily access help, supplement a therapy they are undertaking, and monitor and manage their condition (Richards et al., 2018; Jacob et al., 2022; Torous et al., 2018). DMHIs can also deliver help and advice in real-time, prompting, encouraging, and/or giving emotional or behavioural support (Mohr et al., 2018), thus potentially improving provision of mental healthcare and clinical outcomes (Mohr et al., 2018; Torous et al., 2019; Blandford et al., 2018).

Currently, although end-users have broadly accepted DMHIs (Naslund et al., 2015), their sustained use and clinical results have not been as positive as had been hoped (Jacob et al., 2022; Bakker et al., 2016). There is concern that apps are not retaining people in ongoing treatment, because they are not based on design theory and research (Donker et al., 2013; Mohr et al., 2017). Thus, they suffer from low user engagement and attrition (Eysenbach, 2005). Torous et al. (2018) give a number of explanations for this, but the ones which are of interest in this thesis concern design issues: many DMHIs were seen as having poor usability; not being designed from the user's point-of-view; and, not helpful in an emergency, when they are most needed.

Research and practice in the context of DMHIs touches on two broad areas of literature, Health (covering Health Sciences, psychology and psychiatry etc) and Human Computer Interaction (HCI) (covering user-centred design (UCD), participatory design and software engineering etc). It is recognised in the HCI and Health literatures that DMHI design needs to improve for better user engagement (Bakker et al., 2016; Torous et al., 2019; Koh et al., 2022, *inter alia*), but in seeking to solve this problem, there is some disparity between how design practices are considered, used and reported in the Health literature and in the HCI literature. One design approach which has been used widely in industry is user-centred design (UCD), which involves using tested design processes to find user needs/requirements and pain points within the context of a user activity, and then designing/developing/testing products and systems that align with those needs. In good DMHI designs (for example, Thieme et al., 2016; Wärnestål et al., 2017), multidisciplinary teams from HCI and Health are involved. Multidisciplinary teams are important because while clinicians are experts in medical interventions and treatment outcomes (Blandford et al., 2018), they may lack knowledge about how end-users experience the mental illness or would like to engage with the treatment and the technology associated with the DMHI. Design practice issues are discussed in more detail in Sections 2.2 and 2.3.

One approach would be to include people with mental health problems in the design process. However, this can be challenging, because mental health problems encompass a spectrum of issues, affecting cognition, emotions, behaviours and personality, all of which can potentially disrupt daily functioning. Whilst not all people with a mental illness are vulnerable, mental health issues can lead to various adverse outcomes, including impaired decision-making, problems in relationships, social isolation and financial instability. This may result in vulnerability to stigma and discrimination, social exclusion, exploitation and poverty (WHO, 2019). HCI and Health DMHI designers therefore need to be aware that such vulnerable user groups may present unique challenges that impact the design process (Thieme et al., 2016; Doherty et al., 2010). Due to the vulnerabilities listed above, gaining access to groups of users with mental health issues to gain understanding of the context and the users can be a challenging and complex undertaking (Matthews et al., 2014). This is because, for example, such people may be difficult to locate, reluctant to engage or gatekept by healthcare professionals. In addition, due to challenges caused by the presentation of the mental illness, whilst "standard" UCD methodologies are well established (see Section 2.2), they may not be suitable for effectively engaging with and understanding the needs of these individuals.

To address these concerns, this thesis documents a rigorous, empathic UCD research-based process which details the extensive methodological work in gathering requirements for a DMHI for a vulnerable clinical population diagnosed with Borderline Personality Disorder (BPD). BPD is a "chronically disabling disorder" (Chen et al., 2021, p.1128), with deaths by suicide in around 8-10% of the population and up to 75% experiencing non-fatal suicide attempts (Oldham, 2006; Paris & Zweig-Frank, 2001). Treating BPD patients is complicated by therapy-interfering behaviours (Swales & Heard, 2016), and the disorder is associated with significant stigma (Masland et al., 2023). In the research, I use the prevalent therapy for this disorder, Dialectical Behaviour Therapy (DBT), a long-term, specialised, gold standard treatment (see Section 2.4.3). Specifically, I set out the user requirements for an adjunctive treatment app to sit alongside a DBT programme delivering skills training and one-to-one therapy. This DMHI would assist patients in acquiring and practising the *skills* in the Mindfulness module, the foundation of DBT. The requirements were developed through collaborative engagement with clients and clinicians at *The Retreat York*, a private, charitable, psychiatric hospital. This institution sponsored this research and was key in shaping the research scope and objectives (see Section 1.3).

There is literature (Rizvi et al., 2011, *inter alia*) discussing research into developing DMHIs for DBT in this demanding context (see Section 2.3). However, whilst the apps showed some positive results, there was considerable user attrition; the design aspect of the apps, particularly in terms of engaging with end-users, is not well-documented, and their usability and effectiveness are not clear, as they do not test against user needs, and the reasons for user attrition are not fully explored. Thus, to date the literature has not explored the effectiveness of UCD as a viable approach when engaging with the vulnerable and hard-to-reach user group of patients with BPD undertaking DBT Mindfulness.

The goal of the research was to ascertain how well UCD methods could be used to gather and present user requirements for a DMHI for patients with BPD. The methodology detailed may be employed by design teams, user researchers and healthcare professionals, and may be helpful when doing UCD with other vulnerable groups. This research makes a number of contributions to the fields of Healthcare and HCI. Full contributions are given in Sections 1.7 and 7.5, these include: extending the design literature showing that UCD can work to support the initial stages of a design process in this context, as shown in the URD (Appendix I). I demonstrate the extensive methodological work necessary to fully understand and communicate the user requirements; I also detail the considerable adaption of UCD that was required when working with vulnerable users in a challenging context; and, I show the value and benefits of undertaking this level of work, including understanding the stages of learning DBT and the depth of support needed at each stage.

1.1 Human computer interaction (HCI)

Gathering user requirements in vulnerable populations is challenging. As well as the ethical implications of the impact that the research might have on the users, more solid experience of and guidance for gathering requirements is needed (Søgaard Neilsen & Wilson, 2019; Torous et al., 2018). In addition to end-users in general often being unable to articulate their requirements well or not knowing what design options are available (Gould & Lewis, 1985), different stakeholders of a DMHI may have differing ideas about the context, the content, the system and the goals, and therefore conflicting requirements may emerge, which have to be reconciled. In working with vulnerable, hard-to-reach groups, the nature of the end-users' disorder requires a considered approach to requirements gathering, design and validation (Doherty et al., 2010; Thieme et al., 2013), and may require different stakeholders, such as clinicians, patients, family, carers etc. to be involved in the design process at different points.

There is a growing body of work that takes a human computer interaction (HCI) approach in this context. HCI is a multidisciplinary area of study incorporating fields such as computer science, cognitive science and human factors engineering (Dix et al., 2003). HCI approaches can be effectively used to produce DMHIs that are efficacious and that users want to engage with (Lazar et al., 2017). It focuses on the design of interactive technology and in particular, the interaction between humans (the users, stakeholders and others who may come into contact with the system) and digital systems. In HCI, goals, needs and requirements, as well as objectives and expectations in using a system are clarified through studying end-users, stakeholders and the context of use (Gulliksen et al., 2003; Norman & Draper, 1986; Rogers et al., 2012). From an early model-driven focus on technical issues in first wave HCI, and cognitive paradigms in the second wave (Bødker, 2015), HCI has expanded, becoming more individualised and bringing new ideas about the things that designs can achieve, such as emotional engagement and personal reflection using digital systems (Thieme et al., 2011). Experience-centred perspectives on design, in which users, stakeholders and designers work collaboratively and are seen as feeling, sensing and meaning making activities, have gained significance (Wright & McCarthy, 2008; Thieme et al., 2011; Wright & McCarthy, 2022). Thus, it is important that design teams and stakeholders work together, as far as possible, at all stages of the design and development process, to achieve this. Thus they can try to reconcile any conflicting requirements and produce designs that may include a learning experience for all those concerned.

1.1.1 User-centred design (UCD)

HCI includes a number of different approaches. The one used in this research is UCD, a key methodology, widely used in industry and often involving multi-disciplinary teams to design and develop digital products and services (Norman & Draper, 1986; Gulliksen et al., 2003; Sellung et al., 2022). In UCD, the end-user is an integral part of the software design process, ideally from initial requirements gathering onward. However, in sensitive areas of research, this may not always be possible or ethically responsible, and proxy users may be used at different points in the process (Islind et al., 2023) (see Section 1.1.5).

UCD comprises an array of methods and tools used at all stages of the system/software development process, from gathering and modelling user requirements, to designing interactive systems, and evaluating system designs. These range from overall design processes like contextual design (Beyer & Holtzblatt, 1997), to particular methods of formative research like contextual inquiry, particular formats for communicating user insights, like personas (Cooper, 1999; Pruitt & Adlin, 2010), scenarios (Carroll & Rosson, 1990) or user experience (UX) maps (Kalbach, 2016), to particular methods for evaluating systems and their designs and prototypes, such as heuristic evaluation. In addition, qualitative methods are used to elicit data on behaviour and practices, often with a motivation of providing implications for design, but also in narrating how and what participants do in a given context. Using these types of technique helps to ensure a system meets the needs, goals and capabilities of users (Norman & Draper, 1986; Still & Crane, 2017).

1.1.2 Stakeholder involvement

This section examines how different stakeholders and types of expertise contribute to the design process. This research involves different types of expertise and knowledge: long-term mindfulness practitioners, clinicians who are experts in teaching the therapy used in this research, clinical psychologists who are skilled specialist therapists, and patients who are living with BPD and undertaking the therapy and are the experts on that experience. The brief from my sponsors was to produce an adjunctive DMHI; therefore, in gathering requirements the views of the clinicians, whilst not the end-users, are very relevant as stakeholders who would recommend the DMHI to the clients. In discussing the UCD process, McCarthy and Wright (2022, p.55) assert that "[n]ew understanding is created in the respectful, responsive engagement with dissimilarity." This research tries to engage both clients and clinicians in the research process, as the views of both are important. Engaging stakeholders is key in the development, implementation and evaluation of DMHIs and an important part of socially desirable and acceptable digital innovations (Jirotka et al., 2017). In UCD research in healthcare, end-users are considered to be experts on living with their condition. They know how it manifests, how they react to treatment and the things that work for them to manage the condition, even if those things are not ultimately helpful, for example self-harming behaviours in BPD. However, clinicians are experts in medical interventions and the objectives of a DMHI concerning treatment outcomes (Blandford et al., 2018). They may also have extensive experience with clients and the beneficial outcomes of the therapy. They understand and are good at validating the clients when learning the skills is difficult, when they self-harm or do other therapy-interfering behaviours. Yet, they may lack specialised knowledge about *how* end-users engage with the treatment and the associated technology.

The literature shows that clinicians are clearly keen to exploit the potential of digital technology to help patients with mental illnesses (Bakker et al., 2016, *inter alia*) and to facilitate patients in managing their conditions, with DMHIs that are functional and efficacious; however, patients must also be able and willing to use the DMHIs for long-term engagement and retention. Therefore, if clinicians and end-users are able to communicate it can lead to a better understandings of interaction in the context, which will potentially lead to a positive impact on the design (Hollis et al., 2015; Bond et al., 2023). There are examples where the Health literature offers an incomplete narrative about the design process, in particular, the role of end-users. In the Health Literature the early stages of the DMHI design process have not always been well-documented (Stowell et al., 2018; Huckvale et al., 2019, *inter alia*). Thus, it is difficult to know if a rigorous, user-centric process has been followed. Consequently, clinicians may not fully comprehend the unique needs of end-users within the context of a DMHI. It is clear from examining the research over the last 10 years that this is changing; however, perhaps due to the complexity of the clinical environment, the process is taking some time to embed (see Section 2.3).

1.1.3 Empathic UCD

As part of the substantial methodological work required in this challenging setting, the research used *empathic UCD* (Leonard & Rayport, 1997; Mattelmäki et al., 2014). Empathy in design is "a skillset, including attitudes, skills, and knowledge" (Drouet et al., 2024, p.2), rather than the everyday meaning of a psychological construct. Whilst they both focus on user requirements and experiences, empathic UCD differs from standard UCD in the approaches to understanding this.

The main distinctions are that empathic UCD achieves a deep understanding of the users and their lived experience, as it focuses on understanding the user's emotional experiences and personal contexts. Because people with BPD, a challenging mental illness, often have very strong emotional responses and often have issues with emotion regulation, this is a very important aspect of the approach. Using empathic UCD aims to create products that resonate with users on a deeper emotional level. Whilst standard UCD is interested in emotional responses, it often focuses more on usability and functionality, and on how users interact with a design. Standard UCD delivers an outcome in a usable / satisfying way, but that is not enough when working with end-users in circumstances involving BPD; context and emotions take on more importance, therefore the empathic approach was adopted.

Empathic UCD uses qualitative methods such as narrative interviews, storytelling, and ethnographic studies to gather rich, contextual insights about users' feelings and motivations. Through interviews and ethnographic observation, this research sought and gives representation to user requirements for people with BPD to allow a DMHI design team to understand and empathise with these types of end users. This involves understanding users' lived experiences, emotions and life situation from their perspective (Wright & McCarthy, 2008). To do this, I use empathic narrative-based, story-telling methods (*ibid.*) to model the user requirements of people with BPD using tailored, life-inspired experiences in personas, scenarios and user journey maps (Carroll & Rosson, 1990; Cooper et al., 2014; Kalbach, 2016).

Empathic UCD can enrich the design process by integrating emotional insights and end-user's holistic experience. Thus building on and adding to research with users who have traditionally been outside the design process, due to illness and other vulnerabilities making the process challenging; examples include Foley et al. (2020), working with people with dementia and Thieme et al. (2016), working with inpatients with BPD and learning disabilities. This type of work makes patients less passive in the design process, giving them agency and centring their voices and experience. As well as nurturing empathy, using UCD in mental healthcare can also change the perspective of researchers on working with vulnerable people in challenging and complex situations (Wright & McCarthy, 2022). Thus, this type of research helps such end-users to be seen by researchers and designers as individuals with diverse life experiences, empowered to contribute meaningfully to the design process, and able and entitled to do so (Foley et al., 2020).

1.1.4 Dialogical approach

In empathic UCD, it is important that design teams and stakeholders, for example consisting of patients, clinicians and possibly carers or family of the patients, work together. The mix of expertise, knowledge and experience found in this research was strongly influenced by the *dialogical approach* to empathic UCD (Wright & McCarthy, 2022). In this approach, UCD is a collaborative conversation, where users and stakeholders are active participants in shaping the design, impacting both form and function. This helps to resolve any differences in requirements and produce designs that work for everyone concerned.

In this approach, all those engaged in the design process should do so from their own perspective, seeing the viewpoints of other members in the design process as different, but with everyone being open to learning from each other (Drouet et al., 2024), through discussions. Therefore, the user researcher does not try to become the user (or clinician/stakeholder/proxy), instead they respond to the participants' world-view from their own perspective as a designer, whilst engaging in ongoing, meaningful dialogue with users and stakeholders, throughout the design process. This perspective encourages design teams to engage with stakeholders as partners, appreciating their diverse perspectives and hopefully fostering a deeper connection to the design outcome.

The dialogical approach is perhaps most useful for iteratively resolving issues once the Design Phase starts (see Section 2.2.4 for an overview of UCD phases). Whilst no designs were created in the UCD phases documented here, a dialogical approach works well with empathic UCD from the start of the research, and is helpful when addressing differing stakeholder viewpoints.

1.1.5 Use of proxies

Whilst UCD regards end-users as the primary experts on user requirements (Rogers et al., 2012), user research with vulnerable people in the area of mental health also has to be pragmatic in its approach, due to the issues discussed above. For example, accessing users may be difficult due to health conditions, the research may remind users of past trauma or users may be unable to take part in the whole research process. In such cases, proxy users may be used. These are not the end-users, but are close enough to have a very good understanding of the users or the context. They may be for example, clinicians, family members or careworkers. Using proxies is considered acceptable, as long as end-users are also incorporated into the research at some point (Islind et al., 2023). An example can be seen in Thieme et al. (2016) starting their research on BPD inpatients by engaging with clinical staff, because access to the patients was initially limited. Two advantages of using proxies in research with vulnerable groups are that it minimises the number of interactions with users, and it lowers their repeated exposure to potentially triggering issues (Lazar et al., 2017). However, although proxies can be a valuable knowledge resource, they cannot take the place of users, as their perspectives may be different. Therefore, the data gained from proxies can be used as hypotheses to test with end-users.

In this research, people with clinical expertise in BPD, and a group with an understanding of mindfulness, the foundational DBT *skill*, were used as proxies. Following Gupta & Panagopoulos (2019), a distinction between primary and secondary proxy users can be usefully made here. A primary proxy user is a person who has frequent interactions with the user. In this research, DBT therapists and clinicians were primary proxies. By validating my research with clinicians (Chapter 6), I was able to confirm my findings without repeatedly exposing patients to potentially sensitive themes. Secondary proxy users are, for example, subject matter experts. They may not necessarily have interactions with the users, but have a robust understanding of the context. In this research, long-term, non-clinical mindfulness practitioners were secondary proxies. By speaking to long-term, non-clinical mindfulness practitioners first (Chapter 3), I was able to explore concepts and ideas about mindfulness that might trigger difficult feelings for users with BPD (see Section 1.4.3).

1.1.6 Summary

To summarise, end-users, clinicians, stakeholders and proxies have different types of knowledge and expertise and all have something to offer in this challenging space. Design processes work so that designers can understand and reconcile the positions of stakeholders in order to produce effective solutions for all, with the designer bringing the different knowledge of skills and lived experience together. Thus, by collecting requirements at an early stage in the process, it may help to address challenges around the product being usable, suitable and desirable for the end-users and stakeholders. Using empathic UCD processes, this research produces guidance and models user needs, giving a potential UCD solution to a DMHI for people with BPD. UCD may be a good approach to designing DMHIs for mental health disorders as it provides a bottom-up, iterative design process which involves users and other stakeholders from the beginning. In DMHIs this could aid user acceptance, helping to achieve better retention and adherence, and therefore efficacy (Hollis et al., 2015; Torous et al., 2018).

1.2 Mental health background

The research described in this thesis was grounded in the treatment of a mental illness. This section gives an overview of the mental illness and the therapy which was the focus of the research, as well as the part of the therapy my research concentrated on. Therapy can incorporate different techniques, and one approach to improving mental health is to incorporate mindfulness practice, which is the cultivation of the awareness of a person's internal states and surroundings, into therapy. The therapy which my research focuses on, Dialectical Behaviour Therapy (DBT; Linehan, 1993, 2014) is a mindfulness-based therapy.

1.2.1 Borderline Personality Disorder & DBT

Borderline Personality Disorder (BPD) is a pervasive disorder of the emotion regulation system (Leichsenring et al., 2011), characterised by intense and significant instability across a number of domains, including interpersonal relationships, self-image and impulse control, often provoking chronic self-harm and other self-defeating behaviours, and suicidality. Suicidality covers suicidal ideation, plans and attempts. People who experience suicide ideation and make suicide plans are at greater risk of completing suicide (DSM-5[1] American Psychiatric Association, 2018; Hubers et al., 2018). A high proportion of those with a diagnosis of BPD are at risk of accidental or deliberate death by suicide (Leichsenring et al., 2011). There are also higher rates of mental health service use compared to other mental illnesses (Chen et al., 2021; Paris & Zweig-Frank, 2001). BPD patients can be challenging to treat due to therapy-interfering behaviours (Swales & Heard, 2016) and often difficulties engaging with the therapy due to the presentation of the disorder (*ibid.*). Linehan (1993) proposes that BPD results from the interplay of an invalidating childhood environment and a biological susceptibility to elevated affect.

DBT is a NICE-recommended,[2] gold-standard (Stoffers-Winterling et al., 2012; Choi-Kain et al., 2017) evidence-based treatment for BPD. It was developed specifically to

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[1] Produced by the American Pyschiatric Association, DSM–5 (the Diagnostic and Statistical Manual of Mental Disorders) defines and classifies mental disorders using international authorities in all areas of mental health. It is considered the authoritative guide to the diagnosis of mental disorders in the USA.

[2] The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care in the UK.

help those struggling with behaviours resulting from BPD, in particular affective dysfunction and severe risk of suicide, and has considerable empirical research supporting its efficacy in treating this group. It is primarily concerned with changing the harmful behaviours triggered by the illness through skills-based training and psychotherapy, not with discovering the causes. It is a highly manualised therapeutic method, containing four skills modules: Mindfulness, Distress Tolerance, Emotion Regulation and Interpersonal Effectiveness, each comprising a number of *skills* which are challenging to learn in the early stages. Modules last between four and eight weeks and the Mindfulness skills module is taught after each of the other skills modules. There are also one-to-one weekly therapy sessions. DBT requires patients/clients to be in therapy for 1-2 years, with full mastery of the skills often taking longer. DBT is often not an easy therapy to undertake (Katsakou et al., 2012). One reason for this is that new ways of dealing with thoughts, feelings and problems using DBT *skills* can initially make patients feel vulnerable, as old coping strategies of self-harming are discouraged, but new problem-solving strategies using the *skills* are not yet fully understood, learned or integrated (Linehan, 1993; Lynch et al., 2006). Thus, considerable validation of patients from the therapist is necessary throughout DBT (*ibid.*)

Due to the difficulties faced by clients with BPD, DBT addresses a hierarchy of behavioural targets (Linehan, 1993; Linehan et al., 1993, 1994):

1. Decrease suicidal and parasuicidal behaviours.
2. Decrease therapy-interfering behaviours (e.g., over use of contacting the therapist, leaving therapy before it is finished).
3. Decrease behaviours interfering with the quality of life, such as substance abuse, extreme promiscuity.
4. Increase accessing and using behavioural skills in terms of emotional regulation, mindfulness and self-management.

All of these are targeted by psychotherapy and skills-based training using the four skills modules.

DBT Mindfulness

As described in Section 2.5.5, *Mindfulness skills* are central to and foundational for the other DBT *skills*. Using the skills learnt in the Mindfulness module facilitates emotion regulation using the *skills* (Garland & Fredrickson, 2019; Baer et al., 2004) because it helps patients to recognise intense affect and judgemental thoughts about themselves and others, and aids in managing emotional responses, which in turn helps to lessen self-harming and other self-defeating behaviours (Gratz & Tull, 2011). Mindfulness *skills* in DBT are taught to suit the patients' issues and symptoms. Although DBT skills training is built around the *core skills* of Mindfulness, as revealed during my placement at the *Retreat* and in Study 2 interviews (see Chapter 4), these are also the *skills* which DBT clients struggled the most to learn, understand and put into practice.

Mindfulness within DBT is taught in a specific way, tailored to the presentation of BPD. In DBT, Mindfulness sessions are much shorter than in other mindfulness-based therapies, usually up to two minutes. Standard ways to teach mindfulness, such as awareness of the breath or moving the awareness around the body (known as a body-scan) are avoided due to their potential to trigger clients' trauma issues. Many people with BPD have experienced severe physical or sexual abuse, and mindfulness exercises which focus on the breath or awareness of the body can trigger flashbacks to those events or otherwise trigger overwhelming emotional responses leading to self-defeating behaviours in the clients; thus they are avoided in *skills* sessions (see Section 2.4.1). Instead, clients are taught *skills* including *Observing*, *Describing* and *Participating* within a Mindfulness practice setting (see Section 2.5.5 for details).

1.2.2 DBT and commercially available mindfulness apps

There are a large number of commercial off-the-shelf (COTS) mindfulness apps available; however, they are not suitable for use in a DBT context, particularly for clients at the start of DBT (Dr Julia Coakes, Head of DBT Group, *personal communication*) (see Section 2.5.10). This was one of the most important reasons motivating The Retreat DBT Group in asking for help in developing a DMHI for DBT.

Whilst many mindfulness studies show beneficial effects of COTS apps, some adverse affects have been found in the general population (Creswell et al., 2014), and these may be exaggerated in those with BPD. This is because, COTS apps do not take account of the specific issues and requirements of DBT clients, such as avoiding focus on the breath and bodyscans, the need for having very short practice sessions and the large amount of validation which is necessary for DBT clients, as discussed above. In addition, there is often no support for any thoughts and actions around suicide, self-harm or other self-defeating behaviours which may be triggered. Therefore, as COTS apps do not take into account the context of use by offering appropriate exercises in terms of timing and content, or offer validation of clients' failures or thoughts of self-harm, they are usually not suitable or helpful to DBT patients/clients, particularly in the early stages of therapy. In addition, COTS mindfulness apps that are not designed for the DBT context, may not only have negative results, but could mislead patients and clinicians into thinking that a therapy does not work; however, the failure may lie in the app's not being designed for the context and users, rather than the efficacy of mindfulness (Torous et al., 2017).

1.2.3 Mindfulness

The basic ability to be mindful is believed to be an innate skill held by most people (Kabat-Zinn, 2003). The definition of mindfulness used in this thesis is context-dependent, contingent on whether it pertains to DBT Mindfulness (Section 2.5.5) or the conventional mindfulness framework (Section 2.5). Due to the nature of BPD, Mindfulness practice is somewhat amended in the therapy, as discussed briefly above and in more detail in Section 2.4.4. In a non-DBT context, the definition of *non-DBT* mindfulness is the widely accepted one given by Kabat-Zinn (1993) *"the awareness that arises from paying attention, on purpose, in the present moment and non-judgmentally"*. In the DBT context, the definition of mindfulness extends that of Kabat-Zinn, directing how it should be practised. When discussing the DBT *skill* of Mindfulness, the term is capitalised in this thesis for disambiguation.

It is important to note that mindfulness is not about clearing the mind of thoughts or emotions, a common misconception in non-practitioners. Neither is it a relaxation technique. Mindfulness concerns the impartial observation of physical states and cognitive processes, both pleasant and disagreeable, without active engagement. For example, in practising mindfulness, physical discomfort or negative thoughts are observed, without trying to change them. In mindfulness-based therapeutic interventions, the practitioner or facilitator often prescribes the deliberate cultivation of internal awareness, for example attentiveness to the breath or cognitive processes or the external environment, in the present moment. This process entails bringing the attention back to the focus when it becomes diverted. This approach is sometimes likened to watching a stream pass by, without being drawn into following a particular leaf on the water as it floats downstream. In this thesis, the literature on mindfulness is explored in Section 2.5, mindfulness practice in long-term, non-clinical mindfulness practitioners is examined in Study 1 (Chapter 3), and DBT Mindfulness skills' use is investigated as part of Study 2 (Chapter 4).

1.3 Research context

1.3.1 EngD context and evolution

This thesis documents research completed in the context of an Engineering Doctorate (EngD). An EngD is sponsored by an industrial partner, which directs the focus of the research. The ramifications of an EngD are that the work is academic in nature, but the motivations behind the research come from an industry perspective. This research developed from being sponsored by and working with the DBT Group at *The Retreat, York*, a private, charitable, psychiatric hospital and provider of specialist mental healthcare with counselling, therapy and assessment services. In order to achieve this, it was necessary to gain an understanding of DBT and the therapeutic situation through attending a one-year placement at the *Tuke Centre*, the outpatients clinic at *The Retreat*. This was an important part of learning about DBT and entailed attending twice weekly DBT skills classes, spending time with DBT Group clinicians, as well as talking to other clinical staff. I also had a "clinical" supervisor, who was initially the head of the DBT group. Typically a clinical supervisor supervises clinical practice, whereas this person was like a second academic supervisor, who worked for my sponsor as a Clinical Psychologist and Head of the DBT Group. As part of the EngD, DBT clinical staff requested an adjunctive DMHI which would sit alongside DBT and aid in delivery of DBT skills to BPD clients, with a video game initially put forward as the favoured method of delivery.

1.3.2 Change of research focus and scope

Thus, this research began as an engineering project to design a digital game supporting the delivery of DBT generally. As I gained knowledge, the scope of the research changed, evolving into the current research for a number of reasons. The placement at the *Tuke Centre* revealed the clients' struggle with all DBT skills modules and the Mindfulness module in particular, and it became clear that helping clients to learn Mindfulness, as the foundational and most challenging *skill* was key. I also realised that UCD techniques were not being widely documented in the development of DMHIs, and this was a concern in the literature (Torous et al., 2018; Blandford et al., 2018, for example). Therefore, using UCD techniques to gather requirements, noting where "standard" methods (see Section 2.2) needed to be adjusted and more extensive methodological work done, for a user group with BPD, became the research focus.

From digital game to DMHI

During the analysis of Study 1, which examines how long-term mindfulness practitioners embed mindfulness practice into their lives, I started to think about whether the aims of a digital game and the aims of practising mindfulness (see Section 1.2.3 above and Section 2.5) were compatible, as games encourage flow states (Csikszentmihalyi & Csikszentmihalyi, 1992), which are antithetical to mindful states, which engender attention and awareness (Brown et al., 2007). Thus, I started to consider whether an adjunctive app-type DMHI might be more helpful. To this end I looked into and rejected conventional COTS mindfulness apps as helpful (see Section 1.2.2). Therefore, although Study 1 contributed to the scoping of the research, because it started the change of focus process, changing the focus took time, for a number of reasons. The DBT Group at the *Tuke Centre* were keen on the idea of a game and so I had a lot of buy-in to the idea of producing a game. I had written up considerable literature on digital educational games, flow and immersion and I was heavily involved with the IGGI (Digital Games) research group at the University of York. Thus, myself and my research were very immersed in a games research culture. Therefore, although I had started to have doubts about whether a game was a good solution in this area, the change process did not happen overnight; it took me a long time to abandon the research focus on gathering requirements for a digital game and change to gathering requirements for a DMHI for DBT.

When I applied for ethical permission for Study 2, I was still considering making a game, therefore the client questions covered gaming interests and at a high level, what a game might look like (see Appendix A for Question Schedule). It was only during the analysis of the Study 2 interviews that I finally accepted that a game would not be the most helpful thing for the clients. This was for two reasons: 1. the incompatibility of immersion and mindfulness, and 2. some of the answers showed that clients might have games-related issues. Consequently, I considered a DMHI to be most beneficial for DBT clients and abandoned the idea of a game. The answers to games questions therefore do not form part of the analysis of Study 2.

I briefly considered whether making a hybrid DMHI / game, with DBT exercises interspersed with short games, but after discussion with my clinical supervisor, this was abandoned as not helping clients to focus on DBT skills.

From four skills modules to Mindfulness

Study 2 includes questions about all four DBT skills modules, as it was unclear at that stage whether all four would be included or only the Mindfulness skills module. The data analysis showed that the affective dysregulation and therapy interfering behaviours that are a large part of BPD presentation made the Mindfulness module extremely challenging, but also, once mastered, extremely beneficial to the clients. Therefore, I decided to concentrate on a DMHI focused on DBT Mindfulness skills. The work presented in Chapters 4 and 5, uses information gathered in Study 2 (Chapter 4) about all four skills modules, but the main focus is on the Mindfulness skills module. In addition, the other DBT skills modules could be included at a later date, using sister DMHIs or an extension to the DBT Mindfulness DMHI (see Section 7.7).

1.4 Research overview

1.4.1 Motivations

The motivation for this research was threefold.

1. DBT is a difficult and long-term therapy, with the Mindfulness skills module being both the foundation and the hardest to learn and practice. There is a concrete gap in the literature on designing retention-sustaining and engaging Mindfulness-based DMHIs for people undertaking DBT.
2. There is a methodological gap in whether and how well UCD methods and tools can be used with this vulnerable and hard-to-access group and where it might need to be adjusted.
3. In the Health literature, when designing DMHIs for mentally ill people, the initial design work was often not well described, or focuses on the clinical input, leading to the conclusion that there was a user-centric design description gap.

1.4.2 Research question

The overarching question this research seeks to answer is:

> **How can using user-centred design methods support gathering user requirements for an adjunctive app to support people with Borderline Personality Disorder undertaking the Dialectical Behaviour Therapy Mindfulness module?**

This research examines mindfulness skills' acquisition and use in non-clinical practitioners and DBT clients, and looks at clinicians' experiences of delivering DBT, focusing on the distinct needs, contexts, and constraints of clients / patients with BPD. It investigates and critically reflects on the adequacy and implications of using UCD techniques in the design and development of a DMHI for delivering a mindfulness-based therapy to a vulnerable group with a mental health disorder, reviewing where and how these techniques should be modified for such user groups and use cases. Answering the overall research question adds to design knowledge of working with this group of difficult-to-access users, addressing the challenges a UCD process could help to address in terms of patient retention and adherence to therapy, and adds to the HCI literature by documenting how to gather and convey user requirements in this challenging context and the substantial methodological research effort required to do so.

1.4.3 Research sub-questions

To answer the overall research question, drawing on the research gaps outlined above, I identified four sub-questions that each bring a different analytical lens to the research and help to answer the main research question. I conducted a series of qualitative studies that together make up a possible UCD requirements gathering process, with the results of one study informing subsequent studies, with each sub-question becoming more focal in one or more of the studies. These are discussed in Chapter 7.

Sub-question 1: How do non-clinical mindfulness practitioners and DBT clients achieve and maintain the skills and practice of mindfulness?

This questions is answered through studies 1 and 2. The DBT client group was difficult to access for research, requiring a lengthy ethics process. NHS ethical clearance for Study 2 took a long time (6+ months); therefore, whilst waiting, to help in scoping this research, I ran Study 1 (reported in Chapter 3) examining the aids and hindrances to establishing and maintaining mindfulness practice in long-term, non-clinical mindfulness practitioners (see Study 1). These were secondary proxies (see 1.1.5), who were familiar with the mindfulness content but not the users or the BPD context. Then, in Study 2, I examined how DBT clients and clinicians experience DBT *skills* training, with a focus on the Mindfulness skills module.

Mindfulness is the key skills module in DBT and the focus of the DMHI, but as study 2 showed, Mindfulness skills are seen as the most difficult. To answer to the identified research gap in designing a Mindfulness-skills based DMHI for patients with BPD, based on user requirements, which would hopefully aid retention, I first wanted to look at clients' experiences of establishing a Mindfulness practice. Thus giving knowledge based on the end-users' experiences, which could be input into the next step of the design process. Answering this question gives important content to answer the overall research question; it also contributes to the design practice literature, detailing the extensive methodological work necessary when working with vulnerable and hard to access groups to understand the users and their context, and to convey that to a design/development team.

The non-clinical participants are not the target end-users of a DMHI, but secondary proxies. In using a non-clinical population for Study 1, their experiences facilitated discussions about the clients' DBT skills acquisition experience and highlighted their issues and difficulties. As well as discovering new knowledge about this user group, which had not been researched in the mindfulness literature in this way previously, it helped in other ways in answering the research question:

1. The non-clinical practitioners had lived-experience of part of the process that the DBT clients undergo. The initial study allowed me to derive possible ideas for a Mindfulness DMHI and feed forward *potentially* helpful tasks and features for the clients and clinicians to evaluate in Study 2 and Study 4. Asking clients in-depth questions about negative aspects of their practice may well have been triggering and thus harmful to their state of mind and their therapeutic journey. For example, Study 1 asked repeatedly about times when participants were not mindful and reasons for that; in Study 2 that question might have been detrimental to the clients. That being said, it was very important not to take the experience of the Study 1 participants as the "correct one" or to *measure* the clients' experience against this, and care was taken not to do so in this research.
2. Study 1 helped to define the scope of the project. After running the study, I started to consider that a game to engender Mindfulness was at odds with the purpose of Mindfulness, as games encourage flow states (Csikszentmihalyi &

Csikszentmihalyi, 1992), which are antithetical to mindful states which encompass attention and awareness (Brown et al., 2007). Whilst the change in research focus took some time to happen, due to the original request from the doctoral sponsor (The Retreat, York) being a game, this helped me to eventually reject the idea of a game and focus on requirements for an adjunctive app. Also, conventional mindfulness apps were rejected as unsuitable, confirming that a tailored approach to DBT Mindfulness was needed.

3. The process of maintaining a long-term mindfulness practice was possibly relevant to DMHI end-users who had been in DBT for a long time and were close to finishing the taught part of DBT.
4. DBT is a long-term therapy, taking 2+ years. Clients at the end of the process, have absorbed the use of the *skills*, including Mindfulness, making them part of a lifelong strategy for coping with BPD. In some ways, at this point in their use of the Mindfulness *skills* they resemble the long-term mindfulness practitioners.
5. It helped in learning how to run a qualitative study using methods which are commonly used in UCD, including ethical approval, recruitment, running diary studies and interviews, and qualitative analysis techniques and processes, under ideal operating conditions.

Sub-question 2: What are the DBT client requirements for a DMHI supporting Mindfulness skills acquisition as part of DBT?

This question was answered through Studies 2 and 3. Study 2 (Chapter 4) directly engaged end-users and clinicians as stakeholders in interviews. The analysis of which provided a knowledge base for use in Study 3.

Study 3 (Chapter 5) outlines the user requirements for an adjunctive DBT Mindfulness-based DMHI for people with BPD, modelling the process and the users, and giving the rationale behind them. Users and the DBT process are modelled using UCD tools based on the analysis of the interviews in Study 2, supplemented by design hypotheses from Study 1. These documents were packaged into a User Requirements Document (URD) to be used by designers of a DMHI for DBT for ideation / prototype designs, as well as to inform and measure against in usability testing of design iterations. It also provides reflection material for how to relate and validate differing priorities from clients and clinicians in developing good requirements for a DMHI supporting DBT, acknowledging and responding to the participants' different worldviews from my perspective as a user researcher.

Sub-question 3: How are client-derived UCD requirements viewed by DBT clinicians?

This question was answered by Study 4. After generating the user requirements, including documents generated using UCD tools like personas and user journeys in Study 3, I wanted to know how the clients would respond to the documents in the URD. UCD recommends validating with end-users (Section 2.2). However, unfortunately at this point in the research, the DBT group lost its funding, and accessing other DBT clients proved difficult within the research time frame. I therefore took a pragmatic approach to validating the requirements using DBT clinicians as primary proxies, as they were easier to access within the time constraints. While this is not the ideal UCD process of validating with end-users, the requirements themselves were derived from the client interviews, so they had been involved in the process (Islind et al., 2023).

Validating with clinicians gives crucial insight into how client and clinician views relate, which goes to answering the overall research question. In addition, validating with clinicians allowed me to study to what extent UCD-derived requirements and their representations are perceived as useful and insightful by clinical practitioners, again helping to answer the wider question of whether UCD holds untapped potential for DMHI design and development with stakeholders who may recommend the DMHI to their BPD clients to help them acquire DBT. It also provides reflection material for how much the narrative of the experience, gained from using empathic UCD requirements gathering techniques, was seem as reflecting the experience of a wider group of clinicians.

Findings revealed that the clinicians generally responded positively to the models, although some objected to the process of aggregating clients' data into personas, and within the models, of the time the personas took to acquire Mindfulness.

Sub-question 4: What are the emergent issues and potential amendments for UCD user requirements gathering methods when working on DMHIs for an end-user group with BPD?

This sub-question looks at issues with UCD requirements gathering methodology, and the not inconsiderate amendments and adaptions which are needed when working with vulnerable hard to access groups, like people with BPD. In answering it, I detail how and where using adjusted UCD techniques was necessary, to describe the users, the context and illustrate the requirements of a DBT Mindfulness adjunctive DMHI for users with BPD. All four studies contributed to answering this question. In answering this question I list the adjustments made at all stages.

This was a very challenging area of research. Issues in this area include UCD being a complex, lengthy process because it includes a lot of different steps, and involves human participants. Working with vulnerable populations can add to the time consuming nature of the research, due to difficulties with accessing end-users. Although UCD ideally requires access to end-users throughout the design process, in research with vulnerable populations, this may often not be possible, both for individual reasons for example, the nature of the illness making participants less reliable, medication affecting the ability to take part and more frequent hospitalisations, as well as social/political reason such as loss of funding and access to buildings. Because it is a long-term approach, when doing UCD in any area, there is a risk of loss of access to end-users. However, when working with vulnerable groups requiring a lengthy ethics process, the loss of access may mean that time-constraints require a pragmatic approach, as a new group cannot be easily found. Therefore, partly for these reasons, although it gives excellent end results, a UCD approach has not frequently been used in health for longer-term projects.

1.4.4 Research approach

My approach in doing this research crosses a number of genres, so I define my methodology through analogy.

It is a case-study-like examination of gathering and validating requirements for a DBT Mindfulness-based DMHI for people with BPD. There is wide discussion in the literature on case-study definition, and they have been used in a lot of different ways in research (Flyvbjerg, 2006). It is case-study like in that, it is an in-depth examination of a phenomenon situated within the specific context of mindfulness/DBT (Crowe et al., 2011; Yin, 2003). As discussed in Yin (2003), it answers an overall "How" question. Yin also asserts that the case-study research process should be clearly planned, although this is refuted by Stake (1995) who sees research as changing and evolving as it progresses. The approach taken in this research had to be pragmatic and adaptable. In that way, this research reflects Stake's definition of a case-study. It is also case-study like in that in collecting data in studies 1, 2 and 4, I try to triangulate my findings by using different methods for data collection (Study 1, diary study and interview; Study 2 interviews with clients and clinicians backed up with knowledge gained from a year's ethnographic observation of DBT in action; Study 4 Delphi method over 2 rounds), to increase the internal validity of the data within the study. Another way in which this work resembles Stake's definition of a case-study rather than that in Yin (2003) is the constructivist paradigm within which the work was situated (see 1.5.2), rather than the positivist paradigm favoured by the latter. Case studies are useful for revealing where the problems and benefits of a technique lie. In working with vulnerable end-users who may require the techniques typically used in UCD adjusting to account for this, context-dependent knowledge, such as that found in a case-study is extremely important. I also produce a case-study like detailing of contexts of mindfulness use.

However, it may not be bounded enough in a specific place, a specific time or with specific individuals (Creswell et al., 2014; VanWynsberghe & Khan, 2007) to be considered a true case-study, because different groups are used in the three participant studies. Thus, it would not qualify as a case-study for Yin (2003) or Merriam (1998). Conversely, the research does not cover every aspect of DBT, so may not be in enough depth to be considered a case-study. In addition it goes beyond a case study, because I am collecting data not only for knowledge, but also for a purpose - to gather requirements for a DMHI.

In other ways, it resembles action research (Greenwood & Levin, 2006), in that it explores and reflects a context and produces data to promote reflections on professional practices, but it does not go as far as making changes to those practices, which action research does. UCD in education has been described as "participatory action research" (Keily, 2021), although he asserts that to reduce the methodology to 'problem solving' undervalues the "potential to drive creativity, innovation and learning." Although this research is based on the idea of improving the methods and approach of designers working with BPD patients and other vulnerable groups, no changes were brought about (Greenwood & Levin, 2006). Therefore, it is not full action research.

In other ways it is a design research project (Milton & Rodgers, 2023). However, for pragmatic reasons, it does not offer a design solution, rather it suggests ways user researchers and clinicians could work with people with BPD to make a DMHI, and some methods that could be used in the development of requirements for this group. Thus, it only looks at a small part of the design process.

This research provides a case-study-like examination of using UCD techniques to find requirements for a DMHI for people living with BPD. Overall, it is a rigorous UCD process documentation to help potential DMHI design teams in this and similar areas, but it not only details UCD methodology, as well as producing requirements, I produce knowledge about user contexts and emotional experiences, through the use of empathic UCD. It contains both design outcomes and learning points about using a UCD process for DMHIs to help users living with BPD, as well as assessing how UCD methods need to be adapted for requirements gathering for clients with BPD.

1.5 Research paradigm

This work is based in a constructivist paradigm, based on a relativist ontology, which gives rise to a subjectivist epistemology (Hitchcock & Hughes, 2002). From this my methodology and data collection methods follow (*ibid.*), so that the majority of my research work is qualitative in nature. It is also empathic and the importance of empathetic approaches is found in their implementation. Empathic approaches involve forging emotional bonds with users, enabling the researcher's experiences and attitudes to influence their perception of the user to some degree (Drouet et al., 2024). Thus, in understanding user needs, it is important to see their lived experiences, how they feel and where they are, from their point of view. The quality of empathy is developed through reflexivity, positionality and openness (Wright & McCarthy, 2008). Having listened to their stories and struggles as part of the therapy skills group for a year, it was important to record this as faithfully as possible with the representations.

1.5.1 Qualitative research

In undertaking empathic UCD, I needed to understand how people experienced mindfulness practice and how people with BPD experienced the illness and the therapy they were undertaking. The aim of studies 1 and 2 was to explore the perceptions and experiences of participants in order to develop a deep and comprehensive understanding from which to formulate user requirements. Therefore, I saw the collecting of rich, detailed participant narratives as essential. These narratives could then be interpreted and analysed to extract meaningful insights. Qualitative methods are used to produce detailed, nuanced insights into participants' experiences, issues, triumphs and the general processes that they had undergone (Merriam & Tisdell, 2015). Consequently, a qualitative inquiry approach, focusing on the lived experiences of long-term mindfulness practitioners gaining a life-embedded practice and DBT clients and clinicians and their social interactions, as well as the significance they gave to these things within their social setting, was deemed most suitable.

Studies 1, 2 and 4 use qualitative design methods with a diary study, semi-structured interviews and a Delphi-inspired study (which was part quantitative and part qualitative). Interviews as a methodology are discussed in Section 2.2, with the motivation for individual interview questions discussed in Chapters 3 and 4.

1.5.2 Constructivism

Qualitative work needs an epistemological stance and should be situated in a research paradigm. The three basic elements of a research paradigm are ontology, what aspects of the world can researchers explore to gain knowledge; epistemology, how humans form knowledge; and, the researcher's philosophical standpoint or positionality, which guides their research activities (Moon & Blackman, 2014). This work is situated in a constructivist paradigm, based on a relativist ontology, and a subjectivist epistemology. A constructivist paradigm holds that "knowledge is the production of social and personal processes of meaning making" (Pilarska, 2021). We construct meaning through engaging with the world; therefore, for the same phenomenon, different people may construct different meanings and there is not one 'true' reality. A relativist ontology means that there are multiple realities. Whilst this can be interpreted in two ways (Lee, 2012), for me it means that there are multiple conceptualisations of reality. In a subjectivist epistemology, the researcher and the participants co-create an understanding of the phenomenon being discussed. This means that qualitative research may find different results with a different researcher asking participants the same questions.

This aligns with my philosophical standpoint of the world, my place in it and my responsibilities as a person of privilege in terms of having a family background with two supportive well-off parents who strongly believed in education, and my social privilege from my class, university education and being a white English woman who was an HCI academic. I chose a constructivist research approach because it allowed a humanistic and respectful approach to the participants being researched as well as recognising their right to their own cultural, social and psychological realities. My positionality affected how I analysed and interpreted the data in studies 1 and 2. It was important to be mindful of my personal and professional values during the research process. I was at the time practising mindfulness and had undertaken the MBCT course and a short Buddhist retreat. I was familiar with mindfulness and believed it to be a sometimes difficult but ultimately helpful practice for relief of depression and better emotion regulation. I also knew that it could be difficult and boring.

I believe new knowledge in the research area to be inherently interesting to me personally and others who share my interests, as well as having a practical purpose, but my belief in my research is informed by how I view the world. I see understanding as trying to view the world from other peoples' perspectives. The purpose of gaining such understanding becomes valuable if I can use it to make something that ultimately makes someone's life a little bit easier, because the technology they use works intuitively, delivers the content they want at the right time and in the right way. A constructivist approach was important when the clinicians and clients talked about DBT. They constructed and reported their world-view in different ways, due to their different ontology and epistemology. Using the constructivist research paradigm, it does not make sense to see one group's view as 'correct' and another as wrong. Rather, both may be correct, and I used empathic UCD (Section 1.1.3) to understand participants' experiences and emotional reactions, and a dialogical approach (Wright & McCarthy, 2022) (Section 1.1.4), as far as the constraints of the research allowed (see Section 7.6 for a discussion), to have reflective exchanges with stakeholders, and in resolving tensions in requirements.

1.5.3 Reflexivity

Whilst I did not maintain a reflexive journal throughout the research, I kept an account of some of the observations from my short placement at The Retreat (inpatients) and the Tuke Centre (outpatients). This was not written up as a study because *a priori* ethical permission was not obtained. Reflecting on my notes allowed me to see myself and my attitude to the research and the participants as deeply-rooted in my cultural, political and social beliefs, values and knowledge (Crotty, 2015), but also as changing in response to a new environment. My beliefs and knowledge about the research and the context were strongly affected by my year spent at the Tuke Centre, for example the empathic approach became very important and without this I do not think the representations I produced in the URD would have been as rich.

Expectations

When I first read about DBT, I was puzzled and anxious about various aspects: it seemed very complicated, with a lot of different skills to learn. I was also concerned about the suicidality aspect. Having a close friend who had died by suicide, I understood how traumatic the event is for the friends and family of the person who had died in this way, and I was worried about what to do if this happened to a member of the group. Ultimately, there were no deaths by suicide during my time at the Tuke, but there was self-harming leading to hospitalisation and other manifestations of trauma such as frequent Post Traumatic Stress Disorder induced flashbacks (Mind UK, 2024). In the end this made me feel more empathy for the patients and lead to me wanting to carry out meaningful research that might help people with BPD.

Inpatients

Originally, I planned to work with inpatients at The Retreat. However, after initial observations and discussion with the clinicians, working with outpatients was considered more appropriate, due to the difficulties of accessing and working with the inpatients. I spent a week on Acorn Ward, a specialist DBT inpatient ward at the Retreat, where the most complex BPD patients, particularly those with comorbidities, lived for up to two years whilst attending DBT. That experience had been difficult and frustrating. It was difficult, because I went in not knowing how to talk to the clients, I was a little scared. Frustrating because due to an incident which happened before I was due to go in, the patients were upset and understandably did not want a stranger in many of the groups, where the incident was being discussed. Therefore I did not see DBT in action, but seeing a small part of the patients' reactions made me very aware of the problems caused by the illness.

Outpatients

My research focus turned to the DBT Group at the *Tuke Centre* (The Retreat's outpatient centre). Before starting the placement, I was somewhat worried about meeting the groups and how they would react to me. The first time I attended a skills training group was quite a shock. I felt very nervous about whether the clients would accept me, whether they would be aggressive, very emotional, whether they would shout at me or even attack me. I also felt shame at being worried about attending a session with mentally ill people.

The group set up was a surprise. Coming from an academic background, I'd imagined the skills would be taught in a classroom type setting with the teacher at the front laying out the skills and the 'students' sitting in rows taking notes. The reality was far from this. The group was arranged in a circle with comfortable chairs. Hot and cold drinks were available from the kitchen downstairs if the clients wanted to make them.

DBT skills are designed to be interpreted on an individual level. Therefore, the skills being taught in a given session were applied to a personal situation by each member of the group. Each person talked about how they felt about the skill being taught and how the DBT way of managing it may apply to and help them. Whilst teaching the skills, the facilitators shared a lot of personal information. I made the decision in the first session to be open and honest with the group, as it seemed only fair if they were disclosing their personal issues that I should not hold back. From my initial reservations and fear, as soon as the group started talking, I felt empathetic and protective, wanted to look after them. I was a little shy about revealing things about myself, but realised I could not expect them to do it and not me so I resolved to be as honest as possible, including disclosing my struggle with depression and being open about feelings and the sort of person I am. I did not want to be an outside observer, but a contributing member of the group.

The things that struck me most about that first session was the intelligence, humour and vulnerability of the group members. I also attended an afternoon session with different clients. The difference between the two groups was clear. The morning group felt older, more relaxed and more sombre. The afternoon session was younger, newer and had more energy, with some of the clients forming part of the basis for the two younger personas that I produced in study 3. The clients were no longer research study participants with a passive role in my research, but became seen as active contributors to the research process, instead of examples to be studied. The interaction with the clients helped to shape the scope and direction of the research. As a result, I felt an sense of responsibility to articulate the experiences the participants so generously shared.

Being reflexive did not mean abandoning my pre-conceived ideas about robust research, but rather, it served to illuminate my ideas and ensure that I kept an open mind. This encouraged me to adopt a critical stance and consider the ethical issues associated with my dual role as a researcher and DBT skills group attendee in this research. As I held a position of knowledge and power as an 'insider', this meant that I had to reflect on my position as a group member (Cronin, 2014). In the interviews, I made sure to acknowledged my role in the research process as an EngD student, rather than a client undertaking DBT, to prevent any influence or power arising over the participants' responses. Thus, reflexivity permitted me to become acquainted with how I situated myself in the research process.

Attending weekly Consultation Meetings and observing clients learning *skills* in DBT Skills groups revealed at first hand the deep, chronic effect BPD had on clients' lives, with frequent hospitalisations and progress being made very slowly, particularly in the first six to nine months. Thus motivating the DBT healthcare professionals' keenness to support DBT delivery using an adjunctive DMHI, sitting alongside conventional delivery. My reflexivity consisted of being empathetic towards the participants, appreciating the experiences they shared with me, and collectively making sense of those experiences. I gained a deep appreciation of the challenges faced by the clients. I had never seen anyone having a PTSD flashback before, which happened frequently with some clients in sessions which raised difficult issues. Thus, I gained a good understanding of the presentations of BPD and how DBT could support that, which was helpful in interviewing clients and clinicians for Study 2 (Chapter 4) and in designing the personas and scenarios for the User Requirements Document (URD) in Study 3 (Chapter 5), which I could not have gained just by reading about DBT. Unfortunately, due to time constraints, I did not get ethical clearance to write up my observations as a study.

Clinicians from the DBT Group advised on the research until the group was terminated due to loss of funding and my clinical supervisors, who were DBT-trained, advised on the research throughout the process.

1.6 Thesis structure

Chapter 2 – Background and related work

This chapter covers four contexts relevant to the research. It starts by looking at the UCD context, giving an overview of the UCD design process in HCI. It then presents the Health context with an overview of the design literature for DMHIs and examples of DBT DMHIs. The therapeutic background to the research, dealing with BPD and the therapy used to treat it, DBT follows. Finally it covers the mindfulness context examining Mindfulness in DBT and other mindfulness-based therapies. This clarifies the background and some of the academic motives for the research.

Chapter 3 – Study 1 How Do Long-term Mindfulness Practitioners Achieve Their Practice?

Chapter 3 describes Study 1, a qualitative diary study of mindfulness practice in a long-term, non-clinical population. It explores how mindfulness practice is acquired and maintained, without the added complication of a mental health disorder. It examines the triggers and motivations that help experienced mindfulness practitioners remember and maintain mindfulness in daily life and the constraints on doing so. Four themes were found, with the main finding being two contexts of use for mindfulness, which I term *relaxed mindfulness*, used in non-stressful situations, and *purposeful mindfulness*, used in times of challenge, with the purpose of benefitting from a mindful attitude. Purposeful mindfulness was seen by the participants as difficult without having first prepared by practising relaxed mindfulness. The findings from this research formed a number of hypotheses for Study 2 and design inputs for Study 3.

Chapter 4 – Study 2 How do DBT Clients and Clinicians Experience DBT Skills Training?

Chapter 4 details an interview study examining the experience of DBT skills training in clients and clinicians. Findings using Discourse Analysis showed that early stage clients struggled to understand the concepts in the Mindfulness module. They also described DBT as “like magic”, but were unable to construct a narrative about their abilities or agency to bring about a deep understanding and control of the skills, showing that clients’ self-perceptions and narratives may hide the complexities of recovery; experienced clients were much more able to construct the learning process, although there were still tensions in their narrative. DBT was constructed as a process of gaining in both skills ability and confidence that using the skills was possible and would be helpful.

Clinicians constructed DBT skills training in terms of reacting to clients on an individual level and encouraging confidence and self-compassion in clients. BPD was constructed as causing therapy-interfering behaviours, which means that the therapy can take a long time to work, but this was overcome by validating the clients’ actions whilst encouraging them to change (using the dialectic aspect of DBT). Both participant groups presented Mindfulness *skills* as the most challenging to learn, but the skills that best helped to embed and use the other skills.

Chapter 5 – Study 3 Designing a User Requirements Document

In Chapter 5, Study 3 details how data from Study 2 supplemented by data from Study 1 was analysed to produce a User Requirements Document (URD) for a DMHI for users with BPD undertaking DBT Mindfulness. I used and adjusted UCD techniques for the particular context of users with BPD to produce UCD documents which are innovative due to modelling users with BPD in a previously unseen way in personas and scenarios, and including a very detailed User Experience (UX) journey map with five stages of the DBT learning process, and a detailed 24-hour UX diagram/journey of a DBT early stage user. The URD could be used to produce a DMHI for DBT Mindfulness skills.

Chapter 6 – Study 4 Validating User Requirements with a Delphi Study

This chapter covers Study 4, in which the URD was evaluated in an online study. Aspects of the study were inspired by the Delphi method, although it was not a full Delphi study. DBT therapists from across the UK assessed the URD over two rounds, in order to gain a consensus evaluation of the validity of the representation of clients and their needs. Documents were presented in Round 1 and participants rated various aspects. The documents were then amended according to the ratings and re-presented along with anonymous comments in Round 2; some questions were then re-asked and new questions added. The main findings were that there was consensus that the requirements generated were appropriate. The UX Map and scenarios were seen as excellent models. However, there was tension between experts’ opinions about the personas. While most experts saw them as realistic portrayals of DBT clients, some found the concept of typifying clients problematic. Others did not find the portrayal of DBT client personas experiencing considerable difficulty with Mindfulness reflected their experience of DBT clients.

Chapter 7 – Discussion and Conclusion

This chapter discusses the research questions, the strengths and limitations of the approach taken and the wider context of the previous research. I conclude that UCD methods may be used with people with BPD undertaking DBT, but they require a lot of work and considerable adjustments to take into consideration the extreme affective sensitivity and suicidality of people with BPD. These are detailed here for other researchers to follow and use as guidance if doing research in a similar context. I also examine the usefulness and benefits of this approach. Overall, despite the challenges, I consider empathic UCD was a good choice, as it allowed depth of understanding of the users, but was also flexible in undertaking important work with an under-represented user group.

1.7 Research contributions

It was not clear from the literature how a DBT adjunctive app might be designed using UCD. Therefore, in the four study chapters, this thesis makes five contributions which enhance the fields of design in healthcare and HCI research. These are expanded on in Section 7.5.

Contribution 1

In Contribution 1, I demonstrate that UCD can work to support the initial stages of a design process in the context of working with people undertaking DBT, making explicit the considerable amount of time, planning, emotional labour and work commitment required to engage properly with stakeholders. I show that as well as the substantial work needed in a UCD process, a lot more methodological work is required due to the context. This contribution adds to our understanding of designing with people living with BPD and why it is difficult, detailing the factors contributing to the extensive work. It may help other researchers working in this and related areas, for example, in terms of approach, planning and running such studies.

Contribution 2

This describes the considerable adaptions to UCD necessary for it to operate in the context of working with vulnerable people. For example, considerable adaptions were made due to the ethical clearance for interviewing the clients stating that I could not directly recruit the participants; and in the URD, the models needed to be more explicit than standard commercial personas etc, detailing the manifestations of the disorder, such as thoughts of self-harming, the background and the causes. Specifics of the necessary adaptions can be found in Section 7.3.4.

Contribution 3

Although the work was extensive and involved, the results showed that this effort was worthwhile. In this contribution, I show the value and benefits of undertaking this level of work, including understanding the five stages of learning DBT and what the clients were experiencing at each stage; the depth of support needed throughout the skills acquisition process; the elements which would discourage or stop clients from using a DMHI; and, a deep understanding and appreciation of working with vulnerable end-users to give them a voice in the design process.

Contribution 4

Contribution 4 is a contribution to design practice when working with mental health clinicians. It reveals and looks to overcome tensions in stakeholder narratives, such as the dichotomy between the individualistic approach seen in clinical psychologists towards patients, and the aggregated view of end-users used in UCD, e.g. in personas. This was found using empathic UCD to understand the emotions and experiences of stakeholders, through engaging in a dialogical approach: talking to clients and clinicians to shape and develop requirements, and reflecting this back to clinicians, validating iteratively in a Delphi-style study over two rounds. The URD tries to resolve the differing viewpoints by using five different stages in the DBT journey, including personas at different stages and adding multiple tailoring suggestions.

Contribution 5

Contribution 5 is the full user requirements document (URD; Appendix I), which can be used by a design team in the next stages of UCD to produce an adjunctive DMHI for use by people with BPD, in this challenging context.

1.8 Ethical approval

Ethical approval is extremely important when working with vulnerable populations, where the act of gathering information may have a detrimental effect on the population. Studies 1, 2 and 4 all required ethical approval, as detailed below.

1.8.1 Study 1

Ethical approval for the diary study was granted by the University of York Physical Sciences Ethics Committee. Particular care was taken that the remote participants understood what they were being asked to do and what would happen to their data, in both the diary study and the follow up interview. Participants were emailed regularly throughout the study to check on their well-being.

1.8.2 Study 2

DBT clients are vulnerable and ethical clearance for studies involving the client group was stringent, reflecting this. As some of the clients were funded by the NHS, the requirements gathering study required that ethical approval be given by the NHS. Therefore, this study was approved by the Exeter NREC (NHS Research Ethics Committee) and the Retreat Research Governance Group. The process was lengthy, involving a number of document changes at several stages and re-submission to all parties. An enhanced DBS (Disclosure and Barring Service) check also had to be issued before interviewing took place. After obtaining this ethical approval, University of York ethical approval was given by the Hull York Medical School Ethics Committee.

1.8.3 Study 4

Ethical approval for the requirements testing study was granted by the University of York Physical Sciences Ethics Committee.

Chapter 2

Background and related work

2.1 Introduction

In this chapter I analyse the background to the research, looking at four contexts which are relevant to the research and revealing some of the gaps in the literature which my research helps to fill. It begins by discussing Human Computer Interaction (HCI), focusing in on user-centred design (UCD), show what an ideal design, development and implementation process should look like and examining "standard" UCD techniques and methods. It then looks at the health domain, drawing on DBT app research in the Health research. A DMHI for a mental health condition requires an evidence-based psychological theory underpinning it; therefore, the next context looks at the literature from a therapeutic perspective. The presentation and etiology of Borderline Personality Disorder (BPD) are examined. I consider the gold-standard treatments for the disorder, focusing on Dialectical Behaviour Therapy (DBT), the therapy used in this case study. DBT is a mindfulness-based therapy; however, unlike other mindfulness-based interventions (MBIs), it is taught specifically to help the extreme affective dysregulation and suicidality seen in clients with a BPD diagnosis. As the skill module of Mindfulness is key to DBT, and mindfulness practice in non-clinical long-term practitioners is the focus of Study 1 the chapter then covers the context of mindfulness, examining how other MBIs teach and develop a mindfulness practice, contrasting that approach with the one taken in DBT.

2.2 Design context – HCI

Human Computer Interaction (HCI) is a multidisciplinary area of study, which encompasses a wide range of fields including social sciences, organisational theories and philosophy, due to the complexity of how users interact with computer systems (Cairns & Cox, 2008). HCI focuses on the design and evaluation of interactive digital technologies. HCI is an active field of research to which this thesis contributes. This context examines the design process, methods and tools used in this research. It gives an overview of the research process and the motivations for using this process.

2.2.1 User-centred design (UCD)

This research takes a UCD (Norman & Draper, 1986; Gulliksen et al., 2003) approach to requirements gathering for a DMHI for DBT. UCD is a principled, rigorous, process-centred approach, based on empirical principles. It is a key methodology in HCI, grounded in a comprehensive understanding of users, tasks, and environments, guided by iterative user-centred evaluation during the design and development phases. In particular, the goals, needs and requirements, objectives, expectations, beliefs and actions of end-users are examined (Norman & Draper, 1986; Gulliksen et al., 2003; Rogers et al., 2012). UCD tries to encompass the whole user experience, which means users and stakeholders are involved throughout the design and development process, from initial requirements gathering onward. It is an iterative approach to the design of interactive systems which focuses on the goals, needs and requirements of the system users at each step in order to make systems maximally useful, usable and accessible.

UCD is standard practice in software development nowadays. It is a well-established discipline which is widely and effectively used in industry (Nguyen Ngoc et al., 2022), the civil service (Sellung et al., 2022) and the National Health Service (NHS) (Okafor & Akcay, 2024), to design and develop digital products and services. This allows systems to be made using an iterative process, in close coordination with those using the system. Ideally teams are multidisciplinary and qualitative methods are frequently used to elicit data on behaviour and practices, often with a motivation of providing implications for design, but also in narrating how and what participants do in a given context. One outcome from using this approach is helping to ensure a system is usable.

Usability is a precisely defined term in HCI. It covers a system's *effectiveness* - the system supports the tasks the user wants to do; *efficiency*, so that the system allows users to do tasks very quickly, without making too many errors; *learnability*, the system is easy to learn to use; *memorability*, it is easy to remember how to use the system when users return after periods of non-use; and, *satisfying*, users feel satisfied with their experience of using the system (Nielsen, 1994). Whilst usability is still considered important, positive user experience (UX) is often now the focus of the design of many interactive systems, particularly those used for leisure (Sharp et al., 2019). UX is a multi-dimensional concept of how users experience a system, which covers usefulness, desirability, credibility and accessibility (Rogers et al., 2012), as well as the user's judgements on product features and the emotions the product engenders when being used (Minge & Thüring, 2018).

2.2.2 Why do I use a UCD approach?

In UCD the user is involved at all stages of the design process which gives the user researcher and design team a rigorous and compelling approach to designing what users want. UCD allows iterative adjustments to be made to a design, so that a system meets users' expectations and requirements. This leads to engaging products that people want to use (Rogers et al., 2012). In health services, this translates as digital health interventions that users enjoy and want to interact with, facilitating user engagement, increasing retention of users and improving intervention effectiveness (Yardley et al., 2016; Torous et al., 2017). In addition, poor design may not have an identifiable negative side effect on users, but it may stop users from accepting and adopting new digital interventions in the future (Price et al., 2014).

UCD also gives researchers and design teams more empathy with the end users (Farao et al., 2020), allowing designs that acknowledge and respect the presentations of mental health disorders, as well as the diverse experiences within that group of users (Thieme et al., 2016; Hardy et al., 2018; Jonathan et al., 2021, *inter alia*). It allows users to reject design ideas which may seem innocuous or normal to a design team, but which are anathema to the users. For example, in designing a *prayer companion* to assist nuns in making their prayers pertinent to what was happening in the world (Gaver et al., 2010) (discussed in Wright & McCarthy (2022)), the initial design was for a large screen displaying news in the main reception room. This was strongly rejected by the nuns as too intrusive and in the wrong place. Leading to design refinement of a less obtrusive, better placed design. UCD also allows the design and development of specific interventions for specific contexts (Dix et al., 2003). For example, in people with BPD who can be at risk of self-harming and death by suicide, a therapeutic intervention can not only acknowledge that, but also build in internal support in the form of validation, and external support in terms of an individually modifiable plan for what to do in a crisis and who to contact. Thus, UCD can lead to safer interventions in mental health (Sharp et al., 2019).

2.2.3 Guidelines, methods and tools

UCD comprises an array of methods and tools used at all stages of the design and development process. Design guidelines for UCD include Gould & Lewis (1985); Gulliksen et al. (2003); Holtzblatt et al. (2004) and Still & Crane (2017). In addition, there are design guidelines for specific areas. For example, in the area of using technology to treat mental health disorders, Doherty et al. (2010) and Thieme et al. (2013, 2016), look at designing and evaluating mental health technologies using participatory design (PD). This involves the direct participation of users impacted by the technology under development. PD is based on “principles of collaboration, co-creation, and empowerment” (Simonsen & Robertson, 2012). Users give suggestions, comments and assist in the design process (The Interaction Design Foundation, 2023). UCD does not have to be participatory design, but it can be, and this approach is often used in Health when working with end users in PPI (patient and public involvement) research. Examples include research with child survivors of cancer (Nygren et al., 2017) and people with complex PTSD (Bate & Robert, 2023).

There is also an international standard, ISO 9241-210:2019 *Human-centred design for interactive systems* (ISO, 2019). This standard is widely used in the public sector, for example, as the foundation for NHS design principles in the NHS digital service manual.[1] The six principles in the ISO can be summarised as:

1. Design is based on an explicit understanding of users and tasks: why, how and where they will use the product.
2. Users are involved throughout the design process: not just during evaluation. Their needs are integrated in the design using observations at the start and user tests following a first product version are useful.
3. Design is driven and refined by user-centred evaluation: at all stages. It should not be left for the final stages of the product design.
4. The process is iterative: the optimal solution is found via feedback loops and through ongoing dialogue.
5. The design addresses the entire user experience: In the past, user experience was often associated with intuitive operation, but good user experience is more than that. The aim should be to make it as simple and pleasant as possible, evoke positive emotions and make users want to use the app repeatedly.
6. The design team should include multidisciplinary skills and perspectives.

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[1] https://service-manual.nhs.uk/

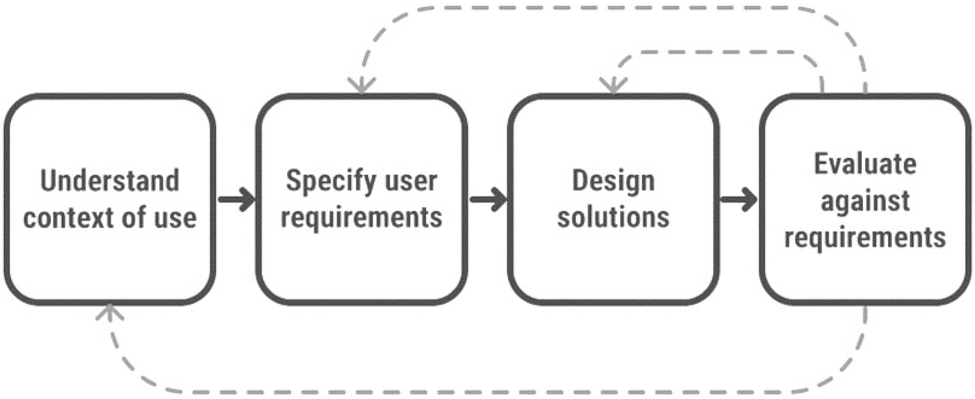


Figure 2.1: UCD design process (source: The Interaction Design Foundation (2023))

2.2.4 UCD design process

The UCD process follows a series of steps through a design and development life-cycle of a system or end product. As shown in Figure 2.1, the process can be split into 4 main phases which are typically carried out iteratively. The UCD process does not specify exact methods for each stage, but there are set things to do in each one:

Understand This step involves user research for a systematic exploration and understanding of user context, behaviours, needs and motivations using diverse research methodologies such as interviews, surveys and ethnography.

Define Here, the research data is synthesised and analysed to identify patterns and insights into user behaviour to inform the design process. This uses methods like thematic analysis and produces artefacts like personas, user journeys and scenarios. It specifies the context of use and the requirements/user needs.

Design In this step design ideation is done with design ideas being produced and refined using design thinking techniques like brainstorming and iterative sketching out of ideas for a design, using input from previous stages.

Evaluate This can be split into 2 stages. It is an iterative process which may be repeated a number of times, with feedback used in refining and improving the design, until it meets the user requirements.

1. Prototyping: paper sketches, wireframes and interactive parts of the design are used to create low- and high-fidelity prototypes to find areas which users want/do not want, like/dislike. These are iteratively developed, with feedback from users and the artefacts used to refine prototypes to ensure they continue to meet the identified user requirements. Before the product goes to implementation and development.

Following implementation:

2. User testing: this step tests the developed software with users to gather feedback on understanding, anything that does not work and usability leading to further design improvements where necessary. This can be done for example through usability testing and A/B testing.

In a UCD design process, small participant groups are typically used, with 5-10 participants taking part in the final user-testing. Whilst companies like Google can do large quantitative testing on features they change, as they have millions of users, in smaller design projects, large-scale Randomised Controlled Trials (RCTs) (Section 2.3) would not normally be run at this stage, in a non-safety critical setting. In the area of Health, clinical safety is of utmost importance and therefore RCTs need to be run before a treatment can be considered safe.

2.2.5 UCD and vulnerable users

We have seen why UCD is an important design methodology. In UCD, as in other HCI research, participants must represent the users, tasks, and environment which are being studied (Lazar et al., 2017). Thus, they have to be the right age (so if designing for older people, then seniors need to be participants) and have the right educational and technical experience (e.g. an interface for an aircraft would require participants who were pilots). This makes research complex, because recruiting specific groups of participants takes a lot of time and can be expensive. When designing for vulnerable groups and contexts this can present extra issues due to the ethical implications of the impact that the research might have on such users.

In HCI with vulnerable groups, for example working with children (Nygren et al., 2017), older adults (Petrie et al., 2016), non-literate people (Thies, 2015) and people with physical and learning disabilities (Croot et al., 2018), and in emotionally sensitive contexts, such as bereavement (Baglione et al., 2018) or domestic abuse (McKay & Miller, 2021), group members should be involved in the design process, as end users as far as possible. However, working with vulnerable populations, and undertaking UCD, such as gathering requirements, can be challenging due to, for example gate-keeping making access difficult or risks of upsetting or even re-traumatising people. Involving people with a mental health disorder in user-centred design is desirable (Coyle & Doherty, 2009) as it allows researchers to understand and empathise with their worldview and appreciate their attitude towards and difficulties with the disorder and the therapy they are undertaking, as well as gathering their requirements. However, access and other ethical considerations may constrain the process (Coyle & Doherty, 2009; Doherty et al., 2010). In people with a mental health disorder there may be issues around, for example, the effects of medication on their ability to answer questions, discussions of the therapy which might trigger negative thoughts and suicidality, and their ability to engage in the requirements process due to the disorder impacting attendance (Johansson et al., 2015).

As well as the ethical implications of the impact that the research might have on the users, there is little solid experience and guidance for gathering requirements for DMHIs in people with a severe mental health disorder (Søgaard Neilsen & Wilson, 2019; Torous et al., 2018). In attempting to understand the context and clinical settings, other frameworks, such as participatory design have been used. Examples of this include to improve children's mental health (Doherty et al., 2010; Matthews et al., 2015), to help children recovering from cancer (Wärnestål et al., 2017) and Thieme et al. (2013, 2016) documents challenging research using *participatory design* with BPD inpatients. However, there is limited work in this area (Yardley et al., 2016; de Beurs et al., 2017). In this type of research, stakeholders in the form of carers, clinicians, and friends and family may become involved in the research, as one way to do research with vulnerable groups is to use proxies for part of the process (see Section 1.1.5). A number of studies use mental health care professionals, in early research stages and / or as a research champion in the clinical setting, as Thieme et al. (2016) did in her research with participants living with BPD.

The approach taken is also important, the empathic UCD methods (Wright & McCarthy, 2008) (Section 1.1.3) used in this research, together with the dialogical approach (Section 1.1.4) helped to develop an empathic understanding of people with BPD and to represent all stakeholder views in the URD design. Wright et al. assert that good experience-centred design requires designers to engage with the users and their culture in rich ways in order to understand how the users make sense of technology in their lives. For example, to return to the *prayer companion* (Gaver et al., 2010) (discussed in Wright & McCarthy (2022)), this research entailed considerable discussions with cloistered nuns, who wanted their prayers to be relevant to current events. The initial design produced presented snippets of news items interspersed with ‘I feel (e.g. lonely)’ statements, for possible prayer topics. The nuns rejected the initial design because they found it difficult to respond to the ‘I feel’ output in their prayers. The amount of this output was cut down, but following conversations with the designers, the nuns realised they could react in their prayers by seeing those making the ‘I feel’ statements as people who did not know how to pray for themselves. Thus, using a dialogical approach and empathic UCD meant that whilst the designers did not understand prayer in the way the nuns did, their approach allowed a deeper understanding of experience and emotional engagement, which their design was able to embody. In this way both the nuns and the designers learned through the process through respectful co-understanding with empathy at the heart of the approach.

Whilst an empathetic approach was taken in Thieme et al. (2016), the design of of other DBT DMHIs, covered in Section 2.3, do not detail how the interventions were designed in great detail. Therefore, to fill this gap, this research describes how empathic UCD methods can be used in the first two steps of the UCD design process. It is known from designing in other vulnerable populations that traditional or “standard” HCI methods need to be adjusted (Waycott et al., 2015; Croot et al., 2018). It is therefore reasonable to postulate that typical UCD methods need adjustment when working with vulnerable people with a mental health condition. From the literature, the adjustments that need to be made for people living with BPD, when undertaking UCD are not known. Therefore, this research considers how the “standard” UCD process above, and techniques detailed below needed altering for UCD requirements gathering with people living with BPD. It considers the disorder’s unique presentation which had to be taken into account in this challenging context, for example extreme emotional dysregulation leading to self-harming behaviours and suicidality in the patients (Linehan, 1993). In doing this, I make adjustments to some of the standard qualitative methods that are used in UCD. These are detailed in the following sections.

2.2.6 User-centred design methods

This section details the UCD methods used in this research thesis, covering diary studies, interviews, Delphi studies, online surveys and the tools involved. It examines what constitutes a "standard" or traditional UCD method. This is then contrasted with how and what changes were made in answering the research sub-questions (Chapter 7).

Diary studies

A diary study is a longitudinal research method which collects data about participants' behaviour, activities and experiences (Lazar et al., 2017). Time-use diaries document what participants did in a certain time frame, such as an hour or a day, helping to build a detailed contextual image of the activity being studied. In a diary study, participants self-record the required information at the required frequency, over a number of days or weeks. Having a record of users' daily activities, as they happen, gives the researcher details of real-time user behaviours and needs in context, which can help in understanding and defining user requirements (Goodman & Kuniavsky, 2012).

Diary studies have a number of advantages (Lazar et al., 2017; Goodman & Kuniavsky, 2012). They allow access to information that it would not be possible to collect through observation studies or in a lab-based study, such as events that do not have a set pattern or may happen unpredictably, such as state mindfulness. They allow the researcher to question what motivates participants to do a specific task (or what prevented them) as well as asking participants about their thoughts, feelings and attitudes. They also stop biases due to recalling an event from some time previously which may be present in an interview or when completing a survey. They are useful for capturing data that might change over time (depending on day/time, participant mood, perception, etc) (Alaszewski, 2006). Diaries are particularly useful for researching usage patterns that cross multiple technologies, locations or environments (Hayashi & Hong, 2011). They can also be helpful when user-defined data is required, for example, when a user could have or wanted to perform an action, but did not do so.

They also have disadvantages (Lazar et al., 2017; Goodman & Kuniavsky, 2012). Participants may not be aware of the details of a behaviour or experience or the reasons for it, in which case they might struggle to log it in a diary entry. Participants may forget to write or be unable to write sufficient entries. In addition, recruitment may be more difficult as the study requires considerable time and effort commitment. It may also be difficult to balance between having enough diary entries and imposing too much on participants' time, leading to entry attrition. Finally, since a lot of data can be generated in a diary study, data analysis may take a long time.

A diary study typically has the following stages (Goodman & Kuniavsky, 2012; Lazar et al., 2017):

- Planning. At this stage, the focus of the study, the behaviour you want to investigate and the timeline are planned. In addition, the design and development of any tools needed for diary entries is completed and any instructions or support materials should be finalised.
- Piloting. Once the participant population has been decided, the study can be piloted using a member of the target group and any necessary changes made.

Recruitment can take place at the same time.

- Study introduction. Once they have been recruited, it is important to meet, or at least speak on the telephone to participants in a diary study to explain how to do the study, the diary schedule, the reporting period and the researcher's expectations in terms of regularly completing the required entries. It is very important to make sure they understand the tools / technology they will be using and to answer any questions they have at this stage.
- Study running. When collecting diary data from participants, two common techniques are used. Participants can be asked to log information about the activity/behaviour under investigation at the time when it happens (i.e. *in situ*). All the details about the activity/behaviour should be documented immediately. Alternatively, participants may record short snippets of information about activities as they occur, as reminders. At the end of each time period (half day/day etc), they write diary entries, elaborating on the snippets and giving the full details. This technique allows participants to capture relevant information before it is forgotten, but does not ask for full details, making it more convenient for participants.
- Post-study. Participants should be interviewed based on their diary entries. This allows further discussion of details and clarification of anything causing confusion.
- Data Analysis. Diary studies can generate a lot of data which requires an appropriate and rigorous analysis method.

Interviews

In a research context, interviews are used when the researcher wants to get detailed and comprehensive data on a topic, which a questionnaire might not provide. It is a live conversation between the researcher and the participant, which unlike a general conversation, is structured and is motivated by a quest for research knowledge gained through the interviewee answering questions (Merriam & Tisdell, 2015). One of the advantages over a survey is that any questions or answers that are not understood can be immediately clarified. Interviews are good for gaining the in-depth knowledge required in requirements gathering, because they allow in-depth investigation through immediately following up an answer with a question about the answer (Dexter, 1970), which a survey does not allow.

There are three main types of interview, from more to less formal these are: structured, semi-structured and open-ended or unstructured interviews. The type of interview used depends on the data the interviewer wants to acquire. For more personal types of data, a less formal style is desirable. The information in this section is mainly a synthesis of Adams & Cox (2008); Sharp et al. (2019); Merriam & Tisdell (2015); where relevant, other research is cited individually.

A structured interview has a list of prepared questions which are asked in order. Each participant is asked the same questions. Questions are typically closed, ie having a fixed list of answers to chose from. However, flexibility is desirable as interviewees often answer questions before they are asked, or discuss things that may require follow up questions not on the list. The more structured an interview, the more the interviewer controls the conversation and the less relaxed the interviewee may feel. This may be reflected in caution in answering questions. This type of question is useful for short interviews or when the choice of potential answers is known.

Semi-structured interviews incorporate features of structured and unstructured interviews, asking closed and open questions. There is a basic interview schedule, so that the same areas are covered in all interviews. Open-ended or unstructured interviews are exploratory and are similar to general conversations around a particular topic; they often go into considerable depth. Open-ended and less structured interviews consider individual participants to have a more subjective stance, with them seeing the world in different ways. Therefore, questions posed by the interviewer are open, meaning that there is no particular expectation about the format or content of answers. Interviews are not consistent across interviewees as each interview may be organised in a different way and cover different aspects of a topic. Less structured interviews are more difficult to analyse, as the data which answers a particular question may be dispersed throughout the interview. In semi-structured and unstructured interviews, a list of topics to introduce, which can be crossed off when they come up is very useful, to ensure that nothing is missed. Unstructured interviews are more difficult to run, and running this type of interview well takes skill and practice (Dumas & Loring, 2008). However, they often reveal richer, more complex data, as it is more like a conversation between the interviewer and the interviewee than an in-person survey, which a structured interview can feel like and so provides a deep understanding of the issue. Participants, may also bring up ideas that the interviewer had not thought about. It is important to be alert to anything which is not clear or is particularly interesting in an unstructured interview to remember to ask follow up questions, known as probes. Again, this takes practice to become skilled.

The questions asked should be carefully tailored to the research question(s) to obtain the necessary information. The interviewer should try to speak as little as possible, encouraging the interviewee to give as much information as they can. It is also important not to pre-empt an answer by asking a leading questions or phrasing a question to suggest that a particular answer is expected. An interviewer also needs to know enough about the interview subject, and the types of participants, to ask relevant questions, wording them to fit the interviewee's understanding (Merriam & Tisdell, 2015).

An interview typically has the following stages:

- Planning. At this stage, the questions which will be asked and the type of analysis that you will do determine the type of interview that will be run. The design and development of the interview schedule or list of topics is then completed and any ethics documents regarding the study are written and ethical clearance applied for. In addition, recording equipment has to be checked and a suitable time and place for the interview organised.
- Piloting. Once the participant population has been decided, the interview can be piloted using a member of the target group and any necessary changes made. Recruitment can take place at the same time.
- Running the interview - Beginning. Greet and welcome the interviewee. As soon as the interviewee is settled turn on the recording device and ask on tape

if they are happy to be recorded. Begin by introducing yourself and the study, check they understand what will happen in the interview, as well as signing ethics forms etc. Then start by asking very general warm-up questions to get them used to the situation and put them at ease, especially in an unfamiliar setting.

- Running the interview – Body. In the body of the interview, the questions are presented in a logical order. Sharp et al. (2019) suggest the more probing/sensitive questions should be asked towards the end, although in semi-structured and unstructured interviews, the question order may change from interviewee to interviewee, depending on how the conversation flows, and how much probing is used. Adams & Cox (2008, pp.22-23) split this part of the interview into two stages, which they term "letting off steam", allowing the interviewee to get any key points off their chest, to stop the same points being repeated throughout the interview and "addressing issues" in which any remaining questions are asked, although they also recommend asking any sensitive questions last.

- Running the interview – Final stages. After the main questions have been asked, there follows a cooling-down period consisting of a few final easy questions and any demographic questions. Finally, the interviewer may sum up the main points/answers. The interviewee is thanked for their time and if necessary the reason for the interview can be explained if this was not done at the start. To close the session the interviewer can switch off the recorder to show that the interview has ended.

- Data Analysis. Interviews can generate a lot of data which requires an appropriate and rigorous analysis method. The data should ideally be transcribed by the researcher while the interview is fresh in their mind, as this is when the analysis process starts, for example, with any themes that are noticed being noted. The more familiar the researcher is with the data, the better and richer the analysis process.

Online surveys/questionnaires

Surveys are a very commonly used research design in both HCI and Health research. It is a flexible approach to investigating an area or specific issue, often using a questionnaire as a tool to gather demographic and opinion data (Sharp et al., 2019; Mathers et al., 1998). Like interviews, questionnaires may use closed- or open-ended questions or a mixture. One benefit of a questionnaire is that it allows a large number of responses to be gathered and access to participants who could not or would not take part in an interview. Like conducting an interview, developing a questionnaire which elicits the required answers is a craft skill. A questionnaire needs to be easily understood by the participants, to ensure that *all* questions are completed and the responses are accurate (Adams & Cox, 2008). Questions need to be very clear and unambiguous, as respondents will not have access to the researcher if anything is not understood. For example, words can mean different things in different contexts, so any context-specific meanings must be made very clear. Examples or definitions may help with this (Adams & Cox, 2008; Sharp et al., 2019). For these reasons a considerable amount of piloting is often needed for questionnaires.

In terms of length, questionnaires should not be too long, as respondents may get bored and rush through the answers or skim-read the questions, especially the longer ones (Adams & Cox, 2008). One way to combat this is to split long questionnaires into different sections, or give respondents the choice of not completing certain parts (Sharp et al., 2019). Respondent motivation and feeling that the questionnaire is relevant to them may also play a large part in how much of it is answered. Questionnaires should be structured logically, with even short questionnaires having similar questions together. The order that questions appear in can also bias the respondents' answers. It may be necessary to have different versions of the questionnaire, although some online survey software allows for questions to be asked in a different order each time, if all questions are on the same subject. Questions should be as simple and short as possible, and only one question at a time should be asked. As with interviews, leading questions should be avoided, as should questions where respondents will give a socially acceptable answer rather than an honest one.

Questionnaires have differing formats, which respondents understand differently and to which they give different types of answers. Adams & Cox (2008) asserts there are 4 types of question, each having different answer scales:

- Simple factual questions – requiring a yes/no answer. E.g. Did you vote in the last election?
  Complex factual questions – requiring some interpretation or analysis. E.g. How many days did you eat meat last week?).
  These require a blank space to enter a number;

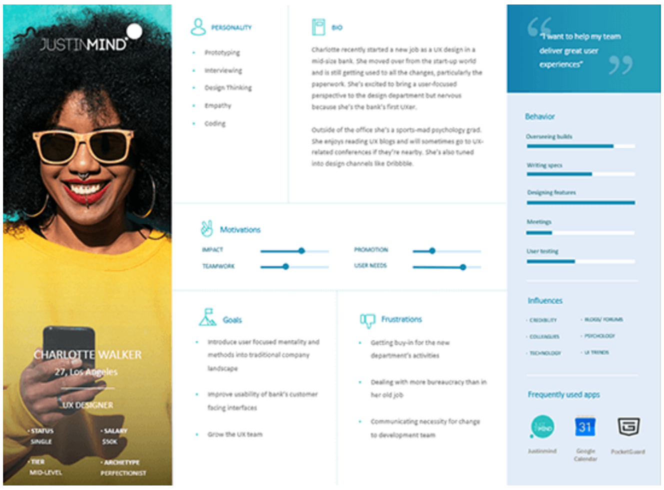
- Closed questions - offer a choice of answers. The number of choices may vary and may also include ranges. E.g. Which age range are you in? 21-30, 31-40, 41-50 etc.);

- Open-ended questions – frequently use a box or a blank space to show respondents the required amount of detail they should give. However, with online surveys, this space can expand to the amount they want to answer.

- Opinions / attitude seeking questions - have a wide number of rating scales and are more controversial in the literature. The Likert scale is the most frequently used scale for opinion questions. Likert scales typically have 5 or 7 options which may all be labelled or just the extreme points may be labelled.
  E.g. How likely are you to vote in the next election? (Please select one answer).
  Not at all 1 2 3 4 5 Definitely.

Delphi studies

Delphi studies are covered in detail in Section 6.2.2. A Delphi study is a research approach often used in Health Sciences. It tries to find a consensus view on a research question among experts such as clinicians, researchers and consumers (Jorm, 2015). In a Delphi study, participants are asked for opinions over a number of rounds. The anonymised opinions of all participants are then fed back in the next round, so that they can reflect on and reconsider their opinion, based on what others have said. This continues until consensus is reached.



JUSTINMIND

CHARLOTTE WALKER
27, Los Angeles

UX DESIGNER

- STATUS
SINGLE
- SALARY
$50K
- TIER
MID-LEVEL
- ARCHETYPE
PERFECTIONIST

PERSONALITY

- Prototyping
- Interviewing
- Design Thinking
- Empathy
- Coding

BIO

Charlotte recently started a new job as a UX design in a mid-size bank. She moved over from the start-up world and is still getting used to all the changes, particularly the paperwork. She's excited to bring a user-focused perspective to the design department but nervous because she's the bank's first UXer.

Outside of the office she's a sports-mad psychology grad. She enjoys reading UX blogs and will sometimes go to UX-related conferences if they're nearby. She's also tuned into design channels like Dribbble.

Motivations

IMPACT
TEAMWORK
PROMOTION
USER NEEDS

Goals

- Introduce user focused mentality and methods into traditional company landscape
- Improve usability of bank's customer facing interfaces
- Grow the UX team

Frustrations

- Getting buy-in for the new department's activities
- Dealing with more bureaucracy than in her old job
- Communicating necessity for change to development team

"I want to help my team deliver great user experiences"

Behavior

Overseeing builds
Writing specs
Designing features
Meetings
User testing

Influences

- CREDIBILITY
- COLLEAGUES
- TECHNOLOGY
- BLOGS/ FORUMS
- PSYCHOLOGY
- UI TRENDS

Frequently used apps

Figure 2.2: Typical standard persona

2.2.7 Personas

When designing a system, users often cannot articulate exactly what they want the system to do, the problems they have with the current system or how to design a system that would give them what they need (Cooper, 2004). To help the design team, personas which are hypothetical archetypes or lifelike, data-driven models of users are employed when discussing design features. Visually, personas usually comprise a photograph, a name and a narrative, which allow the project team to talk about the design in terms of user expectations and goals and to see the design from different users' point of view (Pruitt & Adlin, 2010; Cooper, 1999). Figure 2.2 shows an example of a standard professional persona.

Personas are based on data from users and the characteristics of personas should be traceable to the data they were generated from (Matthews et al., 2012). Although the idea of personas is a simple one, considerable work must be done to generate and refine personas into accurate representations of the target users (Adlin & Pruitt, 2010). When personas are designed well, rather than being designed without a clear shared idea of a system's users, or using vague stereotypes, they allow designers to externalise and specify clear target users and develop an evidence-based picture of end users and their requirements.

Well-devised personas have a number of benefits. Using personas reduces the necessity of having users in the design team (Salmi et al., 2012), which may be a problem if access to the users is difficult; for example, children or people with a mental health disorder. Nevertheless, when possible, co-creation of personas with users who have diverse needs and goals, for example those with physical and mental health disorders or older adults, can engage these groups of users (Neate et al., 2019) and benefit the development team (Woods et al., 2017). Personas can create empathy for users amongst the design team, which may be important in groups traditionally seen as other, or outside the experience of many people (Matthews et al., 2012). Empathy for users can be deepened, either from identification with the personas (Miaskiewicz, Sumner & Kozar, 2008) or an empathetic appreciation of their situation. An example of this might be in the case of elderly users (LeRouge et al., 2013). Personas justify design decisions in terms of what the user wants, rather than what the system can or should do (Miaskiewicz & Kozar, 2011). They allow designers to form an understanding of, and therefore discuss, experiences and circumstances very different from their own, with users who have different expectations and requirements of a system (*ibid.*). Sometimes personas are very different from stakeholders' or designers' existing ideas about them. In organisations where personas are trusted and stakeholders are well-disposed to a change in how users are seen, this can allow the difference between fact and opinion to be reduced (Matthews et al., 2012), giving better products, customer experiences etc.

However, personas are not without controversy as a design method and have been criticised in the literature for a number of reasons. Marsden & Haag (2016) express concerns over persona genders being stereotypes, biased by researchers' processing of complex user information. However, most researchers are aware of this and how to overcome it. For example, Wodtke (2010) asserts that groups working on creating personas almost inevitably create at least one *bad guy*. Getting the persona design team to use empathy to soften and explain the behaviours of the *jerk* persona, when this tendency is noticed can help (Adlin & Pruitt, 2010, p.67), but rigorous source-driven development and validation is also important. Bødker et al. (2012) found personas were difficult to keep in mind, reductionist and not a substitute for real users. However, the personas generated in their study seem to be generic, and the research team chose not to make personas of more difficult system users, even though they would have been representative.

Another criticism of personas has been the variance in the persona design processes used. To tackle this credibility problem a number of step-by-step guides to persona creation have been suggested (Cooper, 2004; Faily & Flechais, 2011; Pruitt & Grudin, 2003, for example). In Pruitt & Grudin (2003) persona creation is based on rigorous user studies which link to documents containing details of all the study data used to form the persona. Faily & Flechais (2011) describes a three-step exercise which processes the interview data to give propositions based on user quotations which can be explored in the persona. A tool which directly connects the coded user data to the personas is then used to preserve accuracy. In my research, a rigorous process based on Adlin & Pruitt (2010) was followed, detailed in Chapter 5.

When rigorous techniques are not followed, or the technique which was followed is not clear, it can lead to a variation in quality (Vincent & Blandford, 2014). Matthews et al. (2102) found some designers did not trust personas. They wanted to see the raw data or even speak to the users. Matthews et al. also found the way that data was formed into personas could be problematic, with disparate material from different sources being incorporated to form *Frankenstein's monsters* (Bødker et al., 2012). Other criticisms include validating persona accuracy as problematic; for example, they may not be based on data which typifies the users, they may not be based on enough data, or they may not be data-driven at all (Chapman & Milham, 2006). Chapman & Miller argue that interviews and ethnographic methods cannot be used to validate data-driven personas. Additionally, since persona creation work is typically qualitative, even when they are grounded in data, they may be seen as lacking the rigour of quantitative research, as they are interpretative and subjective (Chapman & Milham, 2006). However, there can be many reasons for such interpretations. For example, the subjective experiences and impressions of decision-makers may conflict with the personas (Marsden & Haag, 2016).

Another concern is that in making politically and socially engaged social science, whilst striving for objectivity, it is unavoidable for socio-cultural values to be absorbed (Bardzell & Bardzell, 2011), particularly in personas which represent vulnerable people like children, the elderly or people with a mental health disorder. Empathy in HCI research has been a long-term theme (Wright & McCarthy, 2008), but as Marsden & Haag (2016) assert, it is vital to evaluate and consider one's own values and opinions when working on personas, to guard against stereotyping.

Personas have been used previously in healthcare. Turner et al. (2013), for example, used personas and scenarios to model communicable diseases. They have also been used with vulnerable populations, for example in the analysis of serious games for mental health (Mader et al., 2012), in elderly people (Nunes et al., 2010; LeRouge et al., 2013), in representing children who had survived cancer (Wärnestål et al., 2017) and in a tool to support clinicians (Rodrigues et al., 2015). Representing the types of complex issues found in healthcare may be difficult for traditional personas. Therefore, HCI researchers who were not domain experts used participatory design and included stakeholders in the persona development to ensure important details were not lost.

Whilst personas have been criticised in the literature, they have a number of uses in terms of challenging assumptions, modelling users and reducing large amounts of qualitative data to understandable, relatable tools for designers and developers, particularly for vulnerable groups.

2.2.8 Conclusion to HCI

This context motivated the use of UCD in this research, detailed design guidelines including the international standard, and gave a design process overview. It discussed UCD in a mental health setting and why it is challenging doing design work in that context. It then examined the UCD tools and methods used in this research showing how "standard" or traditional methods in UCD work, which are then used to discuss adjustments made for the mental health context in Chapter 7. The next section looks at how design is approached in the Health literature.

2.3 Design context – Health / mental health

2.3.1 Introduction

Having looked at the design process in HCI, I now examine what this looks like in the Health literature. This section examines how DMHIs for DBT are designed and developed in Health. It briefly looks at what motivates design processes in Health, it then looks at examples of apps designed for the research domain in this thesis, DBT for people with BPD. It examines some of the directions Health is taking and ends with how following a more rigorous system, like that recommended in ISO 9241-210, may benefit clinician-developed apps, and how my research could help that process.

The approach to developing DMHIs in Health is different from HCI. Traditionally new developments in Health were pharmaceutical and the NHS has strict development guidelines for new drugs. Initially these guidelines were used to develop apps (Blandford et al., 2018). In the literature on early (pre-2018) Health apps, research often starts the design and development process using evidence-based assumptions about the clinical population (Blandford et al., 2018). A knowledge-based model, based on input from clinicians, is used for the design process and possible outcomes of the intervention.

2.3.2 Design examples - criteria

This section examines the design approach and content of previously released DMHIs which assist the delivery of DBT for people who are undertaking or have undertaken DBT. I begin by defining my inclusion/exclusion criteria.

Inclusion criteria

Searches were undertaken in the latter half of 2020. Search terms were DBT apps, DBT interventions, DBT digital health interventions, DBT support. Searches were conducted using Google Scholar and PubMed academic search engines.

Exclusion criteria

Only apps which stated that they aided in the delivery of DBT for people with a diagnosis of BPD who were undertaking DBT, and which had empirical testing were included. Therefore, the following were excluded:

- online courses and apps which incorporated *elements* of DBT skills training into other treatments, such as CBT, (e.g. Wilks et al., 2018) or
- online courses and apps using *elements* of DBT to target specific behaviours, e.g. to assist people that self-harm (e.g. BlueIce, Stallard et al., 2018);
- smartphone apps targeting specific BPD symptoms, for example suicide ideation, that did not *explicitly* use DBT (for example in Ilagan et al. (2020));
- DBT skills courses delivered via the internet by online training providers (e.g. British Isles DBT Training, 2020);
- apps for use as mobile *Diary Cards* (see Section 2.4.4), which did not offer any skills coaching or provide a connection to a therapist.
- apps available on the App Store for DBT skills which had no traceable literature on design or evaluation.

After rejecting all of the above, four DMHIs fitted the inclusion criteria, discussed below.

2.3.3 The DBT Coach (Rizvi et al., 2011, 2016)

Prototype DBT Coach (Rizvi et al., 2011)

This pilot study developed a prototype text-based adjunct app for DBT patients, coaching them to use DBT skills outside the DBT programme setting. It was used with DBT patients who were also experiencing problematic substance abuse. The prototype app contained only one skill, namely Action Opposite, an Emotion Regulation skill (see

2.4.4). The intention of the app was to help patients to monitor emotional intensity and substance abuse urges. Participants were prompted to name their emotion and use the Action Opposite skill, if they could, to behave in contrast to the dictates of their emotions. For example instead of getting angry, to walk away or react in a calm manner. They were also coached in emotion-specific responses and given advice on managing impulsive behaviour.

Design/development

The prototype was developed iteratively using "extensive feedback" (2011, p.591) from Linehan (DBT founder), end-users with BPD and a co-morbid substance abuse disorder (SUD) and DBT clinicians. However, no further details are given, so the exact design process that was followed is unclear, for example, at what stage participants' information was used, what requirements were gathered from users and clinicians, how the skill used in the prototype was chosen and how the iterative refinements were made. It is not clear whether the skill chosen for the app (*Action Opposite*) was the choice of the clinicians or the patients. Lo-fi user-testing, early prototypes or beta testing of initial designs during development is not documented.

Evaluation

A pre-post evaluation design was used to test the app's feasibility in this patient group. This included clinical testing and usability testing of the new delivery medium (the mobile phone). Twenty-two patients were given a mobile phone with the app installed for an average of 12 days.

To create a baseline for the clinical results, a number of pre-trial assessment questionnaires were completed by the patients including a depression measure test, a test to measure use of skill components, and a 53-item symptom inventory used as an indication of "overall psychopathy". Therapists also completed an assessment questionnaire, asking about participants' skill use. The same assessments were completed post-trial for comparison.

During the trial, participants could use the app as much as they wanted. App usage was monitored on the phone and participants completed a short questionnaire on the phone daily asking them to score how helpful the app was in using the skill. In addition, therapists were contacted weekly to check that patients were not experiencing adverse affects from the app.

A post-trial questionnaire on satisfaction and usability was given. This included items like "ease of use, appearance, overall functionality, and acceptability". Participants scored these using a 5-point Likert scale. The questionnaire did not ask users to comment on why a certain score was given.

Results

In this pilot study, significant improvements in emotional intensity and substance abuse urges were reported by participants post-trial compared to pre-trial levels. Overall use was quite high and a liking for the app was reported. Results were fed into a full development of the app, discussed below.

UCD comment

Unlike in a UCD process, in a clinical design process, the initial design phases are not detailed, so it is unclear what was done. Users and clinicians are mentioned, but their role within the process is not elucidated. Neither is how an iterative approach was carried out. However, the evaluation stage is more involved than in a typical UCD process, using clinical measures. This is important due to patient safety issues, as well as the need to understand clinical as well as UCD outcomes. In developing DMHIs for vulnerable groups, UCD designers need to be aware of this.

Whilst the chosen skill may be useful from the end-users' point of view, it would be helpful to the design process, especially when extending to the full app, to know why this skill was chosen, whether the clinicians or end users saw this as a key skill or a helpful skill to practice, and how easy or difficult the patients found it, for example.

In terms of the UCD outcomes, a 5-point Likert scale, was administered, giving some indication of how the participants experienced using the app. However, adding an option for comment on why a certain score was given would have allowed the researchers information to understood *why* a particular question scored high or low, and what aspects were working/not working, to feed into the development of the full app.

Full DBT Coach study (Rizvi et al., 2016)

Following the prototyping of the DBT Coach app with one skill, in the extended DBT Coach study (Rizvi et al., 2016), the app was expanded to include all four skills modules. It also tracked self-harm urges. It was designed to provide interactive coaching in the use of DBT skills to individuals with BPD, and a recent history of suicidal or self-harming behaviour, undertaking DBT. The evaluation lasted 9 months, from week 1 of DBT to 3 months after the end of the 6 months' DBT programme.

Design/development

The DBT Coach prototype was "expanded to include most of the DBT skills from all four modules" (Rizvi et al., 2016, p.381). No details about the design process are given.

Evaluation

This app was evaluated post-development in a pre-post study. Initial, mid-way and end-point tests included an array of clinical measures as well as usability testing using a 5-point Likert scale. Participants were given the chance to suggest improvements, which included expanding the app to include different parts of DBT; requests for more skills and more coaching on the more difficult skills; expanding the mindfulness stimuli; more tailoring abilities to allow personalisation; and, push reminders. Rivzi et al. see the comments as possible input to a further version, but speculate that they would not know whether these additional features would increase frequency of use and/or improve the effects of the app on important outcome variables. This suggests that asking about these requirements before designing might be a useful way forward, but not one that clinicians like Rivzi et al. were used to or knew how to carry out. By documenting the UCD process of gathering requirements for a DMHI, researchers like

Rivzi et al would have an ISO defined process to follow, as well as an understanding of the considerable methodological work involved and the amendments to a UCD method which were necessary.

Of the 16 participants, four did not complete the experiment. Of those four one did not access the app at all and one did not provide any valid data from using the app. In addition, although the app seemed to have an immediate effect of relieving stress and anxiety, on average it was accessed less than twice a month by the participants.

Clinical findings show that the DBT Coach reduced distress and self-harming urges in the moment. The only treatment outcome which using the DBT Coach affected was a reduction in suicidality. The amount of app usage did not correlate with treatment outcomes apart from a drop in self-harm, where it was predictive.

Results

There were some usability issues with the app. The app was seen as easy to navigate, but it was not used as frequently as expected. Rizvi et al. report that the usability question found that participants were uncertain about how helpful the app was, how much they liked using it and how engaged they were with it. In addition compared to use of the one-skill pilot (Rizvi et al., 2011), which recorded a lot of use in the 2 weeks it was available, this app was accessed a lot less. Rizvi et al. posit that the longer-term availability of the app may have reduced the "novelty factor" making it less attractive to users. The design implications of this, for example building in changes to prevent boredom, or progressing in skills use as the client gets better at using the skills are not considered. One of the reasons asserted for users not using the app was either over- or under-familiarity with the skills, with both putting clients off using the app. Rizvi et al. (2016) posit there may be a "sweet spot" for clients using a skills coaching app. For new clients, with little experience of DBT skills, it may be too difficult to try the skills without more hand-holding or they may not know when to use a skill. Conversely, once clients have good skills ability, they might not need the app's detailed instructions. Again no design implications, for example, having different levels of exercise for clients at different stages in the DBT journey, are considered.

UCD comment

The design process in the full DBT Coach app has no details, so it is impossible to know what was done, whether end users were involved or if an iterative approach was carried out. In rating the usability of the app, it was seen as easy to use, but participants rated it low on how enjoyable and interesting it was to use. This may have been due to requirements not being used in its design and development, leading to the issues discussed above. It was evidently very good that suicidality was reduced, but if a DMHI is not enjoyable users will stop using it, leading to treatment attrition and less efficacy of treatment (Yardley et al., 2016; Torous et al., 2018).

2.3.4 EMOTEO

The EMOTEO app (Prada et al., 2017) was developed to track negative psychological states of high affect which could lead to self-harming and give participants Mindfulness and Distress Tolerance exercises to use when in these states. Few details of the design process are given and no user requirements or user-input at the time of design or used as input are detailed. The app was developed by a group of medical doctors and associates, specialising in psychology and psychiatry with one of the developers advising on the technical aspects, having“previously worked as a computer engineer”.

Sixteen participants used the app over 6 months. All participants were also enrolled in a DBT programme. In the app, participants rated their emotional state and according to their score were then offered a random video or audio mindfulness tracks to help to reduce their emotional stress. Clients used the app more in times of crisis and lowered their score by an average of 2 points, which lessened the threat of them self-harming. However, as they state, and as asserted in the DBT Coach, any changes in client aversive tension are difficult to attribute solely to the app, as improvements could also have been due to DBT therapy.

Investigating the usability and acceptability of smartphone use in this situation is the stated goal of the study. Participants used the app once a day on average, for around 2.5 minutes. They assert that this shows users had “a high level of satisfaction and an interest in the use of [the] app”. However, this is not a lot of time and it is unclear what they did during the 2.5 minutes. The study did not record whether there was any attrition in use or retention loss during the 6 months. Prada et al. assert that the next step is to test the effectiveness of the app in an RCT, before DBT clinicians and patients can use it in therapy. However, I was not able to find a research paper on an RCT, so it is not clear whether this was undertaken.

UCD comment

The design process is not detailed, so it is unclear exactly what process was followed here. In rating the usability of the app, it was seen as easy to use, but there was nowhere to record why a score was given, so that feedback could be taken into a further design of the app.

2.3.5 Medtep DBT

The development process of Medtep DBT (Suñol et al., 2017), an app and a web platform, is described in this paper. It aims to help BPD clients’ experience with DBT and to reduce self-harming behaviours by tracking emotional states and use of skills. A secondary aim was to help clinicians to monitor clients, thus reducing treatment time. The app has three main tools for clients: a Diary Card (see Section2.4.3) with a viewable history, a seven-step Chain Analysis,[2] and a Crisis Plan, which the patient completes themselves. Patients can add helpful individual actions or skill reminders, as well as emergency contact numbers. A shortcut to this feature can also be added to the home screen. The therapist version of the app allows access to all the information entered by the patient.

The sample in the pilot study was 20 clients, using the app over 6 months. Medtep DBT was developed using a team of psychologists, psychiatrists, one of whom had specialist

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[2] A DBT tool which allows clients to describe and evaluate in detail self-defeating and other problem behaviours.

DBT knowledge, and DBT clients. The design and development process is not given in detail, but the clients seem to have stated some requirements during this process, although these are not detailed. The DBT content came from the clinical experts, as would be expected. Low-fi design testing is not mentioned, so it is not known what was done. Round 1 beta-testing was done using the four patients whose "needs and experience" were used at the design stage with another four patients. Changes to the app were made based on the patients' responses. What and how it was tested are not detailed. Final beta-testing was done using a group of clinicians and a group of ten BPD-diagnosed clients who had not had input into the design. Again, the process and feedback is not given in detail. A number of very positive comments are given, and the feedback is stated to have been 'very satisfying', but no further details are available. Suñol et al. state that the criteria for the app was met using the clinicians' "professional experience and in-depth knowledge" (p.115), these are not detailed. The content of Medtep DBT was thus seen as valid. The feedback from the patients was used as input to iteratively develop the final version of the app, which is stated to be undergoing "a randomized Pilot Study" (p.115). This follow-up randomised pilot study of the app, which is stated to have been taking place does not seem to have been published as of September 2022.

UCD comment

There is a iterative design process taking place with experiential and requirements input from patients, and DBT and clinical input from clinicians. It is not clear if a designer was used to put everything together as the process is described in very general terms. This suggests that unlike in HCI, where detail is important, design and development are not seen as a rigorous process where replicability is important by the clinicians. Including a Crisis Plan, which allows clients to put together an individual plan for when things go wrong, is a standard part of DBT and including it in an app is a nice idea and possibly really helpful. It would have been good to know where this requirement came from and how patients reacted to it, to understand the design process better.

The results from testing the beta version of the app are not detailed and potentially biased toward positive reactions, with no criticisms given. As a limitation, the paper states that a social forum for client communication would be desirable, but there is no indication of a requirement for this from the clients. In addition, whilst this may be a useful feature, once clients have completed a chain analysis, they then have to work out which skill to use on their own - this is a recognised part of DBT, but clients often need coaching through this (Linehan, 1993), and if necessary look up how to do it, this support is not part of the app.

2.3.6 Pocket Skills

Pocket Skills (Schroeder et al., 2018) is a mobile web-based app, which educates and teaches users about DBT skills and includes a conversational agent modelled on DBT developer Marsha Linehan (called *eMarsha*). DBT modules of Mindfulness, Emotion Regulation, Distress Tolerance and Addiction Skills are included. Each module has an Introduction which must be viewed and module goals must be set before skills can be accessed. A Diary Card is included, as are daily text messages to remind users to engage with the app.

The app was developed by a team including DBT and HCI experts, but there are few details about the process and no details on talking to DBT client end users or requirements gathering. As in the DBT Coach (Rizvi et al., 2011), an iterative approach using DBT clients for usability testing at different stages of the app development was used. The design decision to include a conversational interface was taken by the researchers, but this was not seen as a requirement. Users were not asked beforehand about the conversational interface, as Schroeder et al. (2018, p.4) state: 'We hoped using [Linehan's] image as the conversational agent would...foster trust in the content.'

In the initial app development users had to go through a long training session on the basics of the skills, before being able to access them. However, on testing it was found that users wanted a faster way to access skills that they already understood, so a skills practice section was added. Schroeder et al. (2018, p.10) acknowledge the importance of talking to users, although this is not of immediate importance to them, as they state: "In the future we hope to investigate exactly how people and therapists would like to use Pocket Skills, both individually and collaboratively."

Like in the other three app studies, the participants were also receiving DBT, making any changes difficult to attribute solely to the app, as improvements could also have been due to DBT therapy. No comparison condition was included in the study. The final version of the app was tested on a larger sample than the previous studies ($n = 73$). Although not all of the participants had a diagnosis of BPD, all were undergoing DBT. Participants reported an increase in DBT skills use. However, the conversational interface elicited a mixed response with only 31 participants liking the interactive interface and seeing it as engaging. Marsha Linehan was seen as trustworthy by less than half the participants ($n = 29$). However, some participants interpreted interactions with *eMarsha* as like a human coach, even though she is completely scripted. Eight participants did not like *eMarsha*, which stopped them from engaging in skills training. However, some of the more introverted participants reported appreciating the absence of a real human.

The usability questionnaire included open-ended qualitatively analysed questions on the app use and usability, allowing detailed feedback to be collected. DBT is only successful when clients fully engage with it and start using the skills (Neacsiu et al., 2010). Most participants (59) thought that Pocket Skills was engaging and had helped them learn and practise their DBT skills, particularly in daily situations. Availability was seen as key, because participants could practice when outside the home, and this kept the skills in the foreground. However, having to be connected to a WiFi network could make life more difficult for the participants in a study of this kind. For Schroeder et al. the implications of this model of delivering DBT skills is that it helps clients to use the skills in their daily life. It brings skills group practice and real life contexts closer together. In addition, they assert that mental health treatments need a mobile component, particularly those which involve learning and using skills.

UCD comment

Again there are few design details and requirements are not used to justify the inclusion of features such as the conversational interface. In addition, there was little flexibility in the app. This is reflected in the assessment of the app, which showed a mixed response, with 31 of the 59 participants liking the interactive interface and seeing it as engaging. Some clients were put off by the human interaction in the app and this was not a feature that could be turned off.

There are other signs that user requirements were not gathered. For example, in the initial app development another design decision forced users to go through a Module Introduction with a long training on the basics of the skills, before being able to access them.

This app was more successful than the previous ones and had more design input. However, it is still lacking flexibility and is not clearly based on user requirements or a design process. Using such a process may help to increase engagement and retention.

2.3.7 Overview of the design process in DBT apps

As shown, the research was documented from a clinical perspective, with the initial design processes not very well documented and user testing given less prominence in the process that in a UCD process. Design practices in Healthcare interventions have a different focus from those in HCI. Clinical outcomes and patient safety is paramount. As the examples in this section have shown, in developing DMHIs for DBT, the Health literature does not detail design specifications, even when users are involved in the process. Exactly what was done and the artefacts in terms of requirements specification are not presented. Therefore it is assumed that design is not done in a methodical way or it is not reported, because this is not considered necessary in this literature. In addition, previous solutions are sometimes proposed and reused when designing DMHIs in the Health literature. For example, The DBT Coach did not report any difference in the design from the pilot to the full version. Compared to the UCD design process given in Section 2.2, particularly in the early days of DMHI design, there were gaps in the way that the Health literature describes designing DMHIs for people living with a mental health disorder.

As can be seen, in the DMHIs overseen by Linehan (The DBT Coach and Pocket Skills) the design process evolved and improved, between 2011 and 2018. There is an increasing mention of involving users in the design process, but this is not given in a lot of detail. However, all the DMHIs have a focus on post-design testing for usability. This is often a not very well defined concept, which is tested quantitatively using Likert scales. This is a good way to ask about usability features; however, to understand why a score has been given, it is a good idea to also allow participants to give qualitative explanations for their ratings (Sharp et al., 2019; Adams & Cox, 2008). In the Health literature, usability feedback is seen as a way to measure what patients thought, rather than a way to improve the DMHI design.

There are a number of problems with these approaches. Firstly, by reusing familiar solutions to simplify the problem space as seen in the DBT Coach (Rizvi et al., 2011, 2016), important complexity and issues found in the previous version may be lost.

However, because UCD emphasises people and their experiences, attention is directed to the use and user-appropriateness of any design ideas.

2.3.8 HCI and Health growing close

Different research fields have their own established practices for conducting research, so that when they encounter HCI problems, they may not be aware of the established methods HCI has developed (Cairns & Cox, 2008). Whilst this may have been the case 10 years ago, since then there has been huge progress in how the design of DMHIs in Health has become more HCI focused, and the design element is now written about more methodically. Due to the cautious nature of healthcare, due to its primary concern with patient safety, this progress is still slow. However, NHS England uses a UCD approach (Okafor & Akcay, 2024), which is very encouraging.

Clearly clinical objectives and outcomes are still important outcomes, but if an app is not usable, engagement and retention of users will be difficult (Bakker et al., 2016). So that within the Health literature, there are more calls for design engagement. Mental health clinicians need to know that "they are prescribing and administering" DMHIs correctly, so that the correct patients receive treatment for the correct diagnoses, using a suitable digital system, which is based on a sound evidence-based foundation Søgaard Neilsen & Wilson (2019). They believe the way to do this is through HCI design as a fundamental part of the process. If the design process is not fully followed in the DMHI development process, clinicians may not fully comprehend the unique needs of end users within the context of a DMHI, until after the product has been released (Huckvale et al., 2019). This wastes time and money and leads to the intervention being less efficacious than hoped. Bond et al. (2023) assert that those involved in the development of DMHIs should "be sure to consult all stakeholders in the design of digital mental health technologies, for example, we should consider the client needs, the reliability of the technology and the endorsements of the healthcare professionals." (p.7). My research, uses an adapted UCD process, which shows researchers how they might use the first two steps in the UCD process to gather user requirements in a mental health setting.

2.3.9 Conclusion to Health

This context examined design research in Health. I present an argument that health researchers, especially pre-2018, often did not report on their early design work – and perhaps did not engage in design work in a methodical manner. From the literature, it was not clear how best to design DMHIs in this context and to aid with this, I detail the methodological work which is necessary to take this approach in a mental health setting, which other researchers working in a similar context can learn from.

The next section looks at the therapeutic context, revealing why it is so challenging, detailing the complexities of BPD and the therapy used in this research, DBT.

2.4 Therapeutic context

There are a large number of psychotherapies to help those with mental health disorders to change behaviour, cope with symptoms and understand issues and problems.

2.4.1 Borderline personality disorder (BPD)

BPD is a debilitating, pervasive mental health disorder of the emotion regulation system, in which severe instability in emotional responses, identity and relationships lead to dysfunctional and parasuicidal behaviours[3] (APA, 2013). The DSM-5 (APA, 2013)[4] categorises BPD as a Cluster B personality disorder (the "dramatic, emotional, erratic" cluster). It is estimated that 1.5% of the US population has a Cluster B personality disorder (Lenzenweger et al., 2007), although Grant et al. (2008) put this as high as 5.9%. Self-injury rates are usually high (up to 90%) (Goodman et al., 2017). There is also intensive use of mental health services and impairment is considerable compared with other personality disorders (Lenzenweger et al., 2007). The majority of BPD diagnosed clients in clinical settings are female (Gunderson, 2014); however, some surveys suggest an equal prevalence of BPD in males and females in the community (Lenzenweger et al., 2007). The situation with gender and diagnosis is complex and outside the scope of the thesis; there is a useful discussion in Sansone & Sansone (2011) about gender with regard to BPD, personality traits and treatment access.

Indicators for BPD include (Linehan, 1993, 2014; APA, 2013):

- Chronic patterns of instability in identity or self-direction; unstable self-image, excessive self-criticism and enduring feelings of emptiness and loneliness. Tendency to polarise and over-simplify, processing experiences and relationships in all-or-nothing terms. Incorrect or distorted beliefs may cause changes in behaviour or misinterpretation of others' actions and motivations.
- Difficulties in interpersonal relationships, especially in empathy or intimacy. Relationships are often intense, vacillating between intense love and hatred, with strong fear of rejection or abandonment. Relationships may be left or ended with undue haste.
- Dysregulation of the emotions, experiencing extremely intense emotions which take a long time to dissipate. Strong secondary emotions such as shame can then emerge, triggering the primary emotion in a repeating cycle. This makes it more difficult to return to a stable emotional baseline.
- Impulsive behaviour, substance abuse, eating disorders, promiscuity, risk-taking behaviours and impulsive overspending in an attempt to stop or mask the intense affect. Self-harming, suicide and parasuicidal behaviour also found.
- Feelings of dissociation, in which after triggering of an unpleasant or painful memory or emotion the normal working of consciousness, memory, identity or

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[3] This means non-lethal intentional self-harm and suicide attempts.

[4] Produced by the American Pyschiatric Association, DSM–5 (the Diagnostic and Statistical Manual of Mental Disorders) defines and classifies mental disorders using international authorities in all areas of mental health. It is considered the authoritative guide to the diagnosis of mental disorders in the USA.

perception of the environment is disturbed. For example, feeling like events which are happening are unreal (derealization).

- Persistent feelings of anger and hostile over-reaction.

BPD is extremely distressing and one of the most difficult disorders to treat for mental health clinicians (Brassington & Krawitz, 2006). The causes of BPD are complex and not fully understood. However, there is frequently a history of sexual, physical and/or verbal childhood abuse, neglect or trauma (Zanarini et al., 2000). Linehan (1993) sees the causes of BPD as biosocial, coming from the *transaction* between biologically-based difficulties with emotion regulation and an invalidating environment. Invalidation of emotional responses, beliefs and expression in childhood by punishment or ignoring them causes the child to feel that their emotions should not be displayed and that the underlying reasons for the emotion must be dealt with internally or cannot be trusted. Thus, the child does not learn how to deal with the problem or the emotion, leaving them more emotionally vulnerable (Robins, 2002; Crowell et al., 2009). They develop a distrust of how they feel, extending to an unstable self-image. As adults, there is a lack of skills to regulate behaviour due to an inability to manage emotional stimuli or regulate reactions (Van den Bosch et al., 2012). This is often interpreted as manipulative or wilful behaviour, leading to feelings of invalidation and self-defeat, which affects functioning at the interpersonal, cognitive, affective and behavioural levels (Van den Bosch et al., 2012). This activates self-harming and other self-defeating behaviours, which help temporarily, but longer-term lead to shame, guilt and further feelings of self-invalidation.

2.4.2 Treatments for BPD

Medication has a limited role as a reliable treatment for BPD, with RCTs[5] showing inconsistent results (Ingenhoven, 2015; Lieb et al., 2010) and no medication with a validated indication for BPD (Bozzatello et al., 2020; Gunderson, 2014), which makes primary care treatment difficult. However, although in the twentieth century BPD was seen as untreatable, by the early 21st century, successful treatment using evidence-based psychotherapies challenged this idea (Choi-Kain et al., 2017). Today, psychotherapies are widely used in the treatment of BPD. However, general mental healthcare professionals must undertake highly intensive training to work with clients/patients with this challenging disorder. The psychotherapies used recognise that support for clinical practitioners is essential within the treatment when working with these clients to prevent burn-out (Linehan et al., 2000).

Empirically-supported psychotherapies are considered the gold standard in therapeutic interventions, and five major evidence-based treatments for BPD have been empirically validated (Stoffers-Winterling et al., 2012; Choi-Kain et al., 2017). The most well-known, well-researched, and most widely available therapy, and the one used in this research, is dialectical behaviour therapy (DBT, Linehan et al., 1991). A discussion of the comparison between DBT and the four other gold standard therapies is given in Section 2.4.5, following details of the different components comprising DBT treatment.

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[5] See glossary for an explanation of RCTs.

2.4.3 Dialectical Behaviour Therapy (DBT)

DBT, the focus of this case study, was used at the *Tuke Centre, York* to treat clients with a diagnosis of BPD. DBT was originally developed to treat chronically suicidal patients (Linehan et al., 1991). It then grew into a comprehensive cognitive behavioural treatment for BPD (Linehan, 1993a, 1993b). DBT is a therapeutic method based on teaching practical skills to help deal with and overcome intense affect responses, leading to dysfunctional behaviours, with poor life quality and psychosocial functioning in those with BPD. It is a modular therapeutic intervention which is primarily concerned with improving dysfunctional behaviours (see hierarchy in Section 1.1.3). Its underlying skills deficit model sees those attending DBT as being self-destructive due to having both a lack of skills in many behavioural domains (for example, being mindful, interpersonal relations, emotional regulation and distress tolerance), as well as a lack of motivation in using any skills they might have (Wilks et al., 2016; Dimeff & Linehan, 2001). DBT proposes that clients with BPD can become more effective in managing their sensitivities and interactions with others through acquiring skills that enhance mindfulness and tolerating distress, with more regulation of the emotions.

DBT is based on cognitive-behavioural principles and strategies, and incorporates acceptance-based philosophy and practice with a dialectical stance and mindfulness from Zen Buddhism (Linehan, 1993, 2014; Brassington & Krawitz, 2006). It is a manualised therapy based on a detailed framework taught to therapists through a rigorous training regime (Linehan, 1993; Rizvi & Swenson, 2010). It comprises four facets: *skills training* in 2-hour weekly group session with worksheets for each skill, one hour of weekly *individual psychotherapy*, intersessional *crisis skills coaching* and a therapists' *consultation team meeting*. DBT was developed to be implemented by a team of clinicians and is one of the most time intensive psychotherapies for both clients and clinicians (Choi-Kain et al., 2017).

The therapy is described below in Section 2.4.4. I then examine the efficacy of DBT in Section 2.4.5, discussing how RCTs showed the efficacy of these psychotherapies to be high in the first 15 years of the 21st century, but more recent meta-analyses of these therapies have highlighted issues both in the strength of the evidence and in study replicability.

2.4.4 DBT therapeutic details

Dialectics

The therapeutic approach in DBT is founded on a dialectical stance, which views the facets of the therapy as only making sense when seen as part of a whole. At the same time, dialectics is also the strategy used to bring about change in the client (Linehan, 1993; O'Toole et al., 2012): in DBT, counselling is approached as a discourse between the client and the therapist. There is a belief that the client can and will change, but also an acknowledgement of the client as they are in the current moment, with all their self-defeating behaviours. Thus, the central dialectic in DBT is *acceptance and change*. Acceptance allows the client's experience and even their maladaptive behaviours to be validated, given past trauma and frequent invalidation during the formative years. However, whilst validating the client's responses within the context of their personal history, the therapist also discusses with the client how their responses and behaviours are dysfunctional within the wider present day context, encouraging responses which promote and maintain beneficial behaviours. DBT therefore looks for dialectical synthesis, with the goal of getting the client to adopt behaviour patterns which are balanced between accepting the current status quo and wanting to make changes (Rizvi & Swenson, 2010). DBT can take a long time to learn; therefore, *acceptance and change* is important for clients and therapists when clients are unable to learn the skills straight away and possibly repeatedly return to self-defeating behaviours, such as self-harming. In the case of the core skill of Mindfulness, which often takes the longest to learn, this may be especially important.

DBT skills

DBT skills training tackles the most frequently reported BPD symptoms in weekly, two-three hour group skills training workshops. DBT skills focus on particular areas of emotional dysregulation and behavioural skills, characterised as lacking in BPD. Clients are expected to practise using the skills outside the group setting, with experiences and reflections discussed at the beginning of the following skills session. Skills training is an important part of DBT. Interventions that include skills training result in less self-harm and depression than DBT without skills training (Linehan et al., 2015). It is also associated with lower dropout rates and greater clinical improvements compared with group therapy alone (Soler et al., 2009). As DBT can be long and expensive, the skills element has sometimes been extracted and taught as a standalone course (Valentine et al., 2015; Linehan et al., 2015).

Mindfulness – the core skill

In the DBT context, the definition of mindfulness extends that of Kabat-Zinn, directing how it should be practised: "*the intentional process of observing, describing, and participating in reality nonjudgmentally, in the moment, and with effectiveness*" (Dimidjian & Linehan, 2003). *Observing*, *Describing*, and *Participating* are specific DBT Mindfulness *skills*, explored in Section 2.5.5 and *Effectiveness* is an Emotion Regulation *skill*. DBT clients are directed to use Mindfulness skills to increase awareness of and pay more attention to the emotions leading to better emotional regulation (being *Effective* in DBT terms).

Mindfulness was introduced into DBT to aid emotion regulation and self-knowledge, with the idea this would help to bring about understanding, and acceptance and change, enabling clients to make better choices (Linehan, 1993). A short Mindfulness exercise (1 - 2 minutes only) is practised at the start of every skills group and consultation team meeting. The DBT Mindfulness skill involves maintaining non-judgemental awareness of what is happening in the current moment, bringing the attention back to the focus when the thoughts wander, often using objects brought into the workshop by the skills trainers. Mindfulness in DBT is divided into three types of exercise, *observe*, *describe* and *participate* (see Section 2.5.5 for further details). Using the skill of Mindfulness facilitates emotion regulation (Garland & Fredrickson, 2019; Baer et al., 2004) because it helps patients to recognise intense affect and aids in regulating emotional responses, which in turn helps to lessen self-harming and other self-defeating behaviours (Gratz & Tull, 2011).

Mindfulness skills are seen as foundational for the other skills (Linehan, 1993, p.144), as changing behaviour builds on clients observing their behavioural responses. Once they focus on their responses, they can then use another skill if necessary to help change the behaviour, for example, to interrupt rumination or help to control impulsive urges (Robins, 2002). It is also the skill which the requirements interviews (discussed in Chapter 4) reveal that clients struggled the most to learn, understand and put into practice. As Mindfulness is a central part of DBT and the thesis, its practice in DBT is expanded on in Section 2.5.5.

Distress Tolerance

The Distress Tolerance module teaches clients skills to *endure* distressing and painful events, but not how to change the situation. This is used in order to lessen or stop self-defeating behaviours, as before fully mastering the skills, DBT clients need considerable support with distressing thoughts and emotions. DBT discourages self-harming and other self-defeating behaviours, which is often the clients' established way of coping with intense affect and distressing thoughts (Linehan, 2014). The client initially learns to manage and survive challenges without self-harming by using Distress Tolerance skills.

Emotion Regulation

Emotion Regulation teaches identification of and coping strategies for intense emotions (Linehan, 1993, 2014). After using Mindfulness to become aware of somatic sensations and cognitive processes, emotions can be recognised and accepted using this skill. This module has the goal of helping clients to understand their emotions, reducing emotional vulnerability and decreasing emotional suffering. It teaches an understanding of different emotions, as it can be a challenge for clients to recognise different emotions. It also examines why emotions evolved and how they can be useful. Erroneous beliefs about emotions are challenged, for example, clients may block negative emotions completely, because they feel strong affect. Therefore, part of this module is about reducing vulnerability to *emotion mind* by lowering emotional responses to a situation, but without completely blocking them. It also addresses decreasing emotional suffering, again using Mindfulness to be aware of the emotion, noting its presence and then creating distance from the emotion. This module also addresses ways to deal with the emotion of shame which many clients feel about their abuse and their behaviours.

Interpersonal Effectiveness

This module teaches assertiveness training and problem-solving skills. These skills are especially important to DBT clients, as they frequently experience turbulent relationships, alternating between avoiding conflict completely or having a confrontation accompanied by intense emotions. The skills taught in this module therefore help to improve the quality of clients' relationships and the outcome of interactions. Skills for use in conversations are taught, in particular when requesting something or declining/refusing a request. In this module, conversations are considered in a deliberate way. Instead of acting or reacting due to an emotional response to a situation, Interpersonal

Effectiveness skills offer clients respect and integrity in conversations. In teaching this skill, clients are asked to think about three types of effectiveness and which one is their current priority (obtaining a goal, maintaining a conflict-free relationship or maintaining self-respect), depending on the purpose behind an interaction. The priorities then set the tone for the conversation and the other skills used.

Other facets of DBT

Individual psychotherapy

Individual sessions are focused around a hierarchy of target behaviours and motivations for using the skills to change the behaviours, which the client develops in consultation with the therapist (Robins, 2002; Baer et al., 2004). Sessions target the most important areas first, such as life-threatening or serious self-harming behaviours. A weekly Diary Card is used to track behaviours and this helps to determine what will be discussed in the therapy session.

Crisis skills coaching

Clients are able to communicate with a therapist between sessions for skills coaching using the telephone, email or text, when they are experiencing times of challenge, such as thoughts of self-harming or other therapy-interfering behaviours.

Therapists' consultation team meeting

Therapists working within the DBT framework have a weekly consultation team meeting where they can voice any professional concerns about clients, as well as therapeutic issues they might be having. The group is encouraged to use DBT skills on their own behaviour, as well as the clients'. This feature was introduced to stop therapists burning out, which can happen when treating clients with BPD, as dealing with immediate life threatening behaviours and serious emotional dysregulation, whilst also trying to achieve longer-term changes, is highly demanding, and seen as a complex task (Linehan, 1993).

2.4.5 Efficacy of DBT - quantitative research

DBT is asserted to be an evidence-based and empirically supported therapy, based on criteria for determining when a therapy can be considered efficacious developed by Chambless & Hollon (1998). They stress the necessity of independent replication before a therapy can be deemed efficacious, with randomised controlled trials (RCTs) having the most impact, but they also emphasise following up RCTs with studies on therapeutic efficacy in clinical settings, using diverse participant groups. This section discusses the efficacy of DBT; compares DBT to other evidence-based treatments, including the gold standard major treatments; and, examines the findings from short- and long-term qualitative studies of DBT.

Comparison of DBT and other gold standard treatments for BPD

Five major evidence-based treatments for BPD have been empirically validated (Stoffers-Winterling et al., 2012; Choi-Kain et al., 2017). As well as DBT, the other four gold standard therapies are systems training for emotional predictability and problem solving (STEPPS, Blum et al., 2008); mentalisation-based treatment (MBT, Bateman & Fonagy, 2009); schema-focused therapy (SFT, Giesen-Bloo et al., 2006); transference-focused psychotherapy (TFP, Clarkin et al., 2007). The main reason these five specialised, intensive psychotherapies are considered to be of gold standard, and particularly helpful in the treatment of BPD, is their inclusion of a number of different facets: group therapy, individual therapy sessions, consultation team meetings and intersession skills coaching (Finch et al., 2019). However, of the five gold-standard treatments, DBT is the only one used solely for the treatment of BPD, with the other four also used in the treatment of other personality disorders and other mental health conditions.

As discussed below, a number of RCTs compare the major treatments; however, comparison research in this area reveals few differences between the gold standard treatments, with Choi-Kain et al. (2017, p.22) asserting that there is little achieved from "horseracing to determine the superiority of any of them". Comparing DBT and MBT (mentalisation-based treatment), DBT clients had significantly fewer incidents of self-harm and better emotional regulation after 12 months of treatment than MBT clients (Barnicot & Crawford, 2019). By contrast, Clarkin et al. (2007) found positive changes in outpatients using both TFP and DBT, seeing the two as broadly equal with respect to wider positive changes in BPD presentation and suicide reduction rates, with some differences emerging. For example, TFP was superior to DBT for improving general BPD symptoms, anger control, depression and anxiety, and showed improvement over more variables (10 out of 12 compared to 6 out of 12 for DBT). However, in a comparison of TFP and SFT, Giesen-Bloo et al. (2006) found that, whilst both treatments showed significant clinical improvements in patients in all metrics after long-term (3+ years) treatment, for all measures, significantly more SFT patients had recovered or were showing clinical improvement than TFP patients. Fassbinder et al. (2018) are currently running a study comparing DBT and SFT, asserting that they are the first to run such a comparison. As of November 2022, the results of this study have yet to be published.

Other studies compare the gold standard treatments to treatment as usual[6] (TAU). Storebø et al. (2020) found MBT was more effective than TAU at reducing self-harm, suicidality and depression. However, the only outcome to show a significant improvement was the severity of BPD. No evidence was found of a difference in effect estimates between the different types of therapy. In an analysis of 75 RCTs, 16 different psychotherapies were found to have been used in the treatment of BPD (Storebø et al., 2020), with DBT and MBT having the most primary trials. Compared to TAU, DBT was more effective at reducing BPD severity, self-harm and improving psychosocial functioning. In the 75 RCTs examined in Storebø et al. (2020), compared to TAU, DBT had better results for BPD severity, self-harm and psychosocial functioning, whilst MBT showed less self-harm and suicidality at the end of treatment.

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[6] Treatment as usual refers to participants receiving whatever existing treatments are available and accessible in their community or health care system.

However, there may be a problem with these early studies. Recent work in systematic reviews and meta-analyses examining evidence for the claims of efficacy of DBT and other major treatments for BDP in RCTs suggests that the evidence across a number of metrics in these earlier studies may be unreliable, weak or lacking (Storebø et al., 2020; Sakaluk et al., 2019), and a number of researchers suggest there is a lack of real-world studies which are able to replicate results in mental healthcare settings (for example, Fassbinder et al., 2018). Whilst Stoffers-Winterling et al. (2022, p.538) suggest there is "reasonable evidence to conclude that psychotherapeutic interventions are helpful for...BPD", they assert that we need more replication studies to increase confidence in the results. Storebø et al. also suggest that the evidence on which early results are based is of low-quality. Further discussion of this 'crisis in replicability' in Health Science is interesting, but outside the scope of this thesis. However, as shown in the qualitative research discussed below, and my research in Chapter 4, DBT is considered by healthcare professionals to be efficacious in the treatment of BPD.

Other comparative efficacy research

As well as comparisons between the gold standard treatments, RCTs of evidence-based treatments for BPD have been categorised into three other categories (Choi-Kain et al., 2017): comparison to treatment as usual (TAU), comparison to treatment by community psychotherapists and comparison to standardised generalist approaches.

Treatment as usual (TAU)

A number of RCTs found that DBT was efficacious in the treatment of BPD compared to TAU. Linehan's original RCT (Linehan et al., 1991) found DBT significantly reduced parasuicidal behaviour, inpatient psychiatric stays and treatment drop out (considered BPD's most challenging features) compared to TAU and showed better therapy retention than TAU. Other RCTs also found positive results for the efficacy of DBT (Koons et al., 2001; Verheul et al., 2003; Linehan et al., 2006; Clarkin et al., 2007). Those studies also assert that DBT reduced other problems associated with BPD, including self-harming behaviours, non-lethal suicide attempts, suicidal ideation, hopelessness, depression and bulimia. In addition, DBT has shown efficacy in RCTs for chronically depressed older adults (Lynch et al., 2003). Particularly in BPD women who are at serious risk of death by suicide there is considerable evidence to show that DBT is effective (Linehan et al., 1991, 1994, 1999, 2006, *inter alia*). Compared to TAU in suicidal women, DBT was found to be more cost-effective with fewer inpatient days, fewer and less severe parasuicides, fewer emergency visits and fewer clients dropping out of therapy (Linehan et al., 1993; Swales et al., 2012). DBT was also found efficacious in an acute-care psychiatric inpatient unit for adolescents (Tebbett-Mock et al., 2020).

There is frequent comorbidity between BPD and other psychiatric disorders where emotional dysregulation can cause undesirable psychological states (Fornaro et al., 2016; Linehan, 1993), such as post-traumatic stress disorder (PTSD), substance abuse and eating disorders. DBT use has also been extended to these areas and behaviours. Several studies have looked at substance abuse in people with BDP. Linehan et al. (1999) found DBT was more effective than treatment as usual (TAU) in treating women with BDP who were also dependent on a range of drugs, with the women in the DBT programme using drugs less both during and after treatment. Retaining clients in the DBT treatment was more effective than TAU, which Linehan speculates may be due to DBT directly addressing therapy-interfering behaviours. Linehan sees this as further evidence that DBT is efficacious in treating BPD clients experiencing a variety of issues. DBT was found to be more effective than Comprehension Validation Therapy with 12-Step in heroin dependent women with BPD (Linehan et al., 2002). van den Bosch et al. (2002) found that DBT could be used with more success than TAU on a group of mixed substance abusers and non-substance abusers with BPD (Linehan et al., 1999). Female binge eaters who also met clinical conditions for BDP responded very well to DBT treatment, with 82% no longer bingeing by the end of the experiment (Telch et al., 2000). DBT was also found effective in two groups of female juvenile offenders in a mental health unit and a general unit (Trupin et al., 2002) compared with a third unit where no treatment was given. Problems with the juveniles' behaviour and staff responses were found to decrease in the mental health unit, but not the general unit, although individuals within this unit showed improvement in self-harm risk scores.

Treatment in the community and generalist approaches

DBT has also been compared to treatment by community psychotherapists with a specialist interest in BPD. Treatment by community psychotherapists helped reduce symptoms, but DBT showed higher reductions in suicidal behaviour, self-harm, inpatient stays, and treatment drop (Linehan et al., 2006; McMain et al., 2009). The gold standard therapies for BPD have also been compared to standardised generalist approaches applied systematically and using specialist knowledge of the complex problems seen in BPD. These studies examine the essential elements of the therapies and their benefits as effective intensive treatments, with findings suggesting that such generalist treatments, particularly when delivered systematically by experienced clinicians produced results as good as TFP and MBT. In a dismantling study of DBT which analysed the essential components of treatment for BPD, Linehan et al. (2015) also asserted that a simplified version of DBT that used the skills training group combined with weekly case management was effective in treating self-harm and suicidality, and reduced cases of hospitalisation. Thus, using skills training and case management is almost as effective as standard DBT, but does not require the substantial financial and clinical resources required by full DBT. In this case, a DMHI supporting the skills would be a potential asset for the clients.

2.4.6 Efficacy of DBT - qualitative research

A small number of qualitative studies have been conducted to explore clients' and clinicians' experiences of DBT, its effectiveness and barriers to skills acquisition. Little et al. (2018) offer a systematic review of seven major high-quality studies. All included studies were assessed as having clear research aims and using an appropriate qualitative methodology. In addition Simons (2010) explores client and clinician experiences in a PhD thesis using interviews analysed with discourse analysis, as I do in study 2 (Chapter 4).

There was considerable consistency in the studies' results. The participants interviewed in most studies were clients, with only Perseius et al. (2003) also interviewing clinicians. The clients reported a number of similar experiences. For example, the efficacy of DBT in effectuating a process of change from life before DBT to the impact the treatment had had on their lives. Self-efficacy in DBT was seen as extremely important in this process. All of the studies discussed how clients saw learning DBT skills as critical to being able to better manage intense affect and handle distress. Participants described how the skills had helped them to manage situations that would previously have overwhelmed them, leading to self-defeating behaviours, like self-harming. The process of skills development, through practice and growing confidence in the skills working, was seen in a number of the studies. In a number of studies, clients emphasised the importance of the need to take ownership and responsibility for their own DBT skills development, which allowed them to be more effective and responsible for learning and using the skills, thereby changing their lives. Participants reported having a better understanding of themselves and the issues caused by BPD which lead to self-defeating behaviours. They also reported having an acceptance of the issues and the fact that DBT did not make the issues disappear, but gave them the ability to manage them better.

Perseius et al. (2003) interviewed ten female participants. Results show that, as in the other studies, life before DBT was difficult. DBT was described as “life-saving”, providing skills for clients to overcome parasuicidal impulses, accept their feelings and manage their lives better. As in other studies, such as Simons (2010), the clients mentioned that they had encountered negative and “disrespectful” attitudes towards them in previous therapy. Simons (2010) asserts that BPD clients are often seen as difficult to work with and face discrimination from clinical staff without specific training in dealing with BPD clients/ patients. This finding was not reported in all studies; however, this does not mean such discrimination did not occur.

The clinicians reported that DBT is life-changing for the clients, but DBT was seen as hard work by both clients and clinicians. The clinicians saw the *therapy method* as the most effective component of the therapy as it is respectful towards clients, taking them and their problems seriously. It encourages clients to be responsible for making their situation better and to actively participate in the therapeutic process. However, the methodology in this study was slightly problematic as the interviews took place at the DBT clinic, which may have led the clients to be less critical of DBT and the therapists. That said, the location may equally have made them feel more secure and able to answer questions as it was a stable, known environment. More problematic was interviewing the DBT therapists in a group, which may have led to the opinions of more dominant or senior team members being asserted and agreed with over those of more junior or quieter team members. Individual interviews would have helped to overcome this problem.

Similar results to this study were reported in Cunningham et al. (2004), who interviewed fourteen female DBT clients. Again, DBT was seen as life-changing, with the skills helping clients to better cope with life. The clients saw gaining confidence and hope for the future as significant. They also considered the therapeutic relationship as extremely important to both validate and push them. However, moving skills from theory to daily life was seen as problematic. Overall DBT was seen as effective in helping to build a *life worth living*, although the study reported an imbalance in the skills that clients used, with some skills, such as *Self-soothe*[7] and *Distract*[8] being commonly used, but others, such as *Radical Acceptance*[9] being rarely used. I suggest this imbalance may have arisen because accepting a painful past (or present) situation like abuse or trauma, without triggering strong affect, is a difficult skill for anyone. From my observations of this skill being taught at the *Tuke Centre*, clients felt that this skill was letting their abuser "off the hook" in some way, although the motivation behind teaching *Radical Acceptance* is not about giving approval, but rather to encourage clients to accept things that cannot be changed, even if they are do not like what happened. This then stops them from becoming stuck in cycles of unhappiness, bitterness, anger and sadness, and ruminating about the past, and therefore ultimately helping them to not suffer.

As in Perseius et al., Cunningham et al. reported that there was a clear belief that change comes from within, and only when an individual takes responsibility for making changes will progress happen: '...it's about me getting off my ass and getting my shit together, not a counsellor doing it for me, and that's why it works' (p.251). In this study, the clients were at different stages of DBT, so were able to discuss their experiences at different stages of the therapy, in particular the struggles they faced at the beginning. This may have been forgotten if they had all completed the treatment. However, this inconsistency can make it more difficult to compare results between clients.

In Hodgetts et al. (2007), unlike in the other studies, some negativity towards choice about DBT was expressed. At the beginning and pre-therapy, the clients believed that there was a lack of agency or choice in undertaking DBT, as it was promoted as the only option by the health service. In the early stages, whilst some clients took to DBT straightaway, others initially felt disbelief/distrust in the therapy, although as in the other studies, therapists were seen as helpful in making changes happen. However, commitment to doing the homework was seen as crucial. Overall, the clients thought that DBT worked, but some clients felt there was an element missing. This was also one of the findings in my study analysis, discussed further in Chapters 4 and 7.

Hodgetts et al. address the ethical point about the potential difficulty of interviewing clients with "intrusive thoughts and dysregulated emotions" (p.342), which I also found important to consider when conducting this type of research. Similar to my findings, contradictory accounts were found in their interviews (see Section 4.6.5), but they assert that participants were able to narrate their experience in a clear enough way. One criticism of this research is that some of the interviews took place up to a year after clients had completed the treatment. This may have led to distorted or forgotten

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[7] A Distress Tolerance skill using mostly physical techniques to reduce the intensity of negative emotions, distress or overwhelming emotions. The idea is to replace something that is painful with something pleasurable and comforting (Linehan, 2014).

[8] Another Distress Tolerance skill in which clients are encouraged to use distraction strategies through various methods to manage difficult feelings and situations and tolerate things that cannot be immediately changed (Linehan, 2014).

[9] Radical Acceptance helps a client to react using DBT *Wise Mind*, rather than using emotional reactions or pure logic (Linehan, 2014). Radical acceptance encourages clients to think before acting. By accepting a past situation without judgement, the idea is to enable clients to make more logical decisions.

memories; however, it could also lead to reflections on the therapy and thoughts about the treatment clarifying in the intervening time.

Tsakopoulou (2009) interviewed nine female DBT clients, looking at what recovery meant for them. This work focuses on BPD, rather than DBT. Tsakopoulou argues that, as a highly manualised therapy, DBT may oversimplify the abstract depiction of human behaviour, leaving out the complexities of human interaction. She disagrees with the conclusion of Perseius et al. (2003) that not deviating from the manual is the only way for the therapist to deliver DBT well, seeing the therapeutic relationship and the clinician's personality as equally important to the therapy. Similar to previous studies, there is a finding of poor client quality of life before DBT, as well as stigma and prejudice within the clients' personal relationships due to their BPD diagnosis. Again, DBT is seen as as giving hope to the clients, but more so than in the other studies, recovery is described as an ongoing process.

Unlike the other studies, which all examine outpatient groups, Desperles (2010) looked at inpatients' experience of DBT. Nine participants with a diagnosis of BPD were interviewed. Eight themes were identified, split into two parts. The first part examined the DBT treatment programme, with two themes: Components of DBT and Effects of DBT. As in other studies (Cunningham et al., 2004; Hodgetts et al., 2007; Perseius et al., 2003), there was an emphasis on acquiring, understanding and having the capability to use the skills in being able to manage BPD by improving affect regulation, controlling behavioural urges and having better interpersonal relationships. This led to less self-harming and other self-defeating behaviours. Part 2 had six themes which cover the journey of undertaking DBT as inpatients: from *A Hopeless Beginning* when the inpatients felt that treatment would not work or they resisted DBT, to *A Brighter Future*. At this stage, at the end of the treatment, participants felt more confident and hopeful about being able to manage the disorder in the future, with a change in their self-view. Unlike Perseius et al. (2003), and similar to Tsakopoulou (2009), Desperles (2010, p.19) sees the therapeutic relationship as extremely important in DBT, asserting that "Linehan (1993) felt [the therapeutic relationship] was at the core of the effectiveness of the DBT strategies." The study posits that the use of DBT for inpatients is as acceptable as for outpatients; however, it accepts that conducting research with these participants can be very difficult.

Like the clients in Hodgetts et al., McSherry et al. (2012) found clients experienced a lack of information about DBT before starting the therapy. However, group skills sessions were seen as important in helping clients to lower their feelings of being alone in their experience, helping them accept their diagnosis and helping them to feel more 'normal'. Group skills sessions also helped clients to develop better skills by listening to other group members. Learning the skills led to better affect recognition and control, and similar to the findings in the other studies, interpersonal relationships became better due to DBT skills acquisition. However, similar to Cunningham et al. (2004), DBT terms and vocabulary were seen as overly complicated, making DBT more difficult. One criticism I have of this research is that the DBT being delivered was not full DBT. It lacked the one-to-one personal therapy element, which was seen as important in Tsakopoulou (2009) and Desperles (2010). In addition, the skills delivery had also been adapted, so that DBT protocols were not completely adhered to. Therefore, as clients did not get the full DBT experience, there is a possibility that this biased the results, making clients more dependent on the group and finding the jargon harder to understand, as there were no one-to-one explanations. Another issue with this study is that the clinicians were not experienced in delivering DBT, which again may have led clients to attribute more importance to help from other group members.

Unlike the studies critiqued above, which mainly number ten or fewer participants (Cunningham et al. $n = 14$), Barnicot et al. (2015) had forty participants, which is a large number for a qualitative study. However, in criticism, they do not cite any previous studies to compare their results to. Unlike other studies, they examine DBT skills training in terms of barriers and overcoming barriers, interviewing clients who completed treatment and those who dropped out during the DBT skills training experience. This gave insights not seen in the other studies whose participants were either in DBT or had finished the program. Two themes concerning difficulties with DBT were reported. Theme 1 examines why *learning* the skills was difficult. This Theme covers anxiety about learning and interacting within the skills group and difficulties around the specialised DBT language and acronyms. Theme 2 looks at the main barriers to *using* DBT skills. In this theme, the main barrier is intense affect, which made accessing and using the skills or even wanting to try to use the skills when in distress very difficult. Themes 3 and 4 examine how participants overcame the difficulties they faced, through having more confidence in engaging with DBT, continuing to try to use the skills even when it became very difficult ("committing") and making the skills more personal to themselves and their life situation, until they became integrated. At this stage, clients could use the skills without having to think about them. In this theme, Barnicot et al. found that when clients considered stopping the treatment, the desire to have a better life was a great motivating force to continue.

Simons (2010) interviewed clients and clinicians, reporting that clinicians constructed themselves as healers and saw clients with BPD undergoing DBT as difficult to deal with due to the clients' slow progress and disruption of their own treatment, which frustrated the clinicians' role as a healer. Like the studies discussed above, the clients saw DBT as positive, even life-changing, as a new identity arose from acquiring the skills, similar to Cunningham et al. (2004), but as in other studies, it was also constructed as difficult, and struggles with mindfulness were ongoing. Clients reported the importance of support from the group and from their therapist, as also noted in McSherry et al. (2012). However, the number of interviewees was small, leading to possible limits in the discourses found.

Longer-term DBT studies

In terms of recovery from BPD, the clinical approach focuses on the reduction of symptoms, so that patients no longer meet diagnostic criteria for BPD. In a systematic review looking at remission and recovery from BPD in eleven cohorts, Ng et al. (2016) suggest that longer-term studies (with a follow-up period of over ten years) see symptoms lessen considerably over time. Several reasons are suggested to explain this, including reduction of impulsivity with age and patients' long-term avoidance of interpersonal relationships. Shorter term studies, for example, Gunderson et al. (2018), also show that for most patients symptoms gradually reduced with age and this was increased by undertaking evidence-based treatments. Ng et al. (2016) also found that remission rates varied from study to study, but symptomatic remission was fairly common, with rates varying between 33% and 99%, and the likelihood of recurrence following a period of clinical symptomatic remission was low, particularly in patients who received a diagnosis at a younger age.

In a review of eleven studies, with 837 participants, Álvarez-Tomás et al. (2019) found that between 50% and 70% of patients had achieved long-term remission, with a mean suicide rate varying from 2-5%. However, these results contrast with Paris & Zweig-Frank (2001), who in a very long-term study, found that of the original 64 participants, 10% had died from suicide after 27 years. Like Ng et al. (2016), Álvarez-Tomás et al. state that diagnosis at a younger age was associated with a higher likelihood of remission. Although, quantitative DBT research which includes follow-up data, reported on in Gillespie et al. (2022), suggests that the majority of participants (51 to 78%) were still undertaking therapy of some kind, after finishing DBT between 12 and 30 months previously.

In the literature, there is concern that although symptoms may reduce with targeted therapies, there has not been enough work looking at the broader efficacy of these therapies (e.g. Bateman et al. (2015)). In addition, Gunderson et al. (2018) suggest that even after symptoms have decreased, BPD patients are often left with mental health issues such as depression, self-harming, and other self-defeating behaviours. Gillespie et al. (2022) found that the end of DBT was not the end of treatment, as all of the former clients they interviewed were still accessing mental health services in some way, but that the use of such services in terms of times accessed and severity of requirements had dramatically declined. The participants, who had all previously completed DBT over two years, continued to report DBT as beneficial. Like the clients interviewed whilst undertaking DBT discussed above, those interviewed by Gillespie et al. also reported DBT as life-changing, with DBT having a positive impact on participants' lives, which allowed them to continue to develop. They reported having greater control over their lives and better skills to cope with life's obstacles and problems, which would previously have seen them using self-defeating behaviours like self-harming to cope. They were also able to make meaningful connections and relationships with other people, which would have been almost impossible previously. The former DBT clients discussed the huge impact in changing their lives that DBT had had, but they were also clear that DBT was not a “miracle cure”.

2.4.7 Where does a DMHI fit into therapy

The digital intervention for DBT requested by *The Retreat* was for something that would help clients on several different levels. Because BPD is therapy interfering, and the skills take a lot of embedding (Dimidjian & Linehan, 2003; Linehan, 1993), DBT is a long-term therapy; therefore, the DMHI would work on a number of levels, depending on where the client was in the therapeutic journey, being based on the different stages of the journey, supporting differing user needs at each stage.

It was requested to sit alongside the therapy as an adjunctive to the therapy, and is not at all meant to replace either the therapy or the role of the therapist, which is very important in DBT. For example, for new clients, it would help them to understand what mindfulness is; remind them of the explanations of all the Mindfulness skills; help to acquire the skills through level-appropriate practices; help to practise Mindfulness skills to become aware of their thoughts and feelings in the moment, for example of wanting to self-harm; remind them to do a Mindfulness skill exercise even for a very short period of time (30 seconds), which would then allow them to take a step back and decide which other skill they could use; it would also include a lot of validation throughout, but particularly for early stage clients.

For clients who were further along the therapeutic journey, it would give them chances to practice Mindfulness skills at different times, to help them to incorporate mindfulness into daily life. With those furthest along the journey, it would come closest to resembling a COTS mindfulness app, but it would still have DBT elements, because even those clients who have been through DBT and are able to access and use the skills can still have periods where they need to use the skills more intensively.

Thus, the DMHI will mainly be used by the clients outside of formal DBT sessions. However, it may be used in individual therapy sessions, for example to facilitate a discussion, to remind a client how one of the features could help with practice, and may be used as one of the short Mindfulness practices which happen at the start of a skills session.

2.4.8 Conclusion to therapeutic context

This section gives an overview of BPD, its presentation and causes. It presents the gold standard therapies used in the treatment of BPD, focusing on DBT with a summary of its main constituents. Mindfulness in DBT is briefly covered as one of the four skill groups, and this is discussed in more detail in Section 2.5.5. The quantitative and qualitative literature on participants with a diagnosis of BPD undergoing DBT is reviewed. This work is discussed in terms of my results in Study 2 in Section 4.6.

This section showed who the end-users of a DMHI for DBT skills are, the types of issues they face from the disorder and what the therapy entails.

2.5 Mindfulness context

Mindfulness has been defined as a quality of consciousness covering awareness of and attention to physical and mental present moment experience (Brown & Ryan, 2003), and the acceptance of the experience in the present moment (Bishop et al., 2004). These two definitions, from a number in the literature illustrate that mindfulness is not a straightforward concept, but a multidimensional system, taken from Buddhism as part of a complex philosophical structure and reduced in a number of ways into Western health and well-being (Grossman, 2019).

It is important for the reader to understand where the concept of mindfulness comes from and how mindfulness practice is used in mindfulness-based interventions (MBIs). In particular, it is important to distinguish between the type of mindfulness taught in DBT and that taught in other MBIs because of the nature of the clients' history and the presentations of BPD. This section begins by briefly covering the origins of mindfulness in Buddhism. I then look at the development of MBIs to regulate and aid mental and physical health, covering the operationalisation of MBIs like MBSR and ending with a description of the skills encompassed by the DBT Mindfulness module.

Following the details of delivering Mindfulness, I give an overview of the literature on how mindfulness is asserted to change behaviour in MBIs including DBT. Although this is not the focus of the thesis, it gives the reader a grounding in why mindfulness practice is used and asserted to change behaviours in MBIs. Following this, I look at the research on the lived experience of mindfulness practice, discussing the efficacy of mindfulness and other related issues. Finally, I discuss why developing a DMHI for DBT was seen as necessary and how existing mindfulness apps are not suitable for DBT clients.

2.5.1 Origins

The word mindfulness is used to describe a multipart concept which was itself part of a complex system of belief. Mindfulness was removed from one system, Buddhism, and implanted in another system, psychotherapy, which has a number of similarities, but also a number of differences (outside the scope of this research, for a discussion see Mikulas (1978) and Robbins (2002)). Mindfulness comes primarily from the Buddhist tradition, although there is a less well-known contemplative tradition in the Christian, Jewish and Islamic faiths. It is one of a number of fundamental teachings in Buddhism and one part of the Noble Eightfold Path (see Figure 2.3) (Buddhist Society, 2014), which outlines the practices which will lead Buddhists to enlightenment (nirvana) and freedom from the painful cycle of suffering and rebirth (Gethin, 1998). However, the eight aspects of the path should not be interpreted as individual steps; rather, they are highly connected and interrelated.

Figure 2.3: The Noble Eightfold Path is a practical guide to the interdependant principles leading to enlightenment or Nirvana (Jendhamuni, 2017)

Mindfulness translates the Pali word *sati*. There is considerable discussion about the exact meaning of the word and how it should be interpreted in the Buddhist literature (see for example Bodhi (2011)). This difficulty in pinning down the concept of mindfulness in a simplistic way can also be seen in the secular mindfulness literature. *Sati* has the idea of present awareness or attentiveness, also called “bare attention” (Thera, 1968), although Bodhi (2011) comments that bare attention was meant only to describe the initial stage of mindfulness. Shapiro et al. (2006) see bare attention as focusing too much on the intellect, without looking at the quality of the mindfulness. They suggest the term “heart-mindfulness” would be a better translation of the Japanese characters for mindfulness (in Buddhism), which includes qualities of emotional warmth, such as compassion and self-compassion in the definition. The core of Buddhist teachings helps to give an understanding of the nature of suffering, where it comes from and how to stop it, with mindfulness being at the heart of these teachings (Bernstein et al., 2019).

2.5.2 Development of mindfulness in the West

Over the last forty years, the practice of mindfulness has gained momentum in the West, and it is currently popular both in mindfulness-based interventions (MBIs) and as a standalone technique (Keng et al., 2011; Spijkerman et al., 2016) for promoting well-being and personal development. It carries the idea from Buddhism that a systematic way of contemplative meditative practice to train the mind can help to develop insight and thus help to overcome suffering (Anālayo, 2019).

The popularity of mindfulness and its ubiquity as a buzzword has lead to some accusations that mindfulness is being packaged as a commodity (Kabat Zinn, cited in Campbell & Christopher, 2012) which is over-commercialised in clichéd self-help books and then used inappropriately, for example, for greedy and selfish ends, or as a way to enforce certain behaviour, as it is being taught without a principled framework (Grossman, 2008; Grossman & Van Dam, 2011). Such “mcmindfulness” or wrong-mindfulness has no reference to Buddhist practices and ethical foundations (Kabat-Zinn, 2015), and sometimes does not have the therapeutic support or framework reminding practitioners to be self-compassionate and loving, which is an important part of Buddhism. However, many people practising mindfulness in a secular context report a deepened sense of spirituality (Shapiro, 1992; Brown & Ryan, 2003). Indeed mindfulness has been seen as bringing an understanding of the interrelationship between all elements of life, including emotions, behaviour, identity and spirituality (Kristeller, 2007). Shapiro (1992) posits that the longer a person meditates, the more religious / spiritual they become.

Concerns about the secularisation of mindfulness and its removal from Buddhist ideas of mindfulness leading to its devaluation (Grossman, 2008; Grossman & Van Dam, 2011; Kabat-Zinn, 2015) are refuted by Baer et al. (2011) and Baer (2019). This research suggests that Western secular mindfulness, in particular the form used in MBIs, may need to be conceived in a way that is not consistent with strict Buddhist interpretations, but does concur with Buddhist and scientific ethics. Dimidjian & Linehan (2003) also speculate that mindfulness research needs to define and reliably measure concepts like *wisdom* and *compassion*. They acknowledge that, in the practical approach used to allow as many people as possible to understand mindfulness in MBIs, “[possibly] something is lost in the separation of mindfulness from its spiritual roots” (Dimidjian & Linehan, 2003, p.167). However, Baer (2011) posits that the goal of MBIs is bringing about improvements in mental health and well-being in patients. Specifically referring to operationalising and measuring mindfulness, which necessarily involves reducing its complexity, she asserts that using the scientific method to discover more about MBIs is important in helping to understand what, if anything, is being improved, and how it is helping patients/clients.

2.5.3 Mindfulness and mental health

The secular use of mindfulness in a therapeutic setting rose to popularity following the founding of a Mindfulness-based Stress Reduction programme to help chronic pain sufferers by Kabat-Zinn in 1979 (MBSR; Kabat-Zinn, 1993, 1990, 1982). Other mindfulness-based interventions (MBIs) followed, as detailed below.

Mindfulness-based Stress Reduction (MBSR)

MBSR uses mindfulness practice to help relieve pain and conditions in which stress is a factor, including cancer, heart disease, anxiety and depression (Kang & Whittingham, 2010). It is an 8-10 week course of weekly 2-hour sessions, consisting of formal mindfulness practice, group discussion and yoga exercises. A number of mindfulness meditation skills are introduced, including mindfulness of the breath and a bodyscan, which involves moving the attention around the body in various ways. There is also "homework" and an expectation that mindfulness will be practised daily when away from the class. MBSR attendees observe emotions, sensations and/or thoughts arising during the practice, with a non-judgemental attitude (Baer, 2003; Kang & Whittingham, 2010).

Acceptance and Commitment Therapy (ACT)

MBSR was followed by other mindfulness-based therapies: Acceptance and Commitment Therapy (ACT; Hayes et al., 2009) focuses on accepting unwanted distressing cognitive and affective events, rather than trying to rationalise them away. In ACT, mindfulness helps individuals to observe and experience thoughts, feelings and sensations both positive and negative, using personal values to guide any actions taken because of them. RCTs show reductions over a 4-month period in symptoms and rehospitalisations in psychotic clients (Bach & Hayes, 2002), as well as reduced self-harming behaviours and improved measures of emotion regulation, mental health, and stress in BPD clients at the end of treatment (using a combination of ACT and DBT; Gratz & Gunderson, 2006). In healthy stressed populations, ACT has been effective in reducing psychological symptoms and burnout in substance abuse counsellors (Hayes et al., 2004).

Mindfulness-based Cognitive Therapy (MBCT)

MBCT (Segal et al., 2002, 2019) was developed to help people with recurrent depressive episodes. Mindfulness meditation exercises are taught in a small group with participants encouraged to do daily formal and informal mindfulness practice at home in between sessions. Practice time increases over the course, starting with awareness of feelings in the body, and building to more abstract phenomenon like thoughts, with mindfulness practice moving from a low emotional focus, like eating, to more emotional content, such as problematic thoughts. Recognising these, without attempting to change them is an important part of the therapy, because the practitioner is no longer using mental energy to fight the depression.

A number of RCTs show that MBIs have efficacy in both clinical and non-clinical outcomes for mental health and well-being. These include anxiety (Green & Bieling, 2012), depression (Strauss et al., 2014), relapse into depression (Kuyken et al., 2008), stress (de Abreu Costa et al., 2019; Chiesa & Serretti, 2009) and mental well-being in patients with cancer (Ledesma & Kumano, 2009).

2.5.4 Operationalisation of mindfulness in MBIs and DBT

This section starts by discussing how mindfulness is operationalised in MBIs like MBSR and MBCT, using formal and informal mindfulness to build up meditation skills over a number of weeks. At the end of the course, practitioners have the skills to practice mindfulness for 30-45 minutes or more on their own. I then examine the DBT skill of Mindfulness and how it is operationalised differently from other therapies.

Formal practice

Buddhism teaches mindfulness using a variety of methods, including formal exercises such as meditating, paying attention to the breath, repeating a word or phrase or closely observing an object (Buddhist Society, 2014). These practices have been incorporated into MBIs, in which mindfulness is typically cultivated in formal meditation practices, such as sitting or walking meditations focusing on the breath or moving the attention around the body (Kabat-Zinn, 1990; Segal et al., 2002).

When learning to meditate using mindfulness, beginners usually start with formal mindfulness practices. Practitioners follow directions such as focusing on a stimulus that grounds the meditation in the present, for example, the feeling of the breath at the nostrils or in the diaphragm, or listening to noises that can be heard internally and externally. Practitioners are also advised what to do when the thoughts wander from the mediation, or emotions and bodily sensations impinge on the process. They are gently guided back to the meditation, sometimes being asked to give a name to what is arising, such as ‘thinking’ or ‘anger’, or being instructed to breathe into a sensation such as itching or a minor ache, rather than changing the position of the body (Baer, 2011; MBSR, MBCT).

Informal practice

Both Buddhism and MBIs also advocate less formal exercises for bringing mindfulness into as many daily activities as possible, especially the mindful carrying out of everyday tasks, like making a hot drink, taking a shower or driving (Kabat-Zinn, 1990; Linehan, 1993b; Segal et al, 2002). When practising mindfulness in daily life, participants are encouraged to bring moment-to-moment awareness to ordinary activities and to gently return their attention to this activity when it wanders away. They are typically asked to bring an attitude of acceptance, allowing, openness, curiosity and kindness to all observed experiences, even if they are unpleasant or unwanted.

2.5.5 DBT Mindfulness skills

Whilst those undertaking MBIs may have mild to moderate mental disorders, such as depression, they usually do not have the severe psychiatric illness found in clients undertaking DBT. The approach taken in DBT therefore has to be very different, teaching *Mindfulness* without formal meditation sessions, breaking down learning the skill into very small, directed steps, whilst at the same time validating the client's reactions to the difficulties of acquiring a mindfulness practice. In addition, those undertaking an MBI are likely to have some familiarity with at least the concept of mindfulness beforehand, choosing to undertake the mindfulness course, whereas those undertaking DBT may never have heard of the concept of mindfulness before starting DBT, which leads to them sometimes find the Mindfulness skill very strange and not understand what is required of them.

Mindfulness within DBT is taught in a very specific way, tailored to the presentation of BPD (Linehan, 2014). It is taught in the 2-hour group skills sessions alternating with the other skills (i.e. *Skill A* for a number of weeks, *Mindfulness* for 4 weeks, *Skill B*, *Mindfulness* etc). Mindfulness practice in MBIs frequently focuses attention on the breath, eating or different areas of the body, known as a *bodyscan*. These exercises are not available to DBT skills trainers, particularly in a group setting, as they can potentially trigger extreme negative responses grounded in past physical or sexual trauma. By necessity, due to the types of clients and the traumas they have experienced, in DBT mindfulness practice is operationalised in a somewhat reductionist way. This allows clients to still benefit from the focusing of attention and present moment awareness, even though they have reduced tolerance for, or no ability to practice formal meditation and the types of exercises this involves, such as focusing on the breath or bodyscans. For example, DBT clients are often not able or willing to spend long periods doing formal mindfulness practice. The *Mindfulness* exercises taught in DBT are all shorter than five minutes, although individual therapists may encourage clients to do tailored longer *Mindfulness* exercises at home, possibly using one of the classic techniques, as they become more skilled and their individual therapist thinks it is suitable. Bringing short mindfulness practice into daily life and tasks is also encouraged.

DBT *Mindfulness* brings substantial therapeutic benefits in helping clients to understand their emotions and in using the other DBT skills to help control emotional dysregulation and other challenges as they arise (Linehan, 2014). It is posited that much of the dysregulation in BPD is due to a lack of mindfulness skills. A lack of trait mindfulness was found to predict borderline indicators (Wupperman et al., 2008) as lower attention, awareness and acceptance were thought to be linked to difficulties in emotion regulation. Conversely, O'Toole et al. (2012) found high levels of trait mindfulness to be a strong predictor of well-being in women with BPD, as it allows better regulation of emotions. *Mindfulness* was found to be better than *Interpersonal Effectiveness* at reducing the severity of BPD symptoms in clients taking a ten-week *Mindfulness* course (Elices et al., 2016) and posited to lower emotion dysregulation by prompting more awareness of emotions as they arise, giving clients the chance to recognise and understand their thoughts and their emotional response, thus creating a separation between the two (Hölzel et al., 2011).

The Mindfulness module in DBT presents mindfulness as a set of skills to aid self-monitoring and be aware of thoughts and emotions in the moment, without judgement. DBT Mindfulness begins by introducing three states of mind (Linehan, 2014):

- *Reasonable mind* refers to using logic and intellect.

- *Emotion mind* refers to being in or using an emotional state.
- *Wise mind* combines both states to produce a reasoned outcome in which the emotional responses are acknowledged and attended to in a calm fashion.

Wise mind is also seen as the dialectical balance between emotion and reason (Pederson & Pederson, 2011). Mindfulness helps to achieve *wise mind* by balancing *emotion mind* and *reasonable mind*. It is posited that as those undertaking DBT often find naming individual emotions challenging, this approach is a way into self-knowledge giving language to discuss broad affective inner states, without naming individual emotions.

Three *what* skills, types of exercise that focus on different ways to be mindful, are taught to help achieve mindfulness:

> **Observe** – observe sights, sounds, smells and tastes, fully experiencing the moment, with any emotions that it brings. This can be a challenge, as pushing an emotion away or using distraction to cope with very intense or unpleasant emotions is more common for DBT clients, and learning this skill can be difficult at first.
>
> **Describe** – in this skill, as well as observing, descriptions are used for things that are seen, heard, smelt, felt etc, as well as any emotions, behaviours or events. This allows DBT clients to make sense of their experience, seeing the difference between thoughts, emotions and events and understanding that thoughts are not absolute truths. It also helps clients to understand which emotions they are feeling, as these can be entangled or not easy to describe. This helps to isolate different feelings of, for example, sadness, anger or fear, which may have been labelled more generally as *feeling bad*.
>
> **Participate** – in this skill, the immediate task is carried out with full attention. This skill may be more challenging to master than the first two. Clients have to be fully absorbed in the task, but mindful of what they are doing. This becomes easier after mastering observe and describe. Clients are often advised to carry out every day tasks, such as making a cup of tea or having a shower, mindfully.

Linehan (2014, p.63) likens the observe and describe skills to close observation of the fingers and counting the beats when first learning the piano. After becoming more familiar with the skill, this close observation is no longer necessary; the observe and describe skills are used less and the participate skills are used more. However, observe and describe may be needed again when encountering something new or if habitual mistakes are being made. She asserts that the observe skills train the attention or focused attention aspect of mindfulness and the describing and especially participating skills train the awareness aspect of mindfulness.

Three *how* skills describe the manner in which mindfulness should be done:

> **Non-judgementally** – not labelling thoughts or events as good or bad. Striving to be non-judgemental makes clients aware of judgemental thoughts. It also helps to evaluate behaviour in terms of consequences, rather than labelling it good or bad, for example *hurtful behaviour* rather than *bad behaviour*.
>
> **One-mindfully** – staying focused on one idea or activity to stop becoming distracted or overwhelmed by thoughts and emotions.

> **Effectively** – doing what works, which requires clients knowing what they want to achieve. It also involves letting go of being right in order to best achieve a goal – clients have often experienced invalidating childhood environments, which makes them reluctant to give up erroneous judgements about people or situations, even if it is not in their best interests. Presenting effectiveness as a skillful response, rather than giving ground, can help the clients to achieve this.

When practising DBT Mindfulness in daily life, clients are encouraged to bring moment-to-moment awareness to ordinary activities and to return their attention to this activity when it wanders away. They are typically asked to bring an attitude of acceptance, curiosity and kindness to all observed experiences, even if they are unpleasant or unwanted.

Mindfulness is an holistic approach to life, but in teaching it in MBIs and especially in DBT, the approach has to be somewhat reductionist. Thus, there is a tension between the complexity and intertwined definition in Buddhism and the operational definitions found in the literature on MBIs. Mindfulness is operationalised into DBT, but not without some problems. As seen above in Section 2.2 and in Chapter 4, the DBT clients have specific backgrounds, often involving considerable trauma, which must be taken into account and which may preclude long formal meditation practice, as well as the use of exercises which focus on the breath or the body. Therefore, Mindfulness in DBT cannot be taught as it is in MBSR or MBCT, and as discussed above, other methods to help clients to develop attention and awareness are used. However, as Study 1 (Chapter 3) will show, longer formal practices develop mindfulness skills more quickly. Thus, in reducing Mindfulness in DBT out of necessity, something of its essence may be lost, which may make it harder to learn and requiring more time. However, the supportive, compassionate framework which Ekici et al. (2020) asserts that Buddhism provides can be seen in the DBT dialectics and further in the Compassion Focused Therapy (Gilbert, 2009), which is not part of DBT, but is taught at the Tuke Centre as part of the DBT course.

In addition, another problem with DBT Mindfulness is that the other three skills modules in DBT (see Section 2.4.3) have clear steps to follow which clients can more easily understand, and also they can see results from following the skill steps fairly quickly. However, Mindfulness is not doable in steps like the other skills. Therefore, it can take a long time to feel competent as a mindfulness practitioner, especially when it is being done in small informal bursts. Unlike the other three skills modules, feedback from doing Mindfulness may be slow, especially in the initial stages, making clients blame themselves for not doing it correctly. Mindfulness may also be taught by inexperienced practitioners, so the explanations and the expectations of the clients may not be dealt with as skilfully as might be desired. To counter the self-blame and self-shaming thoughts Mindfulness practice may engender, at the Tuke Centre clients are taught specific self-compassion skills (Gilbert, 2009), which are not part of standard DBT, but are considered very important for this client-group. This is important because not practising Mindfulness should not become another reason for the clients to castigate themselves.

2.5.6 Mindfulness practices

Mindfulness includes a number of types of practice, which are often conflated, or at least glossed over, in many discussions of mindfulness in MBIs. Bodhi (2011, p.28) states that:

> Mindfulness may be focused on a single point of observation, as in mindfulness of breathing, especially when developed for the purpose of attaining concentration (samadhi). But mindfulness may also be open and undirected, accessing whatever phenomena appear, especially when applied for the purpose of developing insight (vipassana).

The Buddhism view of mindfulness having a number of forms is expounded by Brown et al. (2007) and Lutz et al. (2008), who discuss two forms of mindfulness meditation, which are separate features of meditative practice, that have distinct roles in achieving state mindfulness. The two features of attention and awareness are developed in different meditative exercises. Attention meditations use a focus such as the feeling of the breath or looking at an object such as a mandala. In this meditation, if the attention strays, it is gently brought back to the object. This type of meditation can be used to prepare for an awareness meditation. In awareness meditation the focus is the present moment experience, thoughts, sensations and emotions. Lutz et al. (2008) discuss the background of the two styles in different Buddhist traditions as well as MBIs in more depth, giving examples of what they call *focused attention* which involves sustained attention on an object, and *open monitoring* which covers dispassionately observing present experience.

As seen above, the definition of mindfulness used by Linehan (1993, p. 114) in DBT is training “psychological and behavioral versions of meditation skills usually taught in Eastern spiritual practices”. DBT Mindfulness skills centre on “observing, describing, participating, taking a nonjudgmental stance, focusing on one thing in the moment, being effective”. The DBT *observing skills* can be seen as training the attention or the focused attention aspect of mindfulness, and the *describing* and especially the *participating* skills as training the awareness aspect of mindfulness. However, as discussed above, DBT does not practice long sitting meditations in the Mindfulness skills classes. Unlike in MBSR or MBCT, in DBT the learning pattern involves short 2 – 3 minute Mindfulness practice sessions, using one of the three modes with a variety of foci. As in MBCT and MBSR, the two styles of meditation discussed in Brown & Ryan (2004) and Lutz et al. (2008) (i.e. attention and awareness) are taught implicitly in DBT, and Mindfulness practice is not conceived in these terms.

2.5.7 How do MBIs work?

The research asserts that practising meditation which induces state mindfulness in repeated meditation sessions (Verhaeghen, 2021; Garland & Fredrickson, 2019) increases the tendency to mindfulness in everyday life (trait mindfulness) (Baer et al., 2008), thus benefitting mental health (Kiken et al., 2015; Shapiro et al., 2006). As described in Section 1.2.3, state mindfulness can help practitioners to notice thoughts about and reactions to things, events and sensations by focusing the attention and awareness on only the facts and drawing attention to the thoughts. Approaching experiences mindfully can allow a more direct perception of them, as by recognising the mental commentary or categorisation, responses can be more flexible and objective (Brown et al., 2007). However, there is debate in the literature about the mechanisms underlying this process.

Mechanisms of mindfulness

There is general agreement in the literature that MBIs are efficacious (see above and Section 2.5.9). Finding the mechanisms that underlie therapeutic improvements and mechanisms of change is important in developing and refining MBIs and in changing and developing the therapy and/or the practice, if it is found not to be working. However, there is little agreement about what the mechanisms are. A number of studies see attention as being a significant mechanism in mindfulness practice (Brown & Ryan, 2003; Lutz et al., 2008; Sumantry & Stewart, 2021, *inter alia*). However, as in defining and operationalising mindfulness, there is disagreement over the mechanisms which are in play and even the levels at which the mechanisms operate, with some researchers' mechanisms being sub-components or supra-components of others' systems. Two reviews, Keng et al. (2011) and Hölzel et al. (2011) posit mechanisms based on the literature.

Among other mechanisms, Keng et al. suggest *metacognitive awareness*, also called decentring or reperceiving, i.e. the recognition that thoughts and emotions are cognitive events which do not necessarily represent reality. They suggest this mechanism helps practitioners notice and stop ruminating. However, some papers saw decreased rumination as a mechanism in itself (for example, Coffey et al., 2010; Brown et al., 2015). Others, (for example, Shapiro et al., 2006), see reperceiving as a meta-mechanism, covering several direct mechanisms. Keng et al. consider *exposure* or desensitising through focusing on difficult thoughts without using judgement as closely related to acceptance. However, acceptance is considered a separate mechanism by Baer (2010), who sees self-compassion as involving acceptance, which she considers a very important mechanism. Another mechanism mentioned by Keng et al. is *controlling attention* through various subsystems of attention. However, many authors see attention as a *defining* part of mindfulness rather than a mechanism.

Hölzel et al. (2011) suggest four mechanisms, *attention regulation*, *body awareness*, *emotion regulation* and *change in perspectives on the self*. However, for Teper et al. (2013), emotion regulation is an effect of mindfulness. Here, *present-moment awareness* and *nonjudgmental acceptance* affecting basic cognitive controls are the mechanisms. Finally, Shonin & Van Gordon (2016) assert that mindfulness can work on a number of levels including biological, psychological, social and spiritual. They propose ten mechanisms underlying mindfulness, including *Perceptual Shift*, *Increase in Spirituality* and *Increase in Self-Awareness*.

Mindfulness and behaviour change

One of the mechanisms for mindfulness is asserted to be emotion regulation (Baer, 2010), and in DBT, this mechanism is thought to be extremely important in helping clients to recognise emotions and the thoughts around them as not necessarily representing facts, but a reflection on events. This helps DBT clients to change unhelpful behaviours arising from affective dysregulation. Gross & Thompson (2007) see mindfulness as not changing the emotions *per se*, but rather changing the relationship to the emotions. There is some evidence to show that even small amounts of exposure to mindfulness can help in changing behaviour, for example in regulating negative emotions. This section looks at how this manifests in the behaviour and actions of those practising mindfulness.

The literature suggests that mindfulness lessens levels of ego-involvement, resulting in less aggressive behaviour and less confrontations (for example, Brown & Ryan, 2003). This can be seen in a number of scenarios, from reduction of physical aggressiveness in adolescents to less aggressive behaviour towards opponents in games and less hostility in work situations. Aggression is a complex research area; however, it is posited that it often happens in response to a perceived or real insult, or a rejection of a person or something they hold dear (Baumeister et al., 1996). Those with low self-esteem or those having an exaggerated view of their self-image are highly triggered by ego-threats, which pose a risk to the self-esteem, leading to aggressive behaviour. DBT clients may fall into this group, although there are many such others in the general population.

Mindfulness was helpful in the treatment of three adolescents with Conduct Disorder (APA, 2013), who were referred to therapy including mindfulness due to aggressive behaviour at school which was about to get them expelled (Singh et al., 2007). Their therapist reported how mindfulness practice was at first intermittent, but became more regular when the youths saw the differences in calmness and behavioural control it brought them, with all aggressive behaviour stopping. In a review of DBT and adapted DBT used for treating anger and aggression in a number of populations, some including people with a personality disorder, DBT was found efficacious in 8 out of 9 studies (Frazier & Vela, 2014). DBT used in BPD populations was also found to have efficacy in the treatment of anger and aggression in a number of studies (*ibid.*).

Hostile behaviour not involving physical violence was also found to be lessened by the use of mindfulness, Kiken & Shook (2011) suggest that mindfulness leads to less bias towards developing a negative view in playing a computer game in which participants had to associate novel stimuli with positive or negative outcomes. They suggest this was mainly because participants in the mindfulness condition were better at finding positives. They were also more optimistic in outlook. Inducing mindfulness through a short mindfulness exercise was also shown to have a positive effect on aggression in undergraduates receiving feedback about social rejection from their peers, compared to those who did not do the mindfulness exercise (Heppner et al., 2008). In a further look at hostile behaviour, Bergeron & Dandeneau (2016) found that positive responses to ego threats in two tasks, failing to solve an anagram and recalling a negative personal experience were treated with a positive response by participants who had done a mindfulness exercise compared to those who had not.

Understanding the type, number and level of mechanisms underlying therapeutic improvements in mindfulness in MBIs in the current literature is difficult as there is a melange of levels and theories, with currently no overall accepted set of mechanisms.

2.5.8 Measuring mindfulness

Alongside defining the mechanisms of mindfulness are attempts to measure mindfulness. However, there is a lot of controversy in the research about measuring mindfulness as a construct (Naliboff et al., 2020). Operationalising mindfulness is seen by many as important in helping to determine what aspects of both formal and informal mindfulness bring about an increase in trait/state mindfulness, and whether and in what ways MBIs are efficacious. A number of scales are used to analyse mindfulness quantitatively, employing self-report questionnaires. These have been developed based on a number of sources of data, such as terms found in the literature, the psychologist's experience of mindfulness, others' experience of mindfulness, and features of mindfulness classes (Baer et al., 2011). As in other areas of mindfulness research, different scales focus on different aspects of mindfulness. This is further complicated by a lack of agreement on whether they should measure mindfulness as a trait, as in the majority of scales or as a state, as in the Toronto Mindfulness Scale, (TMS; Bishop et al., 2004; Lau et al., 2006). In addition, the scales can be split into those measuring one facet with a single score, or those measuring more than one facet (Chiesa et al., 2012).

One of the first scales to measure mindfulness was the Freiburg Mindfulness Inventory (FMI; Walach et al., 2006; Buchheld et al., 2001), which measures trait mindfulness using a single score. The Mindfulness and Attention Awareness Scale (MAAS Brown & Ryan, 2003) measures trait mindfulness, focusing on attention and awareness. There is evidence that the MAAS is valid and consistent, and it is widely used; however, criticisms include lack of a control group (Chiesa et al., 2012) and a lack of external referents for the construct validity, lack of evidence that self-reported mindfulness activities are good proxies for real mindfulness, and bias due to the amount of mindfulness experience of participants (Grossman & Van Dam, 2011). Another early attempt to look at how to operationalise mindfulness can be seen in Bishop et al. (2004). In trying to bring scientific rigour to the discipline, Bishop writes about mindfulness as if he has not experienced it, and his ideas on trying to operationalise it are therefore flawed. However, he did help to propose the Toronto Mindfulness Scale (Lau et al., 2006; Bishop et al., 2004). This scale measures state mindfulness after meditation. It consists of ten items and claims to be able to differentiate different levels of meditation experience. Another single-facet scale measuring trait mindfulness is the Cognitive and Affective Mindfulness Scale (CAMS; Feldman et al., 2007).

Other research tries to capture the complexity of mindfulness using a multi-faceted evaluation questionnaire. The Kentucky Inventory of Mindfulness Scale (KIMS; Baer et al., 2004, 2006) examines trait mindfulness through skills developed in DBT and other mindfulness interventions. It uses four sub-scales to evaluate four mindfulness skills: *observing*, *describing*, *acting with awareness* and *accepting present moment experiences without judging*. Baer also developed the Five Facet Mindfulness Questionnaire (FFMQ; Baer et al., 2006) to measures trait mindfulness, and suggests that three of the factors were the best at understanding changes in long-term practitioners, namely *observing*, *non-judging* and *non-reactivity*. The Applied Mindfulness Process Scale (AMPS; Li et al., 2016) is a process measure for evaluating mindfulness-based interventions which measures how practitioners apply mindfulness in their practice.

As well as problems in reaching a commonly agreed definition of mindfulness, the use of self-report questionnaires and quantitative evaluation of mindfulness has been criticised for a number of other reasons. These include a lack of experience of mindfulness practice by the questionnaire developers (Grossman, 2008); large differences in the facets of mindfulness which the questionnaires include, and also differences in the scales which make comparing research results problematic (Brown et al., 2007; Grossman, 2008; Malinowski & Lim, 2015); the meaning of some terms not being understood or being interpreted very differently by non-practitioners of mindfulness (Malinowski & Lim, 2015); and the fact that practising mindfulness could make a person more aware of when they are not mindful, leading to substantial differences in self-evaluation, and pre-post decreases rather than increases in a score. Thus, a more mindful person with a greater ability to self-reflect may score lower than a person with lower trait mindfulness who has less self-knowledge (Grossman, 2008; Malinowski & Lim, 2015). However, this claim is refuted by Baer (2019), who asserts that although this is an interesting idea, in practice it has not been seen in any empirical studies and "remains speculation" (*ibid*, p.45). Reviews show that overall mindfulness scale scores increase after mindfulness training. Where they do not, there are other possible reasons, such as a lack of adequate training or the numbers of participants this affects being so low they are lost in the statistics. In addition, in comparative studies which administer a measuring scale at different points in time, mindfulness practice may affect the items being measured and the understanding of the items, thus measuring a different concept at each application of the questionnaire (Grossman, 2008; Malinowski & Lim, 2015).

To counter the issues with questionnaires, Grossman & Van Dam (2013, p.220) suggest that research should start using new ways to discover how mindfulness works, as "merely linear, additive models that sum putative markers related to mindfulness will not suffice." Grossman (2019) goes further and argues that mindfulness research has a number of serious issues. He asserts that original Buddhist mindfulness depends on understanding and exploring personal lived experience over a long period of time, which becomes problematic when trying to apply empirical research techniques. Further, current definitions and measurements which simplify and deconstruct mindfulness are unscientific, because they are affected by a complex mix of "historical, social, economic, political, and technological factors." (p.102) which means that "Fundamental and accepted scientific criteria are often cast aside in the process" (p.102) and in addition, many of the scientists who study mindfulness have not put in the years of mindfulness practice that is necessary to become an expert on the subject.

The most up-to-date assessments measure mindfulness as a multidimensional construct, using self-report questionnaires. Baer (2019, p.42) considers that although more research is needed, such questionnaires "have reasonable psychometric properties", with multidimensional mindfulness questionnaires revealing, for example, that just practising present-moment awareness may not be helpful, because non-judgementality and non-reactivity also need to be added to the practice. Moreover, Baer sees disparities between psychological and Buddhist interpretations of mindfulness as being "inevitable [but] not necessarily problematic". Grossman (2019) refutes this view. Mindfulness research, he asserts, is not a scientific subject but is swayed by a number of issues including: who is funding the research and for what purpose; the trend for only presenting positive results in academic publishing; problems due to widely diverse definitions and operationalisation; unethical research practices; issues around studying a subjective experience using tools from the natural sciences; different self-report scales with little equivalence; modest effect sizes; Dunning-Kruger cognitive bias; and, differing meanings given to questionnaire items by different participant groups, e.g. practitioners and non-practitioners. To counter this, Grossman suggests instead of try to dismantle and define the “gestalt-like and multi-dimensionality” (p.104) of mindfulness, the research focus should be on the most important individual components (such as attentiveness and prosocial behaviour), naming them for what they are, outside of the mindfulness purview or overarching measure, with Buddhist mindfulness ethics and Western mindfulness being separated. Therefore, there are ongoing efforts to develop better measures of separate factors, for example Hadash & Bernstein (2019).

2.5.9 Lived experience of mindfulness and MBIs

Short-term qualitative studies

There are a considerable number of qualitative studies which examine the experiences of participants who are learning or have recently learnt mindfulness using an MBI. Qualitative studies are very suitable for exploring and describing in-depth the experiences and changes brought about by undertaking an MBI. However, whilst short-term studies give some insights into acquiring a mindful life, they are usually accompanied by a mindfulness course, giving participants a framework and support to learn mindfulness. In terms of learning about how the practice is maintained after the framework is removed, long-term studies have more resonance with my research in Study 1. Examples of short-term studies are included here for completeness, and the results discussed in terms of my study in Section 3.4.

Mason and Hargreaves (2001) discuss participants’ accounts of learning MBCT immediately after the course and longer term. Participants valued the development of mindfulness skills to help with mild to moderate mental heath problems. There were some negative experiences, as participants struggled to learn the skills, but by the end of the course and afterwards, participants saw the skills as helping to bring an attitude of acceptance and the ability to live more ‘in the moment’. For example, they were able to see signs of poor mental health before it started to become more severe (‘warning bells’), which had a positive effect on their mental health. Furthermore, participants reported that mindfulness skills were key in allowing them to make changes, but continued skills practice was crucial to this. In addition, being able to use mindfulness skills informally in everyday life, as well as in formal meditation was seen as essential.

Ma (2002) examines the accounts of 41 participants a year after completing an MBCT course. Her participants reported a number of reasons why mindfulness had helped their mental health, including seeing warning signals of being depressed and being ready and able to carry out an action plan. Participants reported mindfulness bringing changes in personal relationships and life in general, as they felt more confident and more empowered in dealing with their emotions. A positive result was also seen in Finucane & Mercer (2006), who interviewed 13 people three months after they had completed an MBCT course. Participants saw learning in a group as helpful, but considered that more time and ongoing support were desirable after the course ended. One finding which relates to the DBT clients is the negative experience of one participant when undertaking the bodyscan meditation, which triggered extremely unpleasant somatic feelings relating to suppressed childhood sexual abuse.[10] Like Ma (2002), despite some initial difficulties and negative attitudes towards learning mindfulness, Finucane and Mercer found that, overall, participants reported being better able to handle negative emotions and had better personal relationships.

As well as helping with participants' mental health, qualitative studies also show positive results for physical health improvements. It is posited that in the same way that participants with depression and other mild to moderate psychological issues can use mindfulness to help by recognising and sitting with unpleasant thoughts, rather than using distraction methods to avoid them, mindfulness can also help people in great physical pain by bringing their attention to it. At first this seems counter-intuitive; however, a number of research papers advocate being mindful of pain in order to avoid increasing sensitivity and intolerance to it. Morone et al. (2008) reports on older participants (65+ $n = 27$) with chronic lower back pain seeing good results from a mindfulness course. Similar to the way that mindfulness helped participants in Mason & Hargreaves (2001) and Ma (2002) to better notice their emotions and their reactions to them, participants started to recognise how they were reacting to the pain, for example by blocking all bodily sensations. Therefore, their relationship with their bodies and the pain changed when they became aware of this. Better sleep, cognition, and physical and mental wellness were reported as results of following the course, with some participants using mindful attention to the present moment to distract themselves from their pain. Morone et al. posit a number of mechanisms underlying this. One possibility is participants developing greater attention regulation, allowing more awareness of their attention and a stronger ability to direct it. Another posited mechanism is increased awareness of affect and a reduction in negative emotions linked to the pain. The decoupling of pain and the emotional reaction to it allowed participants' recognition of unhelpful coping strategies and the promotion of new ones, enabling them to manage the pain better.

Allen et al. (2009) examine the experience of participants who were interviewed twelve months after an MBCT course about what they had found helpful, meaningful or difficult in MBCT classes for recurrent depression. As in previous studies, participants reported an increase in agency in managing their depression. After MBCT, participants could better recognise signs of relapse into depression and were therefore able to prevent or lessen its impact. Participants reported that they had noticed a slowing down of thought processes and a lessening of rumination, which helped to minimise bodily reactions like a racing heart and get more perspective on an issue. They were also able to pay closer attention to negative thoughts and react to them in a positive way by either practising mindfulness meditation or doing an enjoyable activity mindfully, like taking a walk, which had a beneficial effect. Greater acceptance was also reported. Similar to the participants in Morone et al. (2008) who continued to experience back pain, some participants in Allen et al.'s study still experienced depressive episodes. However, like the participants in Morone et al, they felt better equipped to deal with depression, due to the feelings of having an increase in control. Allen et al. assert this was due to a number of mechanisms, including being able to see depression more objectively, as a

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[10] This experience illustrates why DBT mindfulness skills have to be presented without long formal meditation sessions, during which memories of abuse may be triggered. This is why DBT breaks mindfulness into much smaller directed steps, whilst at the same time giving a lot of validation to the client's negative reactions to mindfulness and the difficulties of their acquiring a mindful practice.

separate illness rather than an intrinsic part of their being; seeing negative thoughts as just thoughts rather than absolute facts; and seeing depression as a state that was not permanent, which would eventually lift, which could therefore be accepted, rather than having to be struggled with. This recognition of the impermanence of depression is a widely reported phenomenon, being seen in Malone et al. and the three studies discussed above (Finucane and Mercer, 2006; Ma, 2002; Mason and Hargreaves, 2001). Again, like in previous studies, personal relationships were positively impacted. Participants reported recognising when they needed to take more time for themselves, as well as recognising and acknowledging their own emotions, which allowed them to communicate better with friends and family. In terms of the difficulties faced by the participants, like participants in previous studies, lack of time to practice was reported as a major barrier. Other difficulties included not having the group support after the end of the MBCT course, disappointment that MBCT had not cured their depression and attributing not using MBCT tools to personal failure.

Langdon et al. (2011) look at the factors that influenced continued mindfulness practice post-MBCT course in 13 participants. They posit a ‘journey of mindfulness’, with participants moving in and out of a ‘virtuous practice cycle’ over time. They also suggest two further higher-order categories which influenced participants, positive beliefs about mindfulness and the influence of significant others. Making mindfulness an integrated part of daily life was seen as particularly important, so that mindfulness became more than an extra activity that had to be done, but was part of a new way of mindful ‘being’. Like other studies, participants also found the support of the group helpful in encouraging them to continue with mindfulness. This is discussed in relation to my findings in Section 3.4.

Not all studies have reported on the positive outcomes of mindfulness and meditation practice. Lomas et al. (2015) present some of the challenges facing around 25% of the male meditators that they interviewed ($n = 30$), undertaking different types of meditation practice. Issues included: firstly, the difficulty of developing mindfulness skills, in which participants discussed the concerns they faced when meditating, such as boredom, difficulty focusing, negative self-talk, and the problems of fitting meditation into a busy life. Secondly, coping with the negative thoughts and negative affect engendered by mindfulness. Lomas et al. report that for a number of the participants, turning towards their emotions, rather than blocking them, through for example alcohol, was demanding. Participants were very surprised at their lack of mental control and the revelation of strong negative affect and thoughts. As in Finucane & Mercer (2006), one participant reported the upsetting revelation of a repressed childhood trauma and the pain which this still caused him. Interestingly, because all the participants were male, this study reports that mindfulness changed how the men saw themselves relating to the wider world. I suggest this also gives an insight into how masculinity is constructed in our society and how society expects men to behave in terms of their emotions and reactions to the world. Thirdly, meditation practice was also found to make some mental health issues worse, in particular depression and anxiety, with participants reporting that meditation made their negative feelings stronger, rather than making them feel better, as participants reported in Mason & Hargreaves (2001); Ma (2002). This may be related to not having a teacher to guide them or a group with whom to discuss the effects of meditation. Finally, in a very small minority of cases, meditation was accompanied by psychotic episodes requiring hospitalisation.

These extreme results were not found in practitioners of mindfulness meditation, and Lomas et al. assert they were due to participants attempting certain advanced meditations without the necessary skills or guidance. However, the potential for meditation to trigger such a reaction is important to know, particularly if it is being used with a population which has a severe mental health condition, in whom such a reaction could be more easily triggered than in the general population.

Whilst this paper puts forward important concerns around the well-being of meditators, a number of criticisms may be levelled at it. Firstly, the research purposely gathered participants from a number of different meditation traditions and backgrounds; however, this can make comparisons between them more difficult, as some are religious practitioners and others are secular. For example, the participants who experienced psychosis were undertaking a very different meditation from the mindfulness meditators. In addition, the majority of the participants are from the Friends of the Western Buddhist Order (FWBO) with only a few participants from other traditions, which could have biased the data. Finally, the length of time the participants had been meditating is given as 0-20+ years, again making comparison between the practitioners more difficult.

Longer term mindfulness studies

In addition to studies looking at the effects in the shorter term of those who are undertaking or have recently undertaken an MBI, the literature also considers long-term meditators, although there are fewer papers on this.

Shapiro (1992) examined 27 participants with an average length of meditation experience of 4.27 years, in an intensive Vipassana meditation retreat study. Participants meditated regularly, spending up to an hour a day practising a variety of meditation types, including Vipassana, mantra, silence, mindfulness and Soto Zen. They were grouped by length of time they had been practising from < 2 years, $2 - 7$ years and > 7 years. This study was partly motivated by a desire to reintegrate the spiritual context into mindfulness meditation which Shapiro asserts has been separated from previous research. Therefore, he hypothesised that being religious would affect length of practice, with the results for this being significant, as the longer length practitioners were the most religious. However, the findings were not significant for the idea that practitioners' goals and reasons for meditating changed over time with continued practice from self-regulation (e.g. reducing stress or pain), to self-exploration (e.g. more self-awareness and self-understanding), to self-liberation (e.g. spiritual or personal growth). Examining participants' initial reasons for beginning meditation in comparison with current goals, some long-term practitioners (11 of the 27) had advanced along the continuum, with more having self-liberation as their motive, but others had the same initial and current goals and five others had gone back (i.e. to the left) along the continuum.

He also found that the participants' stated outcomes from meditating tended to be the same as their stated reasons for meditating. For example, if participants said they wanted to manage stress better, then meditation allowed them to do so. He also found that participants did not practice every day and that reactions to this varied among the participants from being relaxed about it to strong self admonishments. In addition, the reasons that practitioners gave for not practising were mainly external or self-blaming in the two less experienced groups, but more self-compassionate and accepting in the group with the longest length of practice.

In a study examining well-being in long-term mindfulness practitioners (n=77) and non-practitioners (n=75), Lykins & Baer (2009) find that the longer the practitioner's experience, the higher the levels of mindfulness. As seen in the short-term mindfulness research above, the results support the regular practice of mindfulness being associated with increased mindfulness in daily life, less rumination, less emotional avoidance and an increase in self-regulation with more self-compassion and overall well-being. In comparison to the non-practitioners, the practitioners had significantly fewer psychological symptoms.

Pepping et al. (2016) looked at motivations for mindfulness meditation in 190 participants who had meditated for between less than a year and more than 5 years. Of these, 119 had previously practised mindfulness, but at the time of the study were no longer practising. In similar results to the previous studies, they found that participants gave four main reasons for starting a mindfulness practice: firstly, to reduce or cope with negative affect such as anxiety and depression; secondly, to promote well-being and positive affect, such as better self-awareness and more happiness; thirdly, beginning mindfulness after it was suggested by another person; fourthly, for a small number of participants, the practice of mindfulness was started as part of a religious practice.

Those who still had a mindfulness practice were asked why they continued to meditate. The reasons given for this were very similar to the answers to the first question; the majority answered that it was helpful to reduce negative affect and manage negative experiences like anxiety and stress, or to promote well-being. Fewer participants mentioned that they saw it as valuable in some unspecified way, and a small number mentioned mindfulness as part of a religious practice. These categories are similar to (Shapiro, 1992)'s three goals and reasons for meditating. Unfortunately, this study did not ask those who were no longer practising why they stopped, which would have been an interesting follow up question.

As discussed above, in Buddhism, mindfulness and compassion are interlinked parts of a whole system, which in the reductionist westernised version can become lost. In addition, as shown, there has been a lot of focus on *attention* as a mechanism in mindfulness. Singer & Engert (2019) were interested in whether practising attention-focused mindfulness alone could bring about measurable effects in other aspects of mindfulness, such as nonjudgmental acceptance and compassion, or whether specific targeted training was necessary to promote these facets. To examine the differences on effect between different kinds of meditation-based practices, psychological trait questionnaires and interviews in which participants recalled a meditation experience in depth were used (Singer & Engert, 2019; Hildebrandt et al., 2017). They compare *present-moment attention* focusing on breathing and bodyscan exercises; *socio-emotional processes* focusing on loving kindness meditations; and, *meta-cognitive processes and perspective-taking* focusing on observing thoughts and a dyadic perspective-taking exercise. The three practices were delivered in 3 x 3-month modules, with three different groups undertaking the meditations in a different order to avoid bias. The results at the end of each 3-month period found a number of differences in the effects on participants' behaviour, brain and body due to training using the different techniques associated with the different types of meditation.

Participants were rated before and after their daily meditation, with all groups showing an increase in present focus, positivity of affect, warmth, energy and decreased thought distraction. The interviews revealed that each type of meditation was associated with different experiences and sensations. In addition, there were distinct benefits from the different types of meditation. For example, as might be expected, the *present-moment attention* increased body awareness the most, the *loving kindness* meditation, focused on compassion and acceptance, boosted positive thoughts the most, whilst the *observing thoughts* meditation heightened metacognitive awareness the most. However, most interestingly, only the meditations focusing on compassion and ethical motivation (e.g. being non-judgemental, accepting, and having compassion and self-compassion) resulted in changes in these qualities. This suggests that including these types of meditation is important in general mindfulness practice, but particularly important for populations like the DBT clients, where self-compassion and being non-self-judgemental are extremely difficult, sometimes taking years of practice.

Structural changes to the brain were also measured, revealing thickening in very specific areas, depending on which module was being undertaken. For example, the *socio-emotional* module training increased grey matter in the parietal and frontoinsular regions of the brain. Again interestingly, structural changes to a specific area of the brain in a participant predicted changes in their behaviour. For example, an increase in the anterior insular cortex, an area of the brain involved in affective , predicted a growth in compassion after the *socio-emotional* module. They also found a cumulative effect at the end of the nine month period, for example, participant heartbeat perception, which did not show up at the end of the shorter studies. Shapiro (1992) also found that the longer the length of practice, the more self-compassionate and accepting his practitioners were. Therefore, perhaps targeted meditations help these aspects to develop in the short-term quickly, but over time, all aspects will develop. Alternatively, the longer the practitioner practices mindfulness, the more types of meditation they try, leading to the multiple effects seen in this study.

Ekici et al. (2020) examines four experienced practitioners of mindfulness meditation, looking at the effects of mindfulness practice and the processes involved using practitioners of only one type of meditation, Vipassana Mahasi (VM). This study purports to address problems in studies which examine practitioners from different mindfulness traditions, as they assert that the results of these studies, cannot be linked to any specific mindfulness techniques. They found a number of themes. As in previous studies, mindfulness was linked to well-being in terms of experiencing happiness and experiencing meaning and purpose; better self-insights and understanding of others and the world, leading to a better experience of the world and personal relationships. As the participants were from a Buddhist tradition of mindfulness, Buddhist teachings and ethics were considered to be important in helping to acquire and understand mindfulness techniques. This point, and the psychosis and other negative outcomes seen in Lomas et al. (2015) also serve to illustrate the point I made in Section 2.3.2, that removing mindfulness from an ethical or a least a strongly supportive framework may result in difficulties in understanding in minor cases, and mental health issues in the most serious cases.

2.5.10 Why is a DMHI for DBT Mindfulness necessary?

This section examines the issues that need to be addressed by a DMHI. It covers mindfulness inducing negative reactions and looks at what is missing in COTS mindfulness apps, including a lack of therapeutic framework, lack of ability to track or offer support to people with self-harming urges and lack of adaptability to users at different stages in the DBT process.

Adverse effects in mindfulness studies and possible causes

The literature shows that mindfulness has a number of benefits for physical and mental health (Chiesa & Serretti, 2010; Khoury et al., 2013; Baer, 2019, *inter alia*), but like other beneficial therapeutic interventions, unanticipated and possibly harmful side-effects may occur (Crawford et al., 2016). These effects can vary in how they manifest, for example, they may be physical, such as agitation or discomfort, or mental, such as anxiety or confusion, and in the intensity of such experiences. Some beginners to mindfulness practice experience physiological discomfort, primarily in the early stages of learning the practice. In some cases, mindfulness practice can lead to often short-term, temporary adverse effects, like anxiety, physical and mental distress and disorientation (Crawford et al., 2016; Clarke & Draper, 2020; Britton et al., 2021). The adverse effects are not well understood and in some cases it may be that such adverse effects are not due to the mindfulness intervention *per se*, but as mentioned above, part of the change process which effective therapy encompasses, which can cause significant aversive negative states (Dimidjian & Hollon, 2010; Baer et al., 2019). Baer et al. also posit that mindfulness practice "can be unpleasant and challenging without causing harm."

For example, in a study of people undertaking a 3-month MBSR course, many with pre-existing mild-moderate anxiety or depression, Britton et al. (2021) report worsening psychological symptoms in around 40% of participants. Britton et al. state that their results are commensurate with adverse effects following psychotherapy, and "transient negative experiences during [mindfulness-based programmes] should be expected", concluding that mindfulness-base therapies may have negative impacts, but these are similar to other types of psychological treatment. However, Kuyken et al. (2016), in their review of studies on MCBT for depression, assert that mindfulness shows significant therapeutic improvements, particularly with more severe presentations, with studies showing adverse effects as low (0-10%) and at the same frequency as in control groups. In several studies, a few participants who were already experiencing negative thoughts and mood struggled to manage negative thoughts which surfaced during meditation and stopped using the apps, leading to non-completion of the study in some cases (Laurie & Blandford, 2016; Clarke & Draper, 2020). However, only one study (Aizik-Reebs et al., 2021) showed a very high percentage of participants having adverse effects during and after the study (87% with 25% having sustained adverse outcomes). Aizik-Reebs et al. suggest one reason for this may be increased awareness of emotional and somatic states which participants were experiencing prior to the study, but only became aware of due to mindfulness training.

Given that many people turning to mindfulness are doing so to help relieve mild-moderate mental and physical health issues (Little et al., 2018), these results are perhaps not surprising. Mindfulness encourages practitioners to acknowledge and 'sit with' both good and bad thoughts and emotions, without trying to change them or solutionise; however, sometimes these can be very painful and doing so requires a great deal of self-compassion. Standard definitions of mindfulness include self-compassion; however, even with the support of an MBI, such as MBSR or MBCT, practitioners, especially at the start, may find self-compassion difficult to access and become overwhelmed by negative sensations, thoughts and emotions.

Of more concern, around 10% of participants in mindfulness studies also experienced longer-term adverse effects, needing further therapy, and in some cases this led to them stopping mindfulness practice (Lomas et al., 2015). Again similar statistics are reported in those attending psychotherapy (Crawford et al., 2016; Lambert, 2013). In addition, very often these practitioners are practising mindfulness outside of a supervised programme (Lomas et al., 2015). Rarely, the side-effects of mindfulness practice can be a serious psychotic episode. In Section 2.5.9, above, I refer to an extreme negative impact (Lomas et al., 2015). This is a very specific case, using a very advanced meditation technique without supervision, and is extremely rare.

These issues with mindfulness being the case, and given the pre-disposition of those with BPD to affective dysregulation and self-harming in reaction to strong affect, designing a DMHI specifically for this vulnerable user group receiving DBT, which acknowledges, supports and works with these issues is clearly necessary.

DMHI designed for DBT clients

In designing DMHIs for user groups with specific mental health issues, there is a distinct end-user, seeking recovery or help with a mental illness, and thus there is potential for harm to be done by standard apps, which may not take into accounts the users' specific requirements and the support they need. COTS apps are not designed to be MBIs; thus, in COTS apps there is no therapeutic framework to support the users if they encounter difficult thoughts. In people with BPD, such negative thoughts could quickly lead to self-harm. Like other MBIs, DBT helps clients to change by transforming how they relate to distress, rather than focusing on the distress itself (Baer et al., 2019). Clients learn to recognise their thoughts, emotions, and reactions. It enables them to then access further DBT skills, to lessen self-harming, have better interpersonal communication and better deal with their difficult thoughts and powerful emotions. A specific DMHI for DBT would take account of this and provide it to vulnerable end users.

Tracking and supporting negative affect

Chittaro and Vianello (2016) found that using a COTS mindfulness app intensified negative feelings and anxiety for some participants, because they were more aware of their worries. Intensifying feelings of distress in individuals with BPD who may respond by self-harming is a major concern. Baer et al (2019) suggest that it is important to track individuals to further recognise and understand adverse effects in MBIs. The important thing is for the patients/clients and the clinicians or mindfulness teachers to be aware of this possibility. Due to the self-harm and suicidality which is part of a BPD diagnosis, DBT has measures in place to support any deterioration in mental health and increase in desire to self-harm. This includes the ability to contact a personal therapist by phone or email in a crisis, when the DBT skills cannot be used due to extreme affect. Such contact information could be incorporated into a DMHI for DBT Mindfulness, for ease of use in high affective states.

COTS generally do not carry any warnings about adverse side-effects or offer advice on where to go if such adverse effects occur. A DMHI could include a Crisis Area, which is an area of the DMHI where the details of the personal therapist and other professionals details could be stored for ease of access in a crisis situation. This area could also reflect a physical Crisis Box and contain soothing items, for example, music, photographs and reminders of things that help in a crisis, which standard COTS do not include.

Tailoring

COTS mindfulness apps are one-size-fits all, often offering little opportunity for tailoring to the individual's needs. Here we look at some examples of where a DMHI could help.

Suitability of exercises types

As discussed above, many adverse effects can happen in the initial stages of acquiring mindfulness. For example, physical distress can arise when attention is given to specific parts of the body (Creswell et al., 2014). The exercises need to be suitable to the context, for example, exercises involving the breath may trigger memories of trauma. To support and facilitate DBT clients, a DMHI can allow very specific tailoring to fit different stages in the therapy and different physical requirements. Thus, a DMHI which takes into account the types of exercise which may be suitable is necessary.

In addition, often beginners can only manage very short bursts of mindfulness, whereas an app may start with 20 or 30 minutes of meditation, making COTS apps for non-DBT mindfulness unsuitable. A DMHI can have a tailored approach to length and type of exercise.

Different stages

The needs of people with BPD in the early stages of treatment may be very different from those of later stage patients/clients. For example, DBT clients have often not chosen to specifically undertake DBT, it is frequently the only therapy offered. Thus, patients often know nothing about mindfulness when they start. Clarke and Draper (2020) found a basic misconception amongst some participants who were new to mindfulness, leading to adverse effects. Mindfulness was seen by some as a passive process, a quick relaxation or focusing technique, which was "done 'at' [them]", without them having to actively engage. Clarke and Draper suggest that an app clarifying the underlying concepts of mindfulness would have led to a better mindfulness experience. Thus, a DMHI can fully explain the concepts, the skills and the expectations, which may be important for early stage clients.

Validation - acceptance and change

Therapeutic attrition has been discussed above in Chapter 1 as a problem for mental health treatments. Section 2.4.1 discussed the difficulties and challenges that people living with BPD face (Leichsenring et al., 2011), and in Section 2.4.3, I examine DBT, which although considered a gold standard therapy, is difficult (Katsakou et al., 2012) to undertake, due to the nature of BPD being therapy-interfering. One of the key dialectics in DBT is the *acceptance and change* dialectic. This means that given the patients' often awful life experiences, it is understandable why they self-harm and present with other self-defeating behaviours, but they also have to change to have the chance of "a life worth living". As discussed above, the key to DBT is acquiring and using Mindfulness skills, which are highly manualised and slightly reduced from other approaches to mindfulness therapies (cf MBSR and MBCBT).

A DBT DMHI can help with this by containing a lot of validation. This should be both when clients are able to practice, even for short periods of time, and when clients are struggling. For example, rather than sending standard reminders, like COTS apps, which Clark and Draper (2020) reported annoyed and caused anxiety to some participants, personalised messages which give the user the validation they require, so as not to add more anxiety and guilt, can be used.

Issues with existing DMHIs for DBT

Finally, Section 2.3 looked at the main adjunctive apps that have been designed to support DBT. It can be seen from the critique of those DBT apps that whilst they have shown some benefits to patients with BPD, previously produced DMHIs for DBT are still missing a number of points, which the requirements gathered here using UCD can provide.

Section summary

In this section, I discuss why COTS apps for mindfulness are problematic in this context: lack of validation; not having a DBT framework around the exercises; lack of refinement according to the DBT programme stage in the process; and, unsuitability of exercises for some clients, especially in the early stages, as well as the inappropriate length of exercises are some of the issues that a DMHI can help to address. By using UCD, tailoring of the approach can fit the exact requirements of the clients and other stakeholders at each stage of the therapy.

2.5.11 Conclusion to mindfulness context

This section examines the origins of mindfulness and its development in MBIs. It looks at the Mindfulness module in DBT and looks briefly at how Mindfulness skills practice may bring about some of the behaviour changes in DBT clients, considering mechanism and measurements briefly. It then looks at studies on short-term and longer-term mindfulness practitioners, noting how different practices affect both participant behaviour and the grey matter of the brain.

After reading this section, the reader should have an appreciation of the tradition mindfulness came from and how mindfulness has been used in MBIs. In particular how the

Mindfulness *skills* taught in DBT differ from mindfulness taught in other MBIs, due to the nature of the clients' history and the presentations of BPD and the issues in Mindfulness which need to be addressed by a DMHI.

2.6 Conclusion

This chapter discusses the background to the thesis.

The UCD context discusses what a UCD process looks like and why the work is necessary. The Health context examines DMHIs for DBT and the design approach taken in Health. It is followed by the therapeutic context, examining BPD, the mental health condition whose treatment is at the centre of this research, and the therapy used in its treatment, and the focus of the work in this thesis, DBT. This is a mindfulness-based therapy, which teaches four skill modules to clients to help deal with emotional dysregulation and suicidality, with Mindfulness as the core skill module. The context then examines other mindfulness-based interventions looking at how Mindfulness in DBT is necessarily taught in a different way.

A DMHI which helps clients undertaking DBT learn and establish a mindfulness practice needs to embrace a number of the issues discussed in this chapter. These include pushing the *acceptance and change* dialectic, to both encourage clients when they fail to practice, return after a few days away or repeat the same exercise a number of times, showing them that this is fine and understandable, and to show them it will be helpful for them to change. These may need to be optional parts of a DMHI, for the client to listen to or watch if they choose to. Perhaps including short stories of success may help clients.

It needs to have a very good explanation of what mindfulness is and what is expected, as well as what the client may experience, whilst giving helpful feedback and gently pushing the fact that once mindfulness is learnt and used often, it can bring large positive changes in behaviour and emotional dysregulation. It needs to use the steps fully, taking into account the constraints of BPD and the clients' past trauma. It should encourage clients to spend as much time practising as possible, as this is what seems to make a big difference. The tension between the user requirements and the therapeutic requirements will also need careful handling.

The rest of the thesis looks to answer some of the gaps and issues highlighted in this chapter. In particular, it addresses the lack of UCD research on DBT; it uses DBT clients in the design process; it proposes extensions and new uses of UCD methods to address some of the issues found when doing research with vulnerable groups of users, such as people with a mental health disorder. It also suggests ways to engage the Health experts more using an empathic and dialogical approach to doing UCD.

In order to address the first research sub-question, the next chapter describes a study on the experiences of long-term mindfulness practitioners, using a diary study.

Chapter 3

How Do Long-term Mindfulness Practitioners Achieve Their Practice?

3.1 Introduction

As discussed in Chapter 2, Mindfulness is the foundation skills module for DBT (Linehan, 1993; Linehan et al., 1993). Section 2.5.9 also showed how a growing body of quantitative and qualitative work has explored the efficacy and experience of mindfulness practice, examining among other things how practice enhances state and trait mindfulness in mindfulness-based therapies and other mindfulness meditation traditions. As discussed in Section 2.5.9, there is considerable literature on the experience of beginners to mindfulness, covering participants of MBSR and MBCT in particular (Mason & Hargreaves, 2001; Finucane & Mercer, 2006; Allen et al., 2009, *inter alia*). However, the lived experience of long-term mindfulness practitioners has not been examined in as much detail (Machado & Costa, 2015; Shaner et al., 2017; Kambolis, 2021). Neither, at the time of writing were there any diary studies that examined when long-term practitioners were and were not mindful and the triggers and barriers in these cases. Therefore, this study examines how practitioners maintain a long-term mindfulness practice. It explores when they practice formal and informal mindfulness and for what purposes. It also examines whether there were opportunities for being mindful in which they either chose not to use mindfulness or whether other factors prevented them from using mindfulness. There are very few diary studies of long-term mindfulness practitioners and none ask what prevented the use of mindfulness. This study presents new empirical data on the practice of mindfulness in long-term mindfulness practitioners, thus contributing new knowledge to the mindfulness literature.

3.1.1 Motivation

Gaining ethical approval for the study with DBT client participants was a complicated and lengthy process, taking over 6 months to complete and involving three separate sets of approval (see Section 1.8). Whilst awaiting approval, I wanted to gain understanding of embedding and maintaining a mindfulness practice, as this is the foundational skills module in DBT and such knowledge could be important in a DMHI for DBT skills.

In order to better understand the issues in establishing, building and maintaining a mindfulness practice, this research begins by examining how experienced non-clinical practitioners successfully embedded mindfulness skills in their daily lives. I rejected a study with *new* (i.e. people with less than 9 months' experience) mindfulness practitioners as participants, because I particularly wanted to ask participants about times when they were *not mindful* and what, if anything, would have helped them to be mindful. As a fairly new, and having previously lapsed, mindfulness practitioner myself, I was aware of the difficulties, self-doubts and recriminations of learning mindfulness meditation techniques and maintaining state mindfulness. I did not want to add to the stress and self-doubt of participants who were learning mindfulness with a study asking when they *were* and in particular, *were not* mindful. Therefore, I considered that this study needed participants with a mature practice, who would be able to recognise any self-doubt and recriminations this question might trigger without being agitated by them, and who could answer reflectively (Goodman & Kuniavsky, 2012). This study provides an understanding of how long-term mindfulness practitioners stay mindful, as well as insights into when they had and had not been mindful.

3.1.2 Role in the research

This study fulfilled a number of roles in the research:

1. Research knowledge: As a new researcher waiting for ethical approval, a study to gain knowledge about acquiring mindfulness in a non-clinical population allowed me to learn about using the types of qualitative research skills that are typically used in UCD. It taught me how to run a qualitative study using the type of "standard" methods typically used in UCD (see Section 2.2), familiarising me with techniques including recruitment, running a diary study, conducting interviews and carrying out qualitative analysis techniques and processes, under conditions unconstrained by the repercussions of doing a study in a more challenging context.

2. Initial ideas generation: It allowed me to generate some initial design ideas using secondary proxies, with knowledge of the practice of mindfulness. Whilst not employing DBT Mindfulness skills, the final results of using mindfulness in non-clinical practitioners, was to gain awareness of bodily feelings, emotional states and thoughts, which was the same as sought in DBT Mindfulness.

3. Asking difficult questions: This study allowed me to ask questions which would have been unethical with the clients, due to the presentation of BPD. For example, Study 1 asked repeatedly about times when participants were not mindful, which may have triggered negative thoughts leading to self-harm and / or potentially disrupting the therapeutic journey in the clients. It is acknowledged these were secondary proxies, and in no way is the experience of the Study 1 participants seen as the "correct one" or used as a standard against which to *measure* the clients' experience.

4. Possible design ideas: The experiences of the long-term practitioners in acquiring and maintaining mindfulness fed into discussions about the experiences of the clients' DBT skills acquisition journey in the Study 2 questions. The non-clinical practitioners had gained lived experience of part of the process that the DBT clients undergo. Therefore, by looking at mindfulness in a non-clinical population, the initial study allowed me to derive possible ideas for a Mindfulness DMHI and feed forward *potentially* helpful tasks and features for the clients and clinicians to evaluate in Study 2 and Study 4. For example, what kind of support practices, tools, techniques or hacks such long-term practitioners might have developed for themselves. These practices, such as starting the day with a short mindfulness session, gave me inspiration for some of the practices, techniques and support offered to the target end-users.

5. Enhanced understanding: As well as the ethnographic observations, this study gave me additional sensitivity to the challenges in establishing a mindfulness practice, as well as an understanding of the benefits and advantages it can bring.

6. Scoping: After running this study, I started to become aware that a mindfulness game might not be the best option in this context. Therefore my thoughts on, the scope of the research changed and I started considering other options to implement a DMHI. I became aware from the study and my Tuke Centre observations, that the clients needed a lot more support than the non-clinical practitioners. Therefore, the study helped by scoping COTS mindfulness apps as inappropriate in the DBT context (see Section 1.2.2), and starting the process of changing the DMHI requirements research focus from a digital game, as initially requested, to an adjunctive app.

3.1.3 Contributions

The main contributions of this study are as follows:

1. It contributes to the qualitative mindfulness literature on what the experience of long-term mindfulness practice looks like. This is a clear desideratum, as there is comparatively little literature on the long-term practice of mindfulness and its integration into a life over years, and very few of those studies use a diary study method.

2. It inputs into the contribution made by this thesis to the design literature on the time and considerable methodological work which was needed to gather and report requirements for a DBT app, through helping to scope the research, because when I started this study, the suitability of a digital DBT game and COTS mindfulness apps was unclear.

   Study 1 and my experience on placement with the DBT team developed my understanding of why conventional mindfulness needed to be adapted for DBT clients. Thus, this study helped to define the scope of the project by confirming that a tailored approach to DBT Mindfulness was needed. It also started the process of my considering whether a game was the best way to implement DBT skills in a DMHI, which eventually led to changing the research focus from a DBT game to an adjunctive app.

3.1.4 Research summary

The research described in this chapter used a week-long qualitative diary study (Goodman & Kuniavsky, 2012; Lazar et al., 2017) (See Section 2.2) to examine the factors that facilitate and constrain long-term practitioners in integrating mindfulness into their life and maintaining a long-term practice. Specifically it looked at the triggers, motivations, ways of engagement and practices that help experienced mindfulness practitioners remember and maintain mindfulness in daily life and the constraints on doing so. The diary asked participants questions about their experience of mindfulness in the previous few hours. The questions differed according to whether participants answered that they had been mindful in the previous few hours or that they had not. After completing the diary, participants took part in a semi-structured interview to discuss their diary entries and themes around their mindfulness practice. The data was analysed using Thematic Analysis (TA; Braun & Clarke, 2006). The main themes developed from analysing the data were:

1. **Gaining a mindful life** – how participants moved from trying to remember to be mindful to mindfulness eventually becoming seamlessly incorporated into their life.
2. **Contexts of use** – covers two contexts of use, termed in this research *relaxed mindfulness*, used in non-stressful situations, and *purposeful mindfulness* used in more difficult situations.
3. **Time and cognitive demands** – examines the main constraints on mindfulness use, which were strong demands on time and lack of cognitive capacity.
4. **Mindful social interaction** – describes participants using mindfulness skills in social interactions as teachers, parents and managers.

3.2 Methodology

3.2.1 Aims

The research question for this study was: How do long-term mindfulness practitioners achieve and maintain their practice? From this question, the aims were:

1. To understand the factors that assisted and constrained experienced non-clinical long-term mindfulness practitioners;
2. To understand how experienced non-clinical practitioners had moved from being a beginner towards integrating mindfulness into their life and maintaining mindfulness, even in times of high stress or cognitive demand, and what that embedded, lived mindfulness might look like;
3. To consider whether the results from a study on a non-clinical population of what lived mindfulness looks like can fit into and help DBT client users of a DMHI for mindfulness.
4. To understand what using typical "standard" qualitative study *methods* (see Section 2.2), which are frequently used in UCD (e.g. the interviews run here with a non-clinical population) look like. These could then be used as a comparison for the way in which UCD was used to gather requirements in a clinical population.

Whilst the primary aims of this study were to gather knowledge about long-term mindfulness practitioners' behaviour and experiences, as well as knowledge and experience of using UCD methods, I was also interested in whether the knowledge gained could be of use in designing a DMHI for DBT Mindfulness. The limitations of using participants from a non-clinical population to learn about design for a group with a mental illness are discussed in Section 3.4.10 below.

3.2.2 Study design

To achieve the aims, several study designs were initially considered, including questionnaires and interviews (see Section 2.2). Whilst these methods would allow participants a chance to reflect and report on their mindfulness practice and experience, I decided that they would not fully capture what participants actually did on a day-to-day basis. In addition, participants would be asked to remember incidents without having noted them at the time, which might influence their responses. Therefore, a method that could reveal the full picture of mindfulness practice, showing variation on different days and capturing experience *in situ* as it happened, was required (Goodman & Kuniavsky, 2012; Lazar et al., 2017).

I chose a time diary study (Alaszewski, 2006) as the best method of logging participants' data over a period of time, with data being captured twice daily over seven days. I chose a seven-day duration to examine mindfulness practice both at work and on days off (Hayashi & Hong, 2011). The diary study also allowed multiple entries on the same day. Participants were asked to make entries twice a day, a short enough time between entries for participants to remember their mindfulness episodes, but which would not be considered too onerous by the participants. The end of the diary entry week was followed by a semi-structured interview based on the participant's diary entries.

Qualitative interview studies contribute to knowledge, based on the meanings co-created by the interviewer and participant (Pilarska, 2021). Therefore, a qualitative research design was suitable for my research. The semi-structured interview allowed me to delve deeper into the reasons for being mindful and issues when not mindful mentioned in the diaries. Using a semi-structured interview allowed for the content of the interview to be flexibly modified as the participants and I co-created knowledge from the shared experience of questioning and answering, creating the meaning (*ibid.*) Meaning was further co-created through discussions of the codes and themes with my supervisor. The semi-structured interview was especially important given my awareness of mindfulness; the flexibility allowed authentication checks during the interviewing process to prevent confusion or misrepresentation.

Thematic analysis (TA)

I coded and analysed the data using inductive Thematic Analysis (TA), following the method in Braun & Clarke (2006). In TA, data is coded by the researcher through an analytical process and the codes built hierarchically into themes which reflect the researcher's interpretation of participants' experiences around, and attitudes to the research area. This inductive approach allows the researcher to develop codes and themes from the data, rather than using pre-existing codes. Thus, inductive TA allows the researcher to present a more detailed analysis of aspects of the data than a broad quantitative content analysis, giving deeper insights into what happens when practising mindfulness.

The six-phase method advocated by Braun & Clarke (2006, p.87) is detailed below using examples to show its application in the study:

Stage 1 - Familiarisation with data

I read new diary entries twice daily. On completion of the seven-day diary entries, the diary was printed and read as a whole so that I could identify what I saw as patterns. It also allowed me to highlight anything that was unclear. The diary was then used as a prompt in the interview. Writing a full transcription of the interviews and re-reading this and the diaries a number of times before starting to code led to me having great familiarity with the data.

Stage 2 - Generating initial codes

This study took place over an eight-month period, as initial recruitment was difficult. I used the diary entries and interview transcripts of the first five participants to generate the initial codes, which were then expanded with later diary entries.

Within the diary questions, some of the initial codes that I generated were around times of the day and daily activities that participants mentioned *when/where*, for example *breakfast*, *walking*, *waiting*, *at work*. Others included codes around *inspiration*, for example *apps* and *digital reminders*, which I later changed to *Use of technology*; I also generated codes from within the question "What would have helped?", for example, *setting reminders*.

However, as I analysed the data further, I saw that participants had more to say about the mindfulness process in different *contexts*, which I originally analysed as codes of *time* or *activity*, within the diary question which asked participants about times when they were *mindful* or *not mindful*. Therefore, I added codes like *states of consciousness*, *busyness*, *walking* and *eating*, for when mindfulness was used in different contexts. For the things that they found helpful or used to be mindful, I added more relevant codes, refining my initial code, which was *things that would have helped*.

Stage 3 - Searching for themes among codes

Stages 3, 4 and 5 were done iteratively.

I grouped the codes into themes on paper. Some codes were discarded as not relevant to my aims or only applying to one participant. Themes were then developed from the code groups. For example, *relaxed mindfulness* and *purposeful mindfulness* both became themes at this stage, which I developed from codes like *walking* or *stressed*, encompassing both states of mind and places / activities when the different types of mindfulness occurred. I grouped the codes *work* and *busyness* to form the theme *mindfulness when busy*. I also added *willingness* as a theme at this point, as it is one of the dialectics frequently discussed in DBT, and therefore of particular interest.

Stage 4 - Reviewing themes

Themes were reviewed and refined by my constantly checking the data against the theme. The theme *mindfulness when busy* became *Time and cognitive demands*. This theme was extended to include *willingness*, *mindfulness and pace* and *can you be mindfully busy?*.

In another case, I expanded the themes *situation when mindful* and *purposeful mindfulness* into the theme of *mindfulness as a help in stressful situations*, which finally became the theme of *Contexts of use*, covering the sub-themes of *relaxed* *mindfulness* and *purposeful mindfulness*.

Stage 5 - Defining and naming themes

Once the themes were in place, they were discussed with my supervisor, considering the meaning of each theme on its own and as part of the other themes; thus this input from my supervisor added to the co-creation of the themes. At this stage the data extracts used for each theme were organised into an "internally consistent account" Braun & Clarke (2006, p.92) with a narrative detailing why they were interesting.

Stage 6 - Producing the report

The present report explains and illustrates the themes and how they connect to the research question.

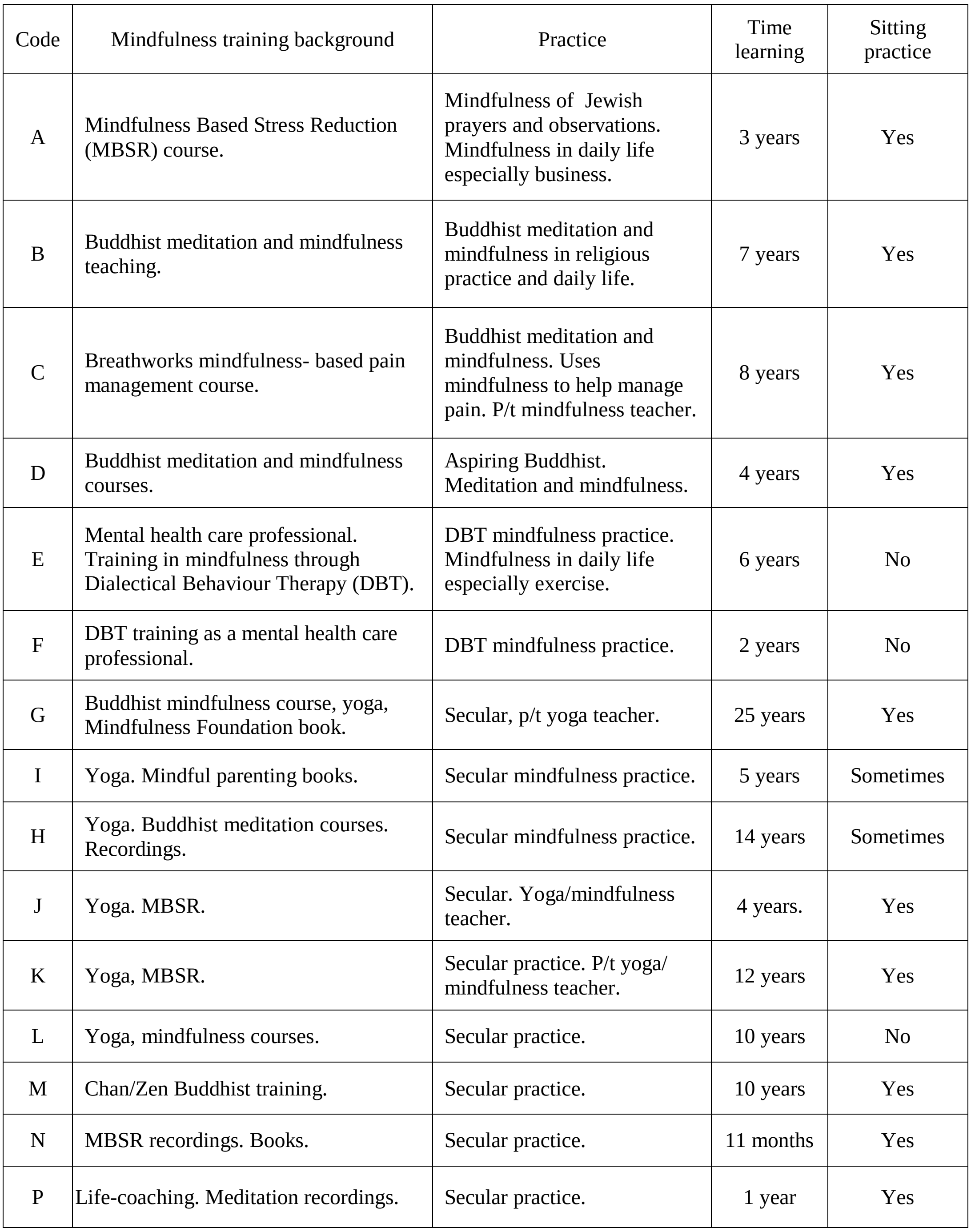
3.2.3 Participants

The participants were adult mindfulness practitioners (*n*=15) who had been practising mindfulness for at least nine months, with the shortest being 11 months. Nine months was chosen as a cut-off point for a number of reasons:

1. Many practitioners undertake an initial mindfulness course or mindfulness training lasting 8-12 weeks. It can take this long to understand what is required in practising mindfulness and to show results by recognising and maintaining state mindfulness (Mason & Hargreaves, 2001). At the end of the 3-month mindfulness course, at the nine month point, practitioners would have maintained their practice without the support of the training programme for a further six months.
2. Habit formation is complex, and can be a slow process. Lally et al. (2010) found it took an average of 66 days (range 18-254 days), in a longitudinal study. Therefore, 6-7 months was allowed for post-training mindfulness habit formation.

I recognise that some studies use a higher time threshold for long-term practitioner participants (years rather than months) (for example Shapiro, 1992; Ekici et al., 2020). In practice, all participants but one had been practising for at least a year, with an average time of 15 years, including an outlier of 25 years (range 11 months - 25 years). Removing the outlier of 25 years, the average time was 6 years. In addition, none of them considered themselves to be in the initial stages of learning mindfulness, and all participants expressed the intention of practising mindfulness on a daily basis.

Participants were recruited using purposive sampling. Methods of recruitment included posters at the University of York, adverts on social media, flyers at a local Buddhist Centre (Madhyamaka Kadampa Meditation Centre, Kilnwick Percy), emailing mindfulness teachers and snowballing from participants to friends and colleagues. This resulted in a participant cohort with training and practice developed in a number of mindfulness approaches and traditions. A summary of the participants can be seen in Figure 3.1 and a discussion of the different types of participant can be found below.



Code	Mindfulness training background	Practice	Time learning	Sitting practice
A	Mindfulness Based Stress Reduction (MBSR) course.	Mindfulness of Jewish prayers and observations. Mindfulness in daily life especially business.	3 years	Yes
B	Buddhist meditation and mindfulness teaching.	Buddhist meditation and mindfulness in religious practice and daily life.	7 years	Yes
C	Breathworks mindfulness- based pain management course.	Buddhist meditation and mindfulness. Uses mindfulness to help manage pain. P/t mindfulness teacher.	8 years	Yes
D	Buddhist meditation and mindfulness courses.	Aspiring Buddhist. Meditation and mindfulness.	4 years	Yes
E	Mental health care professional. Training in mindfulness through Dialectical Behaviour Therapy (DBT).	DBT mindfulness practice. Mindfulness in daily life especially exercise.	6 years	No
F	DBT training as a mental health care professional.	DBT mindfulness practice.	2 years	No
G	Buddhist mindfulness course, yoga, Mindfulness Foundation book.	Secular, p/t yoga teacher.	25 years	Yes
I	Yoga. Mindful parenting books.	Secular mindfulness practice.	5 years	Sometimes
H	Yoga. Buddhist meditation courses. Recordings.	Secular mindfulness practice.	14 years	Sometimes
J	Yoga. MBSR.	Secular. Yoga/mindfulness teacher.	4 years.	Yes
K	Yoga, MBSR.	Secular practice. P/t yoga/ mindfulness teacher.	12 years	Yes
L	Yoga, mindfulness courses.	Secular practice.	10 years	No
M	Chan/Zen Buddhist training.	Secular practice.	10 years	Yes
N	MBSR recordings. Books.	Secular practice.	11 months	Yes
P	Life-coaching. Meditation recordings.	Secular practice.	1 year	Yes

Figure 3.1: Participant background information showing mindfulness training and context of practice

Figure 3.1: Participant background information

Seventeen participants were initially recruited, eight men and nine women. The data of two of the participants was not included in the final analysis (one male and one female). One dropped out after the first day, the other refused to complete the questions in the *not mindful* section of the diary for the times when she had not been mindful and declined to discuss this over email. On further investigation during the interview, it became clear that the participant had not fully understood the instructions and had perceived the *not mindful* questions as judgemental, leading to her feeling hostile to the study. It was therefore decided not to include this participant's data in the final analysis, as it had not been recorded with full understanding or cooperation.

The participants were located in a number of places in the UK, with the majority being in Yorkshire. The primary employment of participants was: office-based work (n=6), research/academia (n=3), therapists (n=2), yoga/mindfulness teachers (n=2), maternity leave from a job in marketing (n=1), and director of a small building company (n=1). Participants also had other jobs, one of the office-based workers worked part-time and was mainly a stay-at-home parent; two of the other participants were part-time mindfulness teachers.

Participant backgrounds

As shown in Figure 3.1, the participants come from a variety of mindfulness training and traditions. A number of participants combined mindfulness with a religious practice. Two participants were therapists from a Dialectical Behaviour Therapy (DBT) background. Other participants came from an MBSR training background and others had learnt mindfulness through methods such as yoga, books and audio recordings. Figure 3.1 also shows that almost all participants had a formal mindfulness practice (often called *sitting*), discussed in Section 3.3.3.

3.2.4 Materials

Diary

In running this study I was influenced by qualitative studies on mindfulness, such as Mason & Hargreaves (2001) and Mackenzie et al. (2007), which asked quite general questions and obtained rich data. The diary study questions were devised to answer the second part of the research question on how long-term mindfulness practitioners *maintained* their practice. This included understanding the factors that assisted the practitioners, such as a certain place or time or another prompt, and those that constrained the practice, such as such as a certain place or time or another constraint. In getting a full picture I also sought to identify how long they maintained mindfulness for, and whether this was possible even in times of high stress or cognitive demand. I also wanted to know how they felt post-mindfulness episode, and whether the feelings engendered by the practice were something that contributed to them maintaining a practice. In addition, because I could not find research asking about when participants were not mindful, I wanted to understand how a long-term practitioner might reflect on the times that they were not mindful without recrimination, and offer themselves (and others) advice on what might have helped them to be mindful. Overall, I wanted to gain a picture of what life-embedded, lived mindfulness might look like. Thus, the final questions were as shown on *Page 2, below.*

The diary was created using Google Forms. It could be accessed on any computer, mobile phone or tablet with internet access. The diary consisted of several short questions asking about the participant's mindfulness practices over the previous few hours (i.e. the previous morning or afternoon/evening). An online solution was chosen because it was accessible to the participants from most locations and easy to check that the diary had been completed for each session. The data was also secure and instantly accessible for analysis.

The form consisted of three pages:

Page 1

> Participants entered their unique number and selected whether they had been mindful or not, using a ***yes/no*** radio button. The answer branched the next question and participants were directed to a different Page 2 depending on their answer.

Page 2

> Selecting '***yes***' directed to the following questions:
>
> 1. Where were you mindful?
> 2. What prompted you to be mindful?
> 3. How long would you say you were mindful for?
> 4. How did you feel after being mindful?
> 5. Any other comments?
>
> Selecting '***no***' directed to the following questions:
>
> 1. Was there a situation where you could have been mindful?
> 2. Did you feel like there was a reason that you could not be mindful?
> 3. Would anything have helped you to be mindful?
> 4. Any other comments?

Page 3

> Participants were thanked for their participation and asked permission to submit their data.
>
> The submitted data was stored in a Google Docs spreadsheet with the date and time stamp automatically added.

Questions were kept short so as not to overburden the participants. They were able to answer as fully as they liked.

Prompt sheet

In addition to a link to the online diary, participants were also provided with a printable sheet with all the questions and short numbered lists, which they could print out and use as an aide-memoir for incidents throughout the day. This allowed snippets to be recorded without impinging on time and inconveniencing the participants. The incidents could then be transferred to the diary and more details completed when convenient. Some participants found this useful, others did not use it.

Semi-structured interview schedule

The semi-structured interview questions were based on a desire to understand the diary entries fully, to have a basis for a deeper understanding of how the participant had embedded mindfulness into their lives, to ascertain what, if anything, had inhibited them from being mindful and how they overcame any resistance. Participants were asked the following:

How did you find the study?

This question sought to check the participant's well-being and to see whether doing the study had revealed anything to them. Any revelations they disclosed were explored further in follow-up probe questions.

1. What initially led you to start practising mindfulness?
2. How long did it take to become an embedded habit in your life?
3. How often do you practise and in what situations?

These questions prompted probing questions where necessary to illicit further information.

Participants were then asked in detail about their diary entries to clarify anything that was unclear, to make sure I had understood all entries, and then to explore in depth anything that inhibited them from being mindful and how they overcame that. The diaries often served as a jumping-off point for in-depth discussions about their mindfulness practices, or were used as examples to illustrate their answers to the more general initial questions.

3.2.5 Procedure

Diary

The diary study followed a qualitative method detailed in Section 2.2.6 (Adams & Cox, 2008; Lazar et al., 2017; Sharp et al., 2019). Shortly before starting the diary study, participants were emailed a link to the diary and a unique identifier. They were then contacted by telephone or we met face-to-face to check that everything was clear, answer any questions and confirm that they were happy to participate. Consent forms were signed and collected at this stage. Participants were able to choose which day of the week to start the study, as long as they were able to complete the diary for seven consecutive days. This gave a length of time including weekdays and weekends over which to view their daily patterns of mindfulness activity. As illustrated in Section 3.2.4, for each diary entry, participants selected whether they had been mindful during the previous few hours. They then completed the appropriate questions.

Completing each diary entry took 5-10 minutes. Ideally, one entry was made at lunchtime, covering the morning, and one in the evening, covering the afternoon and evening. However, some participants were only able to complete the diary once a day, although they had made snippet notes on the prompt sheet during the day, and some participants made entries at different times of the day due to other commitments. This was not seen as a confounding factor, as the data was the primary interest not the time it was entered. In addition, the prompt sheets allowed participants to jot down snippets of the times they were mindful when away from a computer.

The spreadsheet containing the diary entries was monitored several times daily for new entries. This also allowed a check-up on the health and well being of the participants. If participants missed more than one entry, an email checking on their well-being and gently prompting them to continue was sent. The email also reminded them that the study was interested in when they were not mindful and their reasons, in case they had negative feelings or worries about not being mindful.

Interviews

At the end of the study, participants took part in a short, audio-recorded, semi-structured interview. They had been told about this on the Information Sheet at the start of the study, but were re-asked if they wanted to take part. One participant declined to be interviewed, citing lack of time. This allowed the participants to be debriefed about the study and to answer any final questions they might have.

The interviews followed the steps detailed in Section 2.2.6 (Adams & Cox, 2008; Lazar et al., 2017; Sharp et al., 2019):

- Planning. A semi-structured interview schedule was developed, which was supplemented whilst reading the diary entries by individual questions about specific aspects of each participant's diary. Ethical permission had already been granted as part of the diary study. The diary study took place asynchronously and the interviews took place either in participants' houses or a place they had chosen like their studio, or in some cases on the telephone. All interviews were recorded on my Apple iphone.

- Piloting was conducted with the pilot diary study participant, as detailed below.

- Interview Beginning. The participants had all met me previously as we had spoken on the phone or met in person at the start of the study. We had also had some email exchanges; therefore, there was a rapport between us (Dumas & Loring, 2008). After greeting the interviewees and making sure they were settled, I turned on the recording device and asked on tape if they were happy to be recorded. I adopted a chatty, informal style, describing the interview as "a chat about the diaries". I also reminded them that the interview was anonymous (I used a code to introduce each participant on tape) and about what would happen to their data. I started by asking them how they had found taking part in the study. By asking about the overall experience of the study, if the participants had any issues, this gave them a chance to 'let off steam' (Adams & Cox, 2008) about any issues they had encountered. The participants were relaxed as they were in familiar surroundings.

- Interview Body. In the body of the interview, I followed the schedule order, supplementing with additional questions on individual entries and probing when something was not clear. Following Sharp et al. (2019) I asked about the times when they had been mindful first, and left the possibly more sensitive questions about when they had not been mindful until after. Before asking about this I reminded the participants why I had asked this question.

- Final stage. After the main questions had been asked, I asked them if they had anything to ask me or if there were any questions I had not asked but they thought I should have. This was followed by demographic questions and thanking them for their time.

- Data Analysis. Please see section below.

The interviews lasted between 15 and 49 minutes. Participants were asked to clarify anything that was not clear in any of the diary entries, then about their experience of the study, including whether undertaking the study had affected their practice; their thoughts on mindfulness and how it applied to their lives; and, to talk about some of the reoccurring focuses found in the data, some of which I developed into themes during analysis.

Participants were given a £10 Amazon voucher to thank them. Several participants mentioned that though happy to receive the voucher, it had not been their motivation for doing the study.

3.2.6 Pilot study

The study was piloted by Participant M, who had originally learnt meditation and mindfulness in the Buddhist tradition, but was a secular practitioner of mindfulness at the time of the study. The pilot study was conducted in the same manner as the main study in the initial stages, with identity numbers and links being sent to the pilot and the signed consent form obtained before starting. However, the pilot was not prompted to complete the diary, as it was initially felt that email reminders might become annoying.

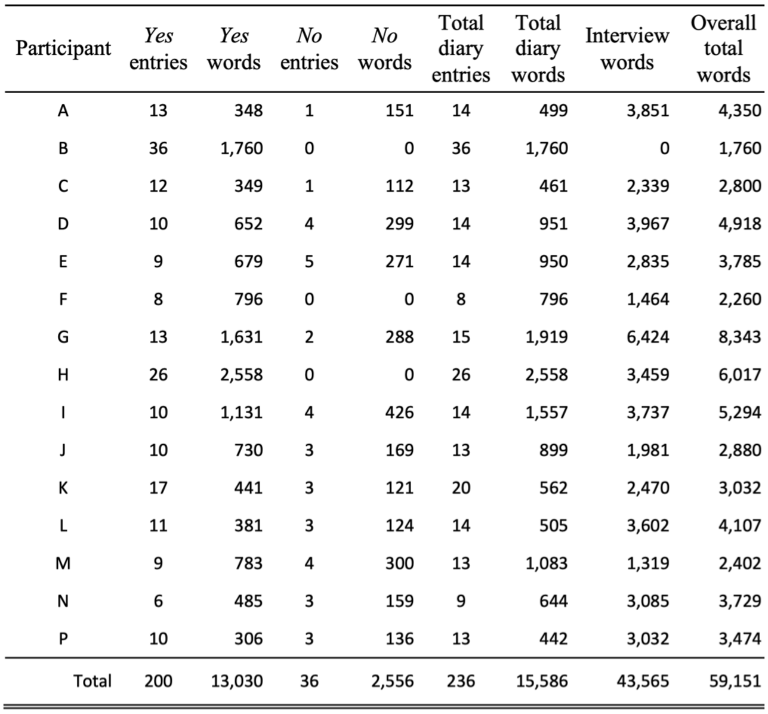
Participant M did miss a couple of entries. During the interview, Participant M mentioned that it would have been useful to have had an email reminder when they did not complete an entry, and that it would also be helpful to receive an acknowledgement of their work at the half-way point. These suggestions were incorporated into the study. It also emerged that it would be helpful to suggest that participants could jot down when they were mindful as they went through the day. This motivated the sending of a prompt sheet on the suggestion of the pilot. Details of the prompt sheet can be found in Section 3.2.4.

The text on Page 3 of the diary form (the submission page) was also changed slightly on participant M's suggestion, to make it clear that there were no further questions and to ask participants' permission to submit their data.

Although the pilot study revealed several points in the way the study was administered that had to be changed before the main study was run, the questions asked in the diary were seen as satisfactory and were not changed; therefore, the pilot's data was included in the final data analysis.

Participant M also piloted the interview with no changes being made.

3.3 Results



Participant	*Yes* entries	*Yes* words	*No* entries	*No* words	Total diary entries	Total diary words	Interview words	Overall total words
A	13	348	1	151	14	499	3,851	4,350
B	36	1,760	0	0	36	1,760	0	1,760
C	12	349	1	112	13	461	2,339	2,800
D	10	652	4	299	14	951	3,967	4,918
E	9	679	5	271	14	950	2,835	3,785
F	8	796	0	0	8	796	1,464	2,260
G	13	1,631	2	288	15	1,919	6,424	8,343
H	26	2,558	0	0	26	2,558	3,459	6,017
I	10	1,131	4	426	14	1,557	3,737	5,294
J	10	730	3	169	13	899	1,981	2,880
K	17	441	3	121	20	562	2,470	3,032
L	11	381	3	124	14	505	3,602	4,107
M	9	783	4	300	13	1,083	1,319	2,402
N	6	485	3	159	9	644	3,085	3,729
P	10	306	3	136	13	442	3,032	3,474
Total	200	13,030	36	2,556	236	15,586	43,565	59,151

Figure 3.2: Diary study corpus data

3.3.1 Data entries

This study comprised a total of 236 separate diary entries from 15 participants. A diary entry records either a mindfulness episode or a time when the participant had an opportunity to be mindful, but was not. Of these, 200 were entries when the participants had been mindful, (i.e. after picking the *Yes, I was mindful* category);[1] 36 were when participants had not been mindful (i.e. after picking the *No, I was not mindful* category).[2] The mean number of diary entries per participant over the week was 15.73 (mean number of *Yes* entries $13.\dot{3}$, mean number of *No* entries 2.4 / participant). There were a lot more entries in the *Yes, I was mindful* category than the *No, I was not mindful* category, perhaps because it was easier for participants to recall when they had been mindful than when they had not, or perhaps because they were hesitant to admit when they were not mindful. In the *Yes* category, some of the participants made a lot of diary entries, while others made fewer. The range for diary entries/participant for *Yes* was $6 - 36$ entries. The range for *No* was $0 - 5$ diary entries/participant.

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[1] See Section 3.2.4 for the Diary front page with the choices offered.

[2] See footnote 1 above.

The entire corpus of both diary entries and transcribed words from the interviews numbers 59,151 words (Diary words = 15,586; Interview words = 43,565). Table 3.2 shows the breakdown by participant of the number of diary entries made and the number of words in the diary entries for the *Yes* and *No* categories, as well as the number of words in the interview transcript of each participant.

3.3.2 Themes overview

The study looked at mindfulness as both a formal meditation and as an informal *quality of consciousness* (Brown et al., 2007) brought to daily life, and captured both practices.

The four key themes that I constructed through analysing the data were:

1. Gaining a mindful life
2. Contexts of use
3. Time and cognitive demands
4. Mindful social interaction

3.3.3 Theme 1 – Gaining *a mindful life*

A mindful life in the context of this study is one in which mindfulness is used throughout the day, mindfulness often happens spontaneously and effortlessly, and difficult situations are approached with a mindful outlook. There is a curiosity to approach the familiar with fresh eyes. To the participants, this is different from *a life with mindfulness* as an additional task in daily life, which must be remembered and explicitly practised. In the latter case, mindfulness may be dropped when the participant gets busy or distracted with other things, as seen in Section 3.3.5.

This theme examines how participants build a mindful life, taking mindfulness from an extra activity to being incorporated into even a very full life. These include having a formal sitting practice or daily mindful morning ritual; incorporating informal mindfulness into daily activities, instead of seeing it as something outside normal activities; being willing and committed to practising being mindful, even when mindfulness or the focus is boring or unpleasant; and, being self-compassionate and non-judgemental, both in dealing with difficulties in building the practice and in managing the sometimes harsh critical inner voice, which mindfulness may reveal.

This theme is split into four sub-themes. I begin by discussing the first two sub-themes of formal and informal mindfulness practices, because these are two different ways of practising mindfulness which were important to building a mindful life, but which did not overlap. The other two sub-themes cover Practice and the virtuous circle and Compassion.

Formal mindfulness

Participants who had acquired and embedded mindfulness into a long-term practice used both formal and informal mindfulness. Almost all participants had a formal mindfulness practice to start or end the day. The state of mind created by a formal mindfulness meditation often gave participants a lasting mindful attitude, and sometimes this was sought out intentionally (Table 3.1). Participants saw formal meditation as extremely important. The majority of participants found a morning meditation of between ten minutes and one hour useful.

Mindfulness meditation performed first thing in the morning was seen by some participants as creating a state which lasted into the day giving them a calm and grounded mental state which they tried to make last throughout the day:

> So, it's about the lasting effect during the day. For me, it's about charging my batteries with awareness and then some days the batteries last longer and some days less. [Participant P – interview]

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
At home in bed this morning. I woke up to the sound of birdsong and so decided to take a mindfulness of sound practice.	I had risen with the intention to take a formal practice first thing anyway and the birdsong just lent itself beautifully.	30 - 40 mins.	Calm, joyful and very present. It has lasted all day.

Table 3.1: Diary entry showing effects of sitting lasting through the day – Participant J

For others, it was seen as a state that they could return to if needed throughout the day. It was a 'springing off' point, or a reminder of how mindfulness felt, which allowed mindfulness to be incorporated into daily activity.

> I'm trying to just find a nice equilibrium, a nice default point that I can return to and trigger myself into. [Participant N – interview]

Some participants discussed their morning meditation in detail. Participant G had a very specific ten-minute morning mindfulness meditation, which ended with setting an intention for her approach to the day ahead:

> So, the first thing is to listen, taste, smell. What can I hear? What can I taste? What can I smell? And then it's where do I feel tense or do I feel tense anywhere? Then, where do I feel relaxed and then how do I feel emotionally inside and then how would I like to feel or what is my intention? [Participant G – interview]

It is important to note that setting an intention is not a standard part of mindfulness, but it was incorporated by several participants. Participant P also used formal mindfulness in the morning and evening to help maintain his mindful state, as well as to set intentions:

> So, in meditating regularly, more or less in the morning and in the evening…in order to be grounded and present, I find it useful to be grateful and to reaffirm where I stand and who I am. So, this helps me to maintain the status of presence and awareness during the day…I ground myself, being grateful to the elements of the earth and to people, those who challenge me, those who support me, and I set my intentions for the day. [Participant P – interview]

Informal mindfulness

Participants who had gained *a mindful life* also used informal mindfulness as part of regular habitual activities such as eating, walking the dog, exercising or doing housework; to maintain focus in a difficult conversation; or to gain objectivity in a stressful situation. Maintaining a mindfulness habit in daily tasks allowed participants to be more readily mindful in more stressful situations.

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
When I was brushing my teeth, just noticing the movements and feelings.	Doing it before when I was brushing my teeth.	5 mins.	Calmer and not feeling like I'm rushing.

Table 3.2: Diary entry of mindfulness whilst brushing teeth triggered by previous practice – Participant F

As an example of repeated informal mindfulness around a daily activity being useful, Participant F was the participant who struggled most to engage with mindfulness. She found that brushing her teeth mindfully one day helped her to build the habit as she attached it to the activity and remembered that it made her feel calm, and she was able to continue mindful teeth brushing for the next few days (Table 3.2).

Practice and the virtuous circle

Experienced participants emphasised that there is no shortcut to having a *mindful life*; practice is necessary and needs to be repeated often, but the rewards help to maintain and increase time spent practising. A number of participants reported that mindfulness was cumulative. The more they practised, the more mindful they became. However, this was not easy at the start of learning. As Participant K discusses below, the benefits are not obvious to begin with. In his case, attending a course to support learning mindfulness helped, as it meant he was obliged to attend classes and do 'homework' practise for eight weeks, after which the benefits became clear to him. Participant E also found a formal course useful at the start, but found the more she practised the more she was reminded to develop her practice.

> I'm sorry, there's no shortcuts, you have to practice. . . It's getting over that hurdle. I understand that you want to see some benefits relatively quickly, because otherwise you don't carry on, but you've got to persist. Otherwise you might quit too soon. . . with the eight week MBSR [course]. . . you get the familiarity, you get the persistence, you get the time to build the habit. [Participant K – interview]

> I suppose initially it was useful to have a discrete mindfulness practice, just to get me into doing it, to get regular with it and have that time to practice. But, I think the more I was doing that, it was just at the forefront of my mind more, and so I would then start to think, okay, I'm going for a walk at lunch or I'm eating this meal, how can I do it mindfully? And

> it did just become part of my way of approaching everyday things really. [Participant E – interview]

Participants saw repeated practice as important, with short regular practice more beneficial than a longer but less frequent practice. Regular practice also led participants to become more mindful of when they were not being mindful:

> The thing that helped was doing it regularly. So for me, it doesn't necessarily matter what the practice is, but it's doing it every day, or even this week with the [study] twice a day, has been really helpful. [Participant A – interview]

> Having a greater awareness and lots of practice [makes me more mindful]. So, I'm not sure there is a particular prompt…but it's practice, constant reminding, checking in with myself in my daily practice. [Participant D – interview]

> I have been mindful much of the time since yesterday. This happens when I am alone quite often, if the conditions are there. There gets to be a cumulative effect, with earlier mindfulness leading to more spontaneous and deeper mindfulness. [Participant B – diary]

Participants discussed how mindfulness had been beneficial in changing their approach to life, embedding a more mindful attitude to difficulties at work and to work-life balance. Participant N spoke of finding a mindful attitude very helpful in dealing with stress, although practising mindfulness in this way had taken time to learn:

> I find I'm less reactive and I can…just step out of it, and well nobody's gonna die, you know. You might just make a little less money this week, if things go wrong, but it's nothing that you can't handle, though as I say it's taken me quite a while to learn to do it…It provides a haven from the kind of creature that I have evolved into, [and] from my past experience and future anxieties. [Participant N – interview]

Participant D discussed mindfulness leading to an increase in happiness and pleasure in life and that the pleasure in practising mindfulness led to more mindfulness:

> I hadn't really connected mindfulness and joy in the past. I'd connected mindfulness and peace, and lower anxiety, and presence. Those sort of things, but I hadn't linked it to joy, and I found by being more mindful and focused on what I was doing, I was getting more out of it and I was being happier as a result. [Participant D – interview]

Linked to practising regularly and repeatedly, commitment to practising was also felt to be important in gaining a *mindful life* by a number of participants.

> So for me, it's being disciplined and making sure I'm doing it regularly. [Participant A – interview]

> I suppose for me it's about scheduling it in my diary. So, at lunchtime, I try to go out for a walk and try and be mindful, rather than thinking I will fit it in when I've got time…and it's likely that I work better in the

> afternoon if I've had the chance to be mindful at lunch. So, yeah making a commitment to scheduling it. [Participant E – interview]

Compassion

In gaining a *mindful life*, participants stressed the importance of the central tenets of secular mindfulness which are taught in the West (see Section 2.5 for the origins and Westernisation of mindfulness). For example, self-compassion and being non-judgemental were seen as valuable, both in dealing with the inevitable failures and difficulties in building the practice, and also in managing the reality of facing one's inner commentary, that is, the thoughts and judgements of the inner voice, which are often not noticed, and which mindfulness highlights for the first time for many people. The negativity of this voice can be a shock. Participants argued that compassion is necessary in building a *mindful life* for several reasons.

> When you're mindful you have to actually own up to your feelings and your thoughts and your behaviours... they're not all very pleasant, you know. So, if you don't develop the compassion alongside, then you can use all of your insight as just another big stick to beat yourself with... and as you practice self-compassion it extends onto compassion for others... [Participant J – interview]

> [Mindfulness] allows [thoughts] to pop up and be dropped, so I'm not carrying those, I'm not charged with those and therefore being more compassionate to others is a much easier thing to do. By practising that, it becomes a state of mind; it becomes part of a mindful life. [Participant D – interview]

Self-compassion is about treating the self with kindness and practising self-forgiveness for mistakes or not being mindful.

> You need to prompt the compassionate side of mindfulness, rather than, 'Oh, I haven't done it', which I think is sometimes what I've found with the ways that I've had of trying to prompt myself. It doesn't actually access the compassionate mind. It accesses the judgemental, 'I haven't done it' mind. [Participant C – interview]

This helps in gaining a mindful life, because guilt over not practising is dealt with using self-compassion. This lessens resentment and other negative feelings which prevent new practitioners in particular practising mindfulness.

Another aspect of developing a *mindful life* was cultivating curiosity about the familiar and having a more direct perception of things and events that the participants were accustomed to, rather than automatically assigning them into habitual categories:

> Whilst walking to work or other locations, I also deliberately cultivate mindfulness, often in response to something I see. This morning in addition to the usual flowers and trees there was also a gummy bear on the ground and two women looking at a bag. [Participant B – diary]

> I just walk the dog and when I'm there, I just look at the things I wouldn't normally notice. I try and notice things, the birds, litter in the bottom

> of the hedge, things like that... Be just more observant of the smells and sights and colours of things, the changing of the seasons... [Participant N – interview]

Participant L observed why mindful attention on the ordinary was so compelling: "By noticing stuff there's more of me or more space for me, it's just a really nice thing".

3.3.4 Theme 2 – Contexts of use

I termed the second theme that I identified through my coding of the data Contexts of use, which I split into two mutually exclusive sub-themes, which I term *relaxed* and *purposeful*. *Relaxed mindfulness* concerns bringing the quality of mindfulness to a relaxed activity such as eating, walking or doing exercise, at a time in which the participant was **not** dealing with a difficult emotion, pain or trying to use mindfulness for a specific purpose, such as *grounding* (a way of staying in the moment by focusing on physical sensations or other sensory experiences). By contrast, *purposeful mindfulness* is the deliberate use of mindfulness to help at a difficult time, for example, when under pressure or deeply focused on an external task. Importantly, purposeful here is not about trying to change thoughts, but about bringing non-judgemental awareness to the present moment. Still, *purposeful mindfulness* was used to help alleviate anxiety, stress or negative states of mind in the participant by focusing on the cognitive events, emotions or somatic sensations the negative state of mind was causing, so that the participant could become aware of them. In doing this, the participant was able to stop fighting or pushing away any negative thoughts or emotions, and rather acknowledge and be present with them. Sub-themes to this context include: ego threat situations; dealing with unhelpful thoughts and emotions by turning towards them; and, anxiety pain and illness. This section finishes with a discussion of relaxed mindfulness helping as a precursor to purposeful mindfulness.

Whilst the two *contexts of mindfulness* were acknowledged as different by a number of the participants, it might be that they are the ends of a continuum, rather than binary choices.

Relaxed mindfulness

I constructed the theme of *relaxed mindfulness* when participants were mindful in a calm or unhurried situation, when participants had the time and mental space to be mindful and were not experiencing emotional pressure or anxiety. It is exemplified by bringing awareness to a formal meditation, or using informal mindfulness in an everyday situation in daily life. The topics examined in relaxed mindfulness are everyday activities, seeing through fresh eyes, being alone, revealing distorted thinking and the upward spiral which comes from practising relaxed mindfulness.

Relaxed mindfulness happened when the participant was doing something familiar, such as waiting, travelling, doing an habitual activity or relaxing. The participants were able to use even very brief chances to practise *relaxed mindfulness*. For example, Participant M (Table 3.3) used a very short mindfulness episode in a common daily occurrence, waiting, and the extract from the diary of Participant H (Table 3.4 shows relaxed mindfulness as part of housework (in bold).

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
In the supermarket, waiting for my friend to do something.	Not having anything else to do, and being stationary, and being around people to observe.	30 seconds tops.	Difficult to say. Not any different from how I was before, I think.

Table 3.3: Diary entry showing relaxed mindfulness whilst waiting – Participant M

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
When I woke up this morning, I practised mindfulness momentarily, as I lay there. At a 45 minute yoga class and a one hour meditation class at London Buddhist Centre. I was also mindful whilst hoovering at the centre and cleaning a Buddha statue.	Quite often, I fall into mindfulness early in the mornings anyway. Attending the yoga and meditation classes were a structured prompt for mindfulness. **Post meditation feelings of relaxation whilst hoovering reminded me that I didn't want to lose my relaxation, so I decided to practise mindfully hoovering.**	In the morning, maybe 5 minutes. 45 minutes during the yoga class, and hour during meditation and probably 15 minutes whilst hoovering and cleaning.	Centred, relaxed, happy, unhurried, friendlier, more open, less judgemental, more positive....

Table 3.4: Diary entry - relaxed formal & informal mindfulness – Participant H

Participants used other daily routines, such as mealtimes, as an chance for *relaxed mindfulness* habituating practice:

> During breakfast I try to cultivate mindfulness, so this is my habit.
> [Participant B – diary]

Eating is a time when the participants did not have to concentrate on anything except food, particularly if eating alone; therefore, this was seen by some as a good time to practice relaxed mindfulness. Other activities carried out when alone and not under pressure were also conducive to relaxed mindfulness, such as walking (Table 3.5).

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
Walking along the river with the baby in a sling - felt able to take in everything around me and share it with her.	The river is always a good place for me, the smell of lime trees, walking.	Maybe the ten minutes of the journey on foot.	Calm, open, ready to be in the next situation.

Table 3.5: Diary entry - relaxed mindfulness whilst walking – Participant L

Participants described being alone as conducive to *relaxed mindfulness*, as did conditions without conflicting activities vying for attention, which gave participants the mental and physical space to practice mindfulness in a situation where they were not anxious, under pressure or deeply focused on an external task. To return to eating as a mindful activity, Participant B remarked on her intentions for mindfulness (reflecting Theme 1) and how being alone helped, whilst eating lunch alone gave Participant I the chance to mindfully focus on the food and the environment.

> It is my habit to try to eat mindfully, and I mostly do pretty well with that when I am eating on my own. [Participant B – diary]
>
> Ate lunch mindfully whilst sitting on a bench in the sunshine on the University campus. Getting away from my desk into open space, peaceful environment, tasty lunch to focus on. [Participant I – diary]

Purposeful mindfulness

In contrast to *relaxed mindfulness*, *purposeful mindfulness* describes mindfully processing *internal* and *external* events when participants felt under pressure, anxious or tense. Participants discussed how using mindfulness in this way moderated them acting impulsively, without thinking, or out of habit. This allowed them to react to a difficult situation more flexibly, with considered choice in their response.

Purposeful mindfulness involved using mindfulness for a specific purpose, for example, to become fully aware of a negative mental state, or uncomfortable thoughts, strong emotions or physical sensations. Purposeful mindfulness is practised in a number of different ways. Through the analysis, two practices that participants mentioned were *checking in* and *grounding*.

Checking in involves briefly taking a short break to focus on thoughts, emotions and somatic feelings to raise awareness of them. It was presented as something most participants did habitually throughout the day, as mindfulness training using relaxed mindfulness had made them very aware of their somatic and affective feelings. Checking in sometimes revealed somatic or affective discomfort or unconstructive ways of thinking. Participants could then decide about accepting the discomfort, using further purposeful mindfulness, or bringing in other techniques like relaxation or challenging negative thoughts. The excerpts show both physical and cognitive examples.

Where were you mindful?	What prompted you?
Throughout a training course today[. . .] we had to do a brief presentation and in the lead up I checked in with myself about how I was feeling vis-à-vis volunteering to be the spokesperson and when carrying out the actual presentation.	The nature of the course to some extent and it is often my habit to “check-in” with myself at random times during the day anyway.

Table 3.6: Diary entry - purposeful mindfulness at work – Participant J

> At home while working on my computer, I suddenly realised that I was very tense and so I did a short breathing space. [Participant C – diary]

> [I]f I’m going to do a presentation, I mindfully become aware of the tension building and the adrenaline that builds, and then I’m five minutes away, I’m a minute away, okay it’s my turn. Breathe in, breathe out, go. [Participant K – interview]

The extracts show *checking in* in mildly uncomfortable situations at work, such as giving a presentation (Table 3.6). *Checking in* helped the participants to understand their cognitive processes and somatic anxiety due to the situation. Through an awareness of the body and the cognitive processes the situation is seen as less stressful, as the affect is lessened. For Participant C, checking in helped with somatic discomfort and pain management. Using purposeful mindfulness in conjunction with a relaxation exercise.

Another form of purposeful mindfulness involves the mindfulness practice of *grounding*. It involves turning the attention to physical sensations of connecting, for example the body contacting with a chair or the way the foot connects with the floor where the practitioner is standing. Participant N noted the importance of grounding in helping him to be mindful whilst at work.

> I use little devices like touching something solid and try. . . to breathe and look at the colours and listen to music and just separate that from the me, that is, from memories and things that I have to do and things that I should be doing. . . as opposed to this rota of duties and responsibilities.
> [Participant N – Interview]

Refocusing and re-centring Participant P’s thoughts through a physical awareness of the surroundings helped to stop him from operating without conscious awareness, which can often happen when deeply focused on a task, for example at work. Grounding involves a change of mental state, especially coming out of a period of intense non-mindful concentration into mindful awareness or focusing of the attention, and a re-centring of the thoughts and physical situation. Grounding allows moments of mindfulness between times when deep concentration is needed.

Participants said that they used grounding to feel more currently present, more aware of somatic states and more connected to their cognitive processes and affective reactions, which they asserted allowed them to be more productive and self-possessed, regardless of external pressures (Tables 3.7 and 3.8).

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
During a pause at work, at my desk.	During a pause at work I thought it would be a good idea to be mindful because I had been intensely focused on work–it is bad for me in a few different ways if I don't take a break and reconnect with self/world/perspective.	Just a few seconds.	More connected and grounded

Table 3.7: Diary entry - use of *grounding* after concentration – Participant B

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
Did a breathing space mindfulness meditation when I got home from work.	I had planned to spend 5 minutes sitting and focusing on my breathing when I got home before going out again[...]it felt like a good end to the working day and start of the evening.	5 minutes.	Calmer, more grounded.

Table 3.8: Diary entry - use of *grounding* after a difficult day at work – Participant E

Ego threat situations

One trigger for purposeful mindfulness was a situation that was potentially ego-threatening, such as the aggressive or angry attitude of another person.

> In a situation like walking down the street and some lad wants to face off with you, you have the option to be slow; you don't have to rush anything[...]those are particularly times when I don't want to react, and I don't want to get drawn into negativity. So, I try and use situations as a trigger, as an opposite trigger, you know. Instead of getting absorbed into somebody's negative vibe, I'll try and use it as a trigger to be mindful. [Participant H – interview]

> You don't jump into writing those ego-driven emails, because it gets nowhere. I assess the situation for what it is, without expressing a judgement on people[...] There are better ways of doing this. So I translate it into a better way of reacting to and writing an email mindfully, for example. [Participant P – interview]

Participant H used purposeful mindfulness to avoid being brought into a confrontation, by becoming aware of the external situation, but also how he was feeling and reacting in the face of aggression, which prevented an ego-driven response. This could also be seen in Participants P's attitude to not sending an email in anger. Mindfulness helped him to take a step back and react more objectively, acknowledging the anger, but not engaging with the thoughts that it generated.

Acceptance and turning towards thoughts

One component of mindfulness is an acceptance of the thing which is under focus, whether it is pleasant or unpleasant. Mindfulness is not about changing the thoughts, but acknowledging them (known as *turning towards*). This does not mean accepting situations that are unpleasant, but that can be changed. However, for unpleasant things that cannot be changed, such as an unpleasant job, which nevertheless has to be done or mildly unpleasant feelings, participants found a mindful approach helpful. Participant G used purposeful mindfulness to help with a minor vexation, to accept doing housework, including her son's washing, which she had previously resented. Using purposeful mindfulness, she described finding she enjoyed the work:

Where were you mindful? / What prompted you?	Time spent mindful?	Other comments	Feeling afterwards?
Mindful housework!! cleaning bath, (son's) washing in, changing (son's) bed, mopping b/room floor husband forgot yesterday / Curiosity to see if I could stay mindful doing chores	in and out of mindfulness for 2 hours while doing jobs.	Set intention in meditation to be less heavy with everything. Gave myself permission to take it gently and create space around the 'have to' tasks (eg to notice flowers, bees,..) and not think I have to get everything done (it won't happen anyway so might as well accept it)	Much less resentful of doing son's washing than usually am. Did it without frenzy and cross tightness. Actually enjoyed the cleaning (and results)

Table 3.9: Diary - purposeful mindfulness during household chores – Participant G

Maintaining awareness of his emotional state with regular check-ins helped Participant A and gave him more physical and mental resources by allowing him to sit with his emotions instead of trying to change them or struggle with them. Participant B used mindfulness to eat an unappetising meal, reminding herself that mindfulness of unpleasant things is important.

> Well, it's as I referred to earlier, where I'm not triggered and angered by things which might have triggered or angered me. It might be that I recognize more and can respond more capably. [Mindfulness] allows me to be aware of myself, and I end up being less tired because I'm not fighting anything. I've therefore got more energy to do more with. I'm just more resourceful. [Participant A – Interview]

> Initially I was not mindful eating my dinner however because I was not enjoying it so much, so I was less inclined to be present. . . Once I became mindful I did find I was full and not enjoying it so much. However, it seems a waste of food to eat without being mindful of it even if it wasn't such a good dinner. [Participant B – diary]

Sometimes thoughts and emotions became ‘stuck’, leading to recurring thoughts about distressing past events, known as *ruminating*. Ruminating can cause feelings of depression or anger. Therefore, some participants used purposeful mindfulness when they recognised such unhelpful patterns of thought to turn towards the thoughts rather than ignoring them or pushing them away. Participant J appreciated that fully experiencing worrying thoughts helped to stop them having power:

> I was having a recurring negative thought that was pulling my mood down and beginning to take hold. I decided to just pay attention to the thought and recognise how my mind persisted in returning to the thought over and over and giving ‘life’ to it. I tuned in to how it was making me feel in the body. I labelled the thought as ‘worry’ and recognised it wasn’t based on any fact other than my own imaginings. [Participant J – diary]

> So, if somebody says something to me in a meeting... my old story would be subconsciously anger, because he reminded me of my father. Whereas now, being in presence, I can hold that. I can think, no, he’s just being him. He’s just saying that because he’s saying that. It’s not about me, and I can respond in a far better state and have a far deeper more engaged, meaningful conversation, through focus and not letting my thoughts interfere. [Participant D – interview]

Purposeful mindfulness can be helpful in response to rumination about past events or unwelcome thoughts. It helps the practitioner to become aware of thoughts as mental events, which can be checked for accuracy and having only the value they are given by the practitioner, rather than immutable facts. Participants discussed how their wellbeing was better for being able to manage unconstructive thoughts by acknowledging them, rather than ignoring them or ruminating. Participant P was able to use mindfulness to help recurrent thoughts and cravings for alcohol and nicotine, and Participant D to overcome illness due to alternating between suppressing thoughts and ruminating.

> When [negative] thoughts pop-up and I can see them, I can make a choice. So, I believe that mindfulness has given me, the awareness of seeing emotions when they come and the option of deciding what to do with them... Before, I wasn’t aware of that; I was simply overwhelmed by those thoughts I was full of addiction, so for me being mindful is one of the elements of the coaching and transformation[...] to get out of those addictions, because it’s broken some patterns that I have in my head. [Participant P – interview]

> I used to suppress stuff and it used to make me ill; so that’s not the way. [Mindfulness] allows [thoughts] to pop up and be dropped, so I’m not carrying those. I’m not charged with those. [Participant D – interview]

Anxiety, pain and illness

Purposeful mindfulness was also used in cases when a participant needed to deal with external or internal stressors, or with anxiety or pain. Participant G remarked that being prompted to be aware and mindful helped reduce feelings of anxiety and made experiences better.

> [Keeping the diary] has been a really good prompt to keep aware, and keep having the intention to be and stay mindful as much as possible through the days. It really helps with feeling anxious and overwhelmed. It deepens the experiences I am having and enriches everything. [Participant G – diary]

Participant I had a mantra (a phrase that she regularly used to prompt purposeful mindfulness), which was triggered when she felt anxiety rising:

> Fairly often now I will stop and think 'what does this moment require?'... if I feel myself starting to feel a bit out of kilter or feeling the situation is getting a bit out of hand. [Participant I – interview]

This allowed a mindful pause to consider her feelings and the situation. She continued honestly:

> Even after I've paused, I might think, 'You know what... I'm still going to shout.' I've paused and I've realised that's perhaps not the best way to go, but it's going to happen anyway.

Thus, even though mindfulness does not always prevent Participant I getting annoyed, her actions and the experience during the annoyance are mindful. There is an awareness and an acknowledgement of her feelings and actions, showing it is possible to be mindfully angry.

Some participants faced issues with serious illness that had forced them to change their lives. Purposeful mindfulness was used to manage chronic pain and other disorders; for example, Participant B, who often felt unwell from chronic fatigue syndrome, managed the feelings using purposeful mindfulness:

> AM: I was feeling quite ill, so I usually try to be mindful for a bit when I don't feel good because it helps.
>
> PM: After lunch I was feeling unwell, so I lay down on a camping mat I have under my desk for such emergencies and was mindful. Later in the afternoon, I was feeling unwell once more, so lay down on the camping mat and was mindful. [Participant B – diary]

Participant C found mindfulness was helpful to manage a chronic pain condition, after completing a Breathworks Mindfulness-based Pain Management course:

> [Mindfulness] is an incredibly powerful tool. It's completely transformed my life. It's changed the way that I experience and relate to my pain condition first of all. [Participant C – interview]

Participant A came to mindfulness following a diagnosis of full-body paraesthesia, a feeling of numbness in the skin, due to an anxiety disorder. Participant A found maintaining mindfulness practice kept the symptoms manageable:

> [Paraesthesia is] a psychological condition that manifests in physical numbness. The diagnosis was due to myself numbing out all the pressures and pushing and pushing and pushing. There was nothing physically wrong with me, and the numbness and the paraesthesia goes up and increases when I'm not mindful... and it recedes and recedes the more at home I am

> with...confronting what challenges me, rather than avoiding and working around things. [Participant A – interview]

Relaxed mindfulness as a precursor to purposeful mindfulness

As shown above, purposeful mindfulness is used in a number of different situations. Participants used it to recognise and acknowledge negative mental states and to help with painful thoughts, emotions and physical sensations. It was used to check in, especially when they were in a situation that was stressful, and for grounding after a period of intense non-mindful concentration. It was also used by a number of participants who were trying to live with pain or emotional distress and threats to their physical and mental well-being from their thought processing. However, a number of participants asserted that practising relaxed mindfulness was necessary for them to develop the skills necessary to use purposeful mindfulness.

> I think it's probably much easier to bring mindfulness to stressful situations when you practice it as an activity, it would be hard just to call on those skills when you're in emotion mind if you're not practising it regularly. [Participant E – Interview]

3.3.5 Theme 3 – Time and cognitive demands

In the first two themes, I looked at the forms, practices, and contexts of a long-term mindfulness practice. In developing this theme I discuss constraints on being mindful, where lack of time and lack of cognitive capacity emerged as the main issues, which feed into one another and are closely linked. *Time constraints* captures moments of being too busy for mindfulness. *Cognitive constraints* cover how participants talked about the states of mind that constrained them from mindfulness, such as feeling rushed, needing to use other modes of consciousness, tiredness and in particular, lack of willingness.

Time constraints

When completing the "not mindful" section of the diary, almost all participants talked about lack of mindfulness in the context of being busy. Frequently, this was due to pressure at work, although for some participants it was in the context of rushing to get a large amount of things done in other areas, as busyness seems to pervade all parts of life. As Participant I said in the interview:

> Busy is the new fine. When someone asks you how you are, it's the new acceptable state. Busy is good and busy is what everyone is up to, and so busy is the new fine. [Participant I – interview]

As was seen in the section on relaxed mindfulness, participants found it much easier to be mindful when they had the time and mental space; therefore, relaxed mindfulness was unlikely to occur when the participants were busy, as there was no time or mental space for it. Mindfulness in a busy situation is almost always purposeful. Several participants pointed out that this was when mindfulness was most helpful, even if they were not able to practise it.

> When I get into a state of mind where I'm being under too much pressure and too rushed. It's almost like then I am too rushed to be mindful. And it's kind of interesting, because that's when you need to use mindfulness most, and yet, that's when it happens. [Participant C – interview]

> Q: I noticed when you said you weren't being mindful, you quite often said that you were too busy or had too many things going on.
> A: Yeah, probably those were the times when it was needed the most, because I was busy and I was doing lots of different things. [Participant F – interview]

> I found [mindfulness] harder to do on days that were very busy. . . During my last bit of time off with the baby, I have been trying to slow down and actually the days when I didn't feel like I had time to be mindful were the days when it would've been most useful. [Participant L – interview]

Busy can mean different things, for example, having a long list of things to do, not having enough time for a number of tasks, having to work at a fast pace or having to do one difficult job in a short time. Within the context of busyness, several participants talked about the *pace* of mindfulness and the pace of a busy life being different, with some considering that the pace of mindfulness was not compatible with being busy. Often busy is about both time pressure and cognitive pressure.

> In work, it's like you're going from meeting to meeting, to this, to that, to that, and you're rushed, you're being rushed. So, how can you be mindful? The thing with mindfulness, I think there's a pace to it. There's something about speed. So, if you're rushing through work it's hard to slow down, because you're rushing, because you have to rush, you have to do it quickly. [Participant H – interview]

For Participant H relaxed mindfulness is not possible, because the pace needs to be slower and for that to happen. That is, relaxed mindfulness can only happens when the conflicting demands on his time or cognitive abilities is less. Participant L, a parent on maternity leave, also saw mindfulness as about slowing down, especially after rushing around or being busy (Table 3.10):

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
Watching my daughter play in the bath. A busy day for both of us but really tried to slow down and focus on watching her this evening.	Conscious that I wasn't giving her my full attention and that we'd been out and about all day.	Fifteen minutes	Closer to her, better able to meet her needs.

Table 3.10: Diary - slowing down after a busy day using purposeful mindfulness – Participant L

Participant I felt that leaving work to become a stay at home parent had allowed her to slow down to the children's pace, in a way that she would not have done previously, which was more conducive to the pace of mindfulness:

> I wonder if I was still in that situation, working four or five days a week, whether I wouldn't have found it so easy to be slower in how I approach life. I think perhaps the practical ways in which I spend my time encourage a slowing down and an appreciation, because you don't want to miss things with the children. [Participant I – interview]

Some participants reported working in corporate cultures where they found it very hard to slow down, because breaks were not taken, or taking lunch away from the desk was frowned upon, making mindfulness difficult:

> Well, you almost don't have the option to slow down, because there's 20 emails to respond to by 12 o'clock, and there's another phone call. So, you can't say, 'Oh I'll slow down', because the work has to be done. And I'd even work through lunchtime, then straight after lunch go to a meeting [Participant P – interview]

> I think [pace not being conducive to mindfulness] is completely true. It's almost designed in. I always tried to take a walk out of the office at lunchtime, to go and get coffee or a sandwich, and it's really frowned upon, you know?...I can't work in the afternoon if I haven't put my head out the door at some point. [Participant L – interview]

Mindfulness helps to make participants very aware of their physical and mental needs and how to meet them. They recognised that the 'no break' work culture is damaging to them. Participants N and M realised the value of slowing down and having a break when they became aware that work was becoming stressful or causing them anxiety:

> If there's a time at work where it's not going too well, just step out of it, and well nobody's gonna die, you know. You might just make a little less money this week. If things go wrong, it's nothing that you can't handle, but it's taken me quite a while to learn to do it. [Participant N – interview]

> There are components of mindfulness that are useful, like if I get too tense or over-excited, my work deteriorates. So, it's good if that sense of awareness...becoming aware that I am tensing up or I am just flapping all over the place. So, that's useful. [Participant M – interview]

However, both Participants N and M had jobs which allowed a large amount of personal autonomy, therefore they could take time out when it was needed.

Some participants thought busyness and mindfulness could be compatible, but only when multi-tasking was not being attempted. Participant E saw mindfulness and pace as possible if it was about mindfully doing one task, rather than attempting to mindfully multi-task, which she saw as almost impossible:

> I do think that concept of one thing in the moment is really useful when you're busy...So, it might be that if I'm working on something on the computer, I'm saying to myself, actually I'm not going to check emails; I'm going to divert the phone and just have all my attention on what I'm doing. So, I think [being mindfully busy] is possible but...[the] mind-set that mindfulness has to be about slowing down, it doesn't. It's about that one thing in the moment. [Participant E – interview]

Participant H later in the interview talked about finding a way around pace not being conducive to mindfulness. He focused on having a short mindful break, rather than trying to be continually mindful throughout the day, like those participants who had more time or less pressured work environments. Thus, he was able to both practice mindfulness and work more effectively:

> I'd come straight back to work from a few days in London and I had quite a few things to do, quite a few tasks. Then the tasks started to overlap. So I thought, 'Hold on. Stop', and I took three minutes to relax and I was able to do it one task after another... So, just those three minutes helped me to basically think calmly and to structure my time and tasks. [Participant H – interview]

For Participant E, doing one task at a time was one way to be mindfully busy, for Participant H, the way was to take very short purposeful mindfulness breaks in between tasks, briefly coming out of a 'busy mode of consciousness' into mindfulness and then back to busy. In doing this, some participants experienced busyness as needing one quality of consciousness, for example, concentration, which was seen as incompatible with mindfulness. However, once this was recognised, the two states could be interwoven by taking a mindful break when time allowed. This enabled them to feel refocused. These participants often used *grounding* or *checking in* as a way to orient themselves between the two states of consciousness. A few participants were therefore able to use busyness and mindfulness, even when multi-tasking. Mindfulness does not have to last for a long time. It can be a checking in or grounding between tasks lasting 30 seconds.

> During a pause at work I thought it would be a good idea to be mindful because I had been intensely focused on work–it is bad for me in a few different ways if I don't take a break and reconnect with self/world/perspective. [Participant B – diary]

> [Mindfulness happens] when there is a switch between what you're doing, so you might be focused on something for a period of time and then an email comes in or the phone rings, and that transition or post that transition, it gives you an opportunity to slip a little bit of mindfulness in, before dropping back into whatever the activity was. [Participant K – interview]

Whilst a number of participants found even very short bursts of mindfulness to be useful, others needed to take slightly longer breaks when they were very busy and getting stressed or anxious. They used this as a trigger to take a break to practise purposeful mindfulness.

> A couple of weeks ago I was in a very stressful situation at work. I said I'll go out for five minutes and I meditated for 3 minutes. It was a very stressful situation, that was leading me to shout, be angry and I thought: No, I don't want to be there. I go out and meditate; I calm down and go back. [Participant P – interview]

> I found when I'm really busy with the business, I go back to my old default settings and forget to just take a step out of it and have a little meditate or just a relaxing session... If I feel myself going down the old road, then I

> deliberately take a step out of the situation. . . and just separate that from the things that I have to do and things that I should be doing. [Participant N – interview]
>
> At work I was getting to the point where I was getting really cross about manipulating a Word document. I could feel myself getting really het up and tense. . . I thought: 'What does this moment require?' and this moment requires me to go outside and have a quick walk. [Participant I – interview]

Whatever the work environment they were in, whether stay at home parents, looking after a house, having a job with a lot of autonomy or being in a more regulated office environment, all participants saw mindfulness as a necessary part of the day, even for short burst or during breaks. For them, it was not an extra thing they did in the evening, but was integral to their approach to life. Therefore, forming a mindfulness habit, had been built around the work tasks in whatever way could be managed.

Cognitive constraints

Cognitive constraints also prevented mindfulness, with the most prominent being a lack of willingness to engage with the practice. Participants reported that they had remembered to be mindful, but chose not to be. Participants were able to recognise when they were being wilful in not using mindfulness. For example, Participant F sometimes struggled to be mindful when she was busy and tired:

> Yeah, sometimes I feel like I come straight from work to something else, then straight from there back home, and by the time I get home I think: 'Oh, I'm really tired I'll go straight to bed.' So, it's just, I should really sit and think, I've only got to do two minutes, I could just do two minutes' mindfulness, but I think sometimes, I will do it tomorrow.
>
> Q: What, if anything, would help you to be more mindful?
>
> A: I think just having a word with myself that I can do it and be a bit more, have a bit more willpower, a bit more willingness. I should really sit down and actually it would probably help to think about it in that sense.
> [Participant F – interview]

Some participants realised that they had thought about mindfulness when they were busy, but had made a choice not to be mindful:

> [T]here is a quality of speedy blocking [mindfulness] out. . . It's easy to fall into that state, i.e. choosing to block stuff out. Very short mindfulness, but choosing not to continue. I think it happens when I get, well it's about state of mind isn't it? When I get into a state of mind where I'm being under too much pressure and too rushed. [Participant C – interview]

Another reason for choosing not to practice mindfulness was that the participant did not need purposeful mindfulness, as they were relaxed. This meant they could be mindful about chosing not being mindful, as shown in the extracts from the diaries of Participants E (Table 3.11) and J (Table 3.12).

However, there are times when mindfulness is not easy and being willing to be mind-

Was there a situation where you could have been mindful?	Did you feel like there was a reason that you could not be mindful?	Would anything have helped you to be mindful?
Could have been more mindful during my tea.	Had tea whilst watching TV - doing two things at one and also chatting with my partner - not very mindful!	Seems harder at the weekend to be mindful when there is more stimulation and maybe feeling more relaxed anyway.

Table 3.11: Diary-choosing not to be mindful because of other activities – Partic. E

Was there a situation where you could have been mindful?	Did you feel like there was a reason that you could not be mindful?	Would anything have helped you to be mindful?
Not especially, although could always take mini informal practices in any situation.	No, didn't really choose to as I was immersed in office work and family visits.	Remembering to take five minutes break!

Table 3.12: Diary-choosing not to be mindful because of other activities - Partic. J

ful, especially when the mindfulness felt boring or unpleasant, was a mark of those participants who had attained a life with mindfulness deeply integrated.

> I tried to be mindful on the way home because that is my habit. It did not go so well because it was rainy and windy and that makes me less interested in being present. However I think it's important to try. [Participant B – diary]

One constraint on mindfulness was that many participants did not want to be mindful all the time, because they wanted to be in other modes of consciousness or claimed that mental states such as focusing on a creative or academic idea, deep concentration on work, or immersion in a video game, book, or TV precluded mindfulness. Similar to the discussion around the pace of mindfulness being too slow for the pace of work in the previous section, Participant M introduced the idea of the pace of mindfulness being too slow for creative thinking and constraining his thought processes. For Participant M, mindfulness was not desirable at times when he needed to use a different mode of consciousness, in which he was not constrained from freely following trains of thought without full awareness. Participant E also found modes of consciousness without mindfulness to be desirable and useful.

> I feel there is a conflict between the type of thinking work and creative thinking I like to do and mindfulness... Basically my work and my creative pursuits, which are very meaningful to me, largely involve thinking. Thinking cannot be truly mindful, as far as I can tell, because it involves getting caught up in the thinking and moving from train to train... Being mindful just slows me down. That's often part of the practice and it's a distraction... but most of my creative work does seem to happen when I'm just going with the thoughts. [Participant M – interview]

> I'm not sure that it's possible to be mindful all the time...I think if I had an expectation that I could be mindful all the time, I'd just be setting myself up for failure really and actually I think you'd then lose something about the experience of being mindful, if you try to do it all the time...Sometimes it's nice just to daydream and not be aware. So, I'm not sure that I do want to live completely with awareness. [Participant E – interview]

> I guess mindfulness involves a bit of space perhaps between you and what you're doing and maybe other sorts of immersive experiences require you to lose that for periods of time. So, maybe you can't be mindful for every second of your conscious life, but I think it's still possible to be mindful at points in all of those things, and I think you possibly need to for air...But, when you're working at it's best, you just lose track of time and you're not being mindful about it, because you're not that conscious and present about it, in fact quite the opposite. [Participant I — interview]

3.3.6 Theme 4 – Mindful social interaction

Having looked at some of the factors that facilitate and constrain building a long-term mindfulness practice as such, this theme covers situations in which mindful social interaction took place, how mindfulness affected the interaction and how participants used mindfulness in social situations. Participants talked about mindfulness in a number of settings involving social interaction. Situations included conversations with friends, supervising a student, dealing with colleagues and looking after young children. Therefore, this theme covers three sub-themes: Teaching and training, Mindful work interactions and Group/social mindfulness. Participants reported that being mindful in these interactions brought overwhelmingly positive results, but it was not always easy.

Mindful social interaction used both external and internal focus. Mindful listening requires concentration on what the other person is saying. In doing so, it helps to bring in skills of compassion and being non-judgemental, which are emphasised in Western, secular mindfulness teaching. However, the words of the other participant in the conversation may also give rise to thoughts, feelings and judgements that are not pleasant or distract the listener into irrelevant trains of thought. In addition, staying grounded in the present moment and not being pulled astray by affective or cognitive processes also requires self-compassion and not being self-judgemental. This helps the listener to acknowledge any uncomfortable thoughts or self-judgements, without trying to remove them, leading to better focus on what is being said.

Figure 3.13 gives an example of Participant C using mindful listening to stay focused and aware, even though the subject being spoken about was difficult for the speaker and for Participant C to listen to, bringing up her own difficult thoughts. Participant P also found listening led to great compassion for others.

> I realised that I was not listening to myself, so it was quite natural not to listen to others and have compassion for others. Mindfulness has made me first, be aware about myself and listen to myself, and then there is like a

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
On a retreat at the Leeds Buddhist centre.	listening to someone talk about a difficult experience and trying to stay grounded in my experience while attending to them.	5 minutes	connected with others and with my own feelings about a shared experience.

Table 3.13: Diary - mindfulness in listening to difficult words – Participant C

> progress of being more able to listen to others and be more compassionate to others. [Participant P – interview]

Teaching and training

Participants who were teachers, trainers and lecturers reported using mindfulness in a professional setting to improve interactions with students, as can be seen in Participant J using mindfulness to help her relate to and understand her students (Table 3.14). A short mindfulness episode when dealing with a student was also beneficial for Participant M (Table 3.15).

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
I was teaching a mindfulness class and was using mindfulness to be present with my students and aware of how I was relating to and responding to the delicate and tender issues that they were raising with their own practice and experiences.	The nature of my work - i.e. teaching mindfulness to others.	Two hours during teaching the class.	Grounded, calm and now tired.

Table 3.14: Diary - mindful yoga class teaching – Participant J

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
In my office, during a supervision with a PhD student.	The presence of the student was a factor. The exact trigger, not so sure. I quite often stop and become deliberately mindful of my PhD students.	10-15 seconds - it was the middle of a conversation.	Not sure. Slower, possibly, like I had stepped down to a lower pace.

Table 3.15: Diary - mindfulness facilitating PhD student supervision – Participant M

Mindful work interactions

Participants reported that mindful social interactions at work made the work environment better for them and for those they worked with.

> When I'm not present and I'm not aware, I don't team up with other people. I refuse cooperation. I refuse positive feedback, because I'm in an ego state where I'm right and they are wrong...and if I'm not clear I set the wrong expectation, with clients, with teams. I don't give the right instructions to the team. So, mindfulness at work means also being more profitable and creating a better environment with colleagues, with teams and clients. [Participant P]

This extract also shows other themes, such as using purposeful mindfulness to stop ego-driven interactions and give objectivity to reactions. Participant B does voluntary work visiting housebound people for a local charity. She found a mindful interaction with one of the clients she was visiting made the experience more enjoyable (Table 3.16):

Where were you mindful?	What prompted you?	Time spent mindful?	Feeling afterwards?
Whilst doing my voluntary work in the morning.	When I was doing my voluntary work I found I was taking it a bit too seriously and not enjoying myself, so I became a bit more mindful in response to that.	Remained more mindful for the next hour or so	Calmer and a more enjoyable experience for me and [person visited]

Table 3.16: Diary - mindfulness whilst doing voluntary work – Participant B

Group/social mindfulness

In both formal and informal settings, practising social mindfulness, in groups or with other people who practice mindfulness, was seen as helpful and important. Most participants had learnt mindfulness in a group setting and some participants found the continuing support of a meditation group, a religious group or a yoga group to be helpful. This gave them the chance to practice formal meditation and also a chance to talk about experiences of mindfulness with like-minded people. Participant D mentioned that he enjoyed team sports and found Buddhist group meditation meetings very helpful. Participants A and D sometimes worked together, they both reported that using mindfulness in meetings made them more productive and focused.

> Going to [Buddhist Centre] and Tuesday night classes and meditation classes and getting into a routine of doing that, made doing it at home, in work, on the train, in the car, easier as well, by having somewhere to go or a group to join. For me it's about being in a group, and learning in a group, and then practising on my own. It was the group and the energy of the group. I'm a team sports kind of guy and it's always been like that, so learning in the group gave me more confidence, more opportunity to practice alone. [Participant D – Interview]

> In meetings [mindfulness is triggered by] grounding before we start our business. I say let's just ground ourselves, bring ourselves present, bring ourselves into focus. In some of the business meetings I've done this week, I've set an intention for the meeting at the start of the meeting and just kept that focus, kept that presence, that mindfulness. [Participant A – interview]

Having detailed the themes, I now discuss them, the wider implications for the research questions, and the confounds and limitations of the study.

3.4 Discussion

This study examined the factors that facilitated and constrained experienced, non-clinical long-term mindfulness practitioners in integrating mindfulness into their lives using a week-long diary study and follow-up interviews.

In this section I first look at the factors aiding and constraining mindfulness as a life-ingrained practice, before turning to the design implications for the findings. This is followed by a discussion of the implications of the study in terms of end-users, a reflexivity section, and I conclude with a discussion of the study's limitations.

3.4.1 Contexts of mindfulness

From the data, I developed different contexts for mindfulness.

Formal relaxed mindfulness

Formal relaxed mindfulness was seen as an important practice for embedding mindfulness and giving participants a reference for a mindful state, Amaro (2010, p.268) suggests why this might be:

> Retreat is like five-finger exercises. You run the scales over and over again so that when the time comes to improvise, to get out there and play, your fingers know where to go. You don't have to think about it. The point of the exercises is not to perfect the running of scales. You may become very good at scales, but the point of the scales is to be able to produce music.

I propose that formal sitting mindfulness has the same purpose as practising scales, to allow practitioners to be able to bring mindfulness to a situation when needed. Like practising scales leads to being able to improvise music, the mind is so used to being in a mindful state that it does it without too much effort, during times of busyness or conflicting cognitive constraints, such as difficult thoughts. Practising *sitting* at the start of the day to build mindfulness, implies that even for experienced mindfulness practitioners, mindfulness is something that must be done every day to maintain a *mindful life*, with mindfulness being deeply embedded.

An unexpected finding was the use of a formal morning practice, as well the feelings experienced post-sitting, as a reference point to a mindful state which could be accessed later. This suggests that informal mindfulness is easier with a deeper mindful state as a reference point to help access mindfulness at any time. Humans reference a state of being (or an emotion) more easily by referring to an associated memory – for example telling a person to feel happy is much harder than eliciting a happy memory and asking them to remember how they felt at the time. This is reflected in the literature, which found formal mindfulness helpful for calm, relaxed feelings post-formal meditation (Mason & Hargreaves, 2001) and improving mindfulness skills in everyday life, leading to reduced stress and enhanced well-being (Carmody and Baer, 2007).

Informal relaxed mindfulness

The use of frequent informal relaxed mindfulness was seen in all participants, which suggests they often took the opportunity to practise when it was easier to do so. It was frequently cultivated during daily activities such as eating, waiting, walking, etc., which was also seen in Mason & Hargreaves (2001). Using relaxed mindfulness in non-stressful situations, suggests it helps to embed mindfulness for use in more stressful situations when purposeful mindfulness is called for, as mindfulness is easier when the cognitive system is not under conflicting demands. However, the participants often found ways to incorporate mindfulness in such situations, which suggests that both formal mindfulness and relaxed informal mindfulness can both be seen as a kind of ‘scale practising’.

3.4.2 Purposeful mindfulness

Purposeful mindfulness allowed more objectivity and awareness about a difficult internal or external situation, which suggests one reason why state mindfulness is effective at helping to deal with unwelcome or difficult thoughts. Participants were able to process the thoughts and the emotions as temporary states, allowing distance from immediate reactions to bring a more objective outlook, as the emotions are not tightly tied in with the thoughts. Not fighting negative thoughts or trying to find solutions to problems and worries is seen as employing the *being* mode of mind instead of the *doing* mode of mind (Teasdale & Segal, 2007). This suggests that practitioners had the mental space to choose how to proceed and what actions to take, if any, in a challenging situation. A mindful approach to negative thoughts and feelings allowed them to become a thing to be noticed, rather than an absolute fact. The more aware stance gave participants more clarity in recognising when their thoughts were based on a false premise, such as worries or fears without a basis in reality. Mason & Hargreaves (2001) found a similar category in MBSR participants called *warning bells*, in which mindfulness helped participants to become aware of worsening mental states, like depression, before they had taken hold and this was also seen elsewhere (Finucane & Mercer, 2006; Ma, 2002). This suggests that awareness of emotional and cognitive states can help to address them before they become entrenched, leading to calmer affect. Mindfulness leads to participants becoming more aware of their reactions and having a more objective stance on negative thoughts and emotions. Brown et al. (2007, p.212) asserts that mindfulness gives “an immediacy of direct contact with events as they occur”, which allows cognitive and behavioural reactions to have more flexibility and objectivity. In addition, the results suggest purposeful mindfulness helped in both managing painful physical conditions and destructive distorted thinking. This suggests that as well as mindfulness allowing practitioners to deal with difficult life situations more objectively, it also helps in changing the attitude towards these things. This was also seen in the mindfulness helping participants to notice their bodily reactions to back pain, changing their relationship with the pain, resulting in better mental health (Morone et al., 2008). Mindfulness in MBSR (Kabat-Zinn, 1993) and MBCT (Segal et al., 2002) is used to promote an accepting attitude to physical and emotional pain: by changing how it is seen, the relationship with the thing causing pain is changed. Mindful acceptance, in turn, promotes a non-judgemental attitude toward these sensations, counteracting rumination, a clinical term for the thoughts becoming stuck in an unhelpful pattern about a distressing situation without resolving the problem (Lyubomirsky & Nolen-Hoeksema, 1993), as well as fantasy and suppression. Another common use for purposeful mindfulness in the participants was *checking in*. This helped them to detect early warning signs of problems by regularly examining thoughts, emotions and bodily sensations, so they could make a reflective decision on what to do next, without reacting in the moment.

Affective dysregulation may mean that participants experience heightened emotions when the ego is being threatened. As seen in the participants' responses, mindfulness can prevent an ego-driven response, whether physical or verbal. Brown et al. (2007, p.281) suggest that mindfulness quietens the ego, which lessens automatic, self-centred actions. Instead of focusing on the reasons why a person is angry, mindfulness encourages an awareness and openness to the main physical sensations of anger.

3.4.3 Constraints and overcoming them - practice, commitment, willingness, compassion

Commitment and willingness were seen as important by the participants. Participants were able to be mindful even when the experience was not objectively pleasurable (e.g. eating food that was not tasty or viewing litter in the hedgerow). This raises several points. Mindfulness challenging routine habits of perception may be helpful in challenging difficult thoughts, feelings and emotions, and has been found to help recognise and interrupt automatic judgements and evaluations (e.g. Brown et al., 2007), by adding a small amount of processing time between experience and reaction.

3.4.4 Different practices affecting results

Although this research did not focus on the different types of contemplative practices discussed in Singer & Engert (2019) and Hildebrandt et al. (2017). The different facets of mindfulness that they discuss could be seen in the participants' diary entries and interview answers. The participants had a variety of practices and reported using mindfulness for a number of different purposes. Singer & Engert (2019) assert that differential training affects the subjective experience, behaviour, brain and body of the practitioner.

This differentiation can be seen in the differing experiences of a number of the participants. For example, Participant I, who was at home looking after small children, reported frequently using the mantra 'What does this moment require?' as a trigger to practice mindfulness termed by Singer & Engert an *Observing-thoughts Meditation*. This allowed participant I to focus mindful awareness on her thoughts and reactions to situations, especially those involving the children, in the moment. She then reported being very aware of her thought processes, which enabled her to decide how to react to them, even if that involved being angry. However, the anger was accompanied by an awareness that this was a choice that she was making.

Singer & Engert also report that participants who practised bodyscans experienced more body awareness. This can be seen in Participant C, who described using mindfulness as part of her Buddhist practise, but also as a way to deal with chronic back, neck and head pain following an injury. She practised daily bodyscans as well as short, mindful body-focused breaks, examining how she was using her body and how she was reacting to the pain. She reported that this had led to her experiencing and relating to her pain condition in a new and better way than previously. Participant A also used mindfulness in this way, discussing how he had become very ill through not paying attention to his mental and physical states, and how mindfulness practices like bodyscans and physically checking in had cured his condition.

For Participant P, it was important to practice compassion and loving kindness. He described a morning and evening mindfulness practice which frequently involved a loving kindness or other compassionate component. The result was that he found this allowed him to react more compassionately at work, with colleagues, employees and customers, which he reported as beneficial to his life quality. Participant J was also able to be self-compassionate by practising loving kindness meditations to help her deal with distressing thoughts.

3.4.5 Overcoming constraints

The findings indicate that as well as using the different contexts of use discussed above, a large part of fully integrating mindfulness into a life involved overcoming the constraints on mindfulness. Demands on time and cognitive capacity limited the ability to be mindful. However, participants found a number of ways around this, which shows that mindfulness and busyness can be compatible. The more experienced practitioners were able to incorporate mindfulness into busy times, taking every opportunity for short mindful episodes, which suggests that this may be an ability that increases with practise and experience. The results also suggest that short, regular practice was more beneficial than longer, but less frequent practice, in weaving mindfulness into a busy life. The literature widely asserts that practising mindfulness with regular frequency allows practitioners to react in a more positive way to events in their daily lives (Kabat-Zinn, 1993; Baer, 2009; Brown et al., 2007, for example). As seen above, setting an intention or making a commitment to be mindful each day was found helpful, pointing to a positive attitude to practise being beneficial. Incorporating mindfulness into daily activities, as seen above, so that it becomes as habitual as other things that are done daily, demonstrates that context may be important for triggering a mindfulness reminder.

3.4.6 Integrating mindfulness

The results suggest that at a certain point mindfulness moves from being something that requires a reminder to practise to being an embedded habit. However, prior to this it can be difficult and frustrating, as mindfulness can take time to show an outcome. The results suggest two elements which helped maintain the participants' practice.

Firstly, once results happened, they were very pleasant, engendering thoughts of wanting more. Recognising that results are cumulative and may be very subtle at first was widely cited as important among the participants and is seen in the literature (Machado & Costa, 2015; Carmody & Baer, 2008). This suggests that the time before practise starts to show results needs to be extremely well supported, so that practitioners do not give up at this stage. Secondly, practise also promotes awareness of non-mindfulness and situations where it would be possible or even helpful to be mindful. This suggests that at this stage, ironically, becoming more mindful makes practitioners more aware of when they are not being mindful. In those prone to self-criticism, this is where emphasising self-compassion and non-judgementality, as well as validating all efforts to be more mindful, may be important.

3.4.7 Implications for DBT DMHI

Whilst the purpose of this study was not to gather requirements, the findings in this thesis may have implications for the design of a DMHI.

The nature and use of purposeful mindfulness suggests that the DBT clients start by using this context of mindfulness, due to the effects of BPD. It may be the case that they do not have the chance to practice relaxed mindfulness at the beginning of the therapy, because they are almost constantly in crisis as the clinician interviews in Study 2 showed. Thus, mindfulness becomes extra challenging as acquisition takes longer and results appear more slowly. In addition, many of the issues that were reported as constraining mindfulness in the non-clinical participants may impact more intensely on DBT clients.

All of these suggestions would be optional parts of a DMHI and following UCD processes should be tested with end-users in a prototype in the Design phase.

Setting a reference point

Incorporating the suggestion of a formal morning mindfulness session, which almost all participants did in some form, into a DMHI may help DBT clients in acquiring mindfulness. This would give them an experiential reference point of a mindful state from which to access and experience mindfulness for the rest of the day. Whilst formal mindfulness techniques based on the breath are not used in DBT due to possible triggering of trauma memories, other methods for doing formal mindfulness could be used, as seen in the practices described above, for example, listening to birdsong or paying attention to other sights and sounds.

Short bursts of practice

Relaxed mindfulness was seen as very important in establishing a mindfulness practice by the participants and results were very much seen as cumulative. As those undertaking DBT may only be able to manage short mindfulness events (Linehan, 1993), particularly at first, this may be something to encourage in a DMHI including Mindfulness skills. For DBT clients frequent, very short episodes, in the order of 1-2 minutes or even less, might be a good approach to acquiring Mindfulness skills, as engaging in even very brief periods of mindfulness practice would yield better outcomes compared to not engaging at all, and may build a cumulative effect.

Building the mindfulness muscle

Practising mindfulness in a relaxed state was seen by participants as ‘building the mindfulness muscle’. Thus creating beneficial conditions for purposeful mindfulness in stressful moments, which can be frequent for DBT clients (Linehan, 1993). However, participants pointed out that it was very hard to produce purposeful mindfulness without having practised relaxed mindfulness. Purposeful mindfulness may be particularly required in DBT, especially when the client needs to work out which other skills should be used in a difficult situation. Therefore, a DMHI for DBT Mindfulness may need to provide support for both relaxed and purposeful mindfulness practice.

Relaxed mindfulness - finding the right time

The results suggest that mindfulness is easier to do and to learn if it is practised in a calm frame of mind before it is attempted in a state of heightened emotion or with additional cognitive load making it more difficult. DBT clients, especially at the start of therapy, often experience stress and anxiety, so that each time they do mindfulness it is purposeful. It is very hard for them to practice relaxed mindfulness, because they are not very often relaxed and without conflicting cognitive demands. DBT tries to encourage clients to practise Mindfulness when not under pressure. A DMHI could encourage this by allowing clients to make suggestions or set themselves reminders about when might be a good time to practise. Thus, a DMHI might encourage the use of relaxed mindfulness when doing very familiar things by helping to identify mundane everyday activities, when clients are not stressed, and making those the focus of short mindfulness practice.

Interspersing with other things

It is helpful to recognise that sometimes there is only time for brief periods of mindfulness. This can still be helpful, however. Interspersing brief periods of mindfulness with concentration or immersion, for example at work, when watching a TV programme or even when looking at social media on the computer should be suggested as possibly helpful to build up practice.

Self-compassion and validation

The study showed that participants emphasised the importance of self-compassion both in dealing with inevitable failure and difficulties associated with building a mindfulness practice. They also placed importance on managing the reality of the inner commentary, which even for non-clinical practitioners can be very negative and self-critical.

Mindfulness for people with BPD often means exposing themselves to the inner thoughts that self-harming behaviours have protected them from. Once revealed, these thoughts can be very challenging, as they often involve memories of abuse and feelings of shame about the abuse (Linehan, 1993). There is often a deep fear of experiencing these emotions and hearing these thoughts, which may be overwhelming, and may lead to further self-harming behaviours. Self-compassion should therefore be an even more essential focus in a DMHI for BPD/DBT clients. It is very important that a DMHI take this into account. However, in DBT clients, even with a lot of encouraging, accessing self-compassion is extremely difficult (Gilbert, 2009), which makes the validation aspect of DBT very important as well.

It *may* be beneficial to explain to clients that practising more compassionate mindfulness for others and the self leads to changes in the brain, which would bring about changes in their behaviour, helping them to be more self-compassionate. This is one of the more risky assumption and would certainly need to be tested in a prototype at the *Design* stage of UCD.

Helping impulsivity

The results show that using purposeful mindfulness moderated participants in acting impulsively or out of habit, giving them flexibility and considered choice in their responses. This aspect of mindfulness is a DBT skill and is very much encouraged (Linehan, 1993); it can be very difficult, as impulsive behaviour is one of the presentations of BPD. Therefore, a DMHI should emphasise this aspect of Mindfulness.

Rumination

Rumination is a clinical term for thoughts becoming stuck in an unhelpful pattern on the causes and effects of a distressing situation, without being able to resolve the problem (Lyubomirsky & Nolen-Hoeksema, 1993). Rumination is common in DBT clients (Baer et al., 2008). A DMHI could promote purposeful mindfulness to recognise and interrupt such unhelpful patterns of thought, as well as to encourage mindful acceptance of thoughts, leading to a non-judgemental attitude toward the sensations. This may help to counteract rumination as well as fantasy and suppression of thoughts, as found by Allen et al. (2009). Furthermore, the DMHI should facilitate the use of mindfulness to assist DBT clients in becoming aware of thoughts as mental events, which can then be checked for accuracy, rather than being seen as immutable facts, which DBT Mindfulness tries to encourage.

Somatic awareness of emotions

Mindfulness encourages an awareness and openness to the physical sensations of emotions like anger, instead of focusing on the reasons for being angry. However, those with BPD may find linking physical sensations to emotions challenging (Linehan, 1993). Attention to the feeling of the emotions in the body and the viewing of the thoughts as cognitive events, which are not necessarily truths, leads to better emotional regulation (Baer, 2010) and actions based on reflection, rather than an automatic response (Brown & Ryan, 2003). Mindful anger is possible, but it is based on reflection. This suggests aggression from others and angry responses can be helped using purposeful mindfulness. DBT was widely found to be efficacious in treating anger and aggression in different populations (Frazier & Vela, 2014). As anger can be a common emotion in people with BPD (Ellison et al., 2016), recognising and processing the emotion and its causes in terms of an ego-threat, using purposeful mindfulness and bringing in other DBT *skills* may be helpful in a DMHI.

Checking in for early warning

A common use for purposeful mindfulness in the participants was *checking in*. This helps to detect early warning signs of problems by regularly examining thoughts, emotions and bodily sensations. In a DMHI for DBT, it may be important to encourage clients to frequently check in to see how they are feeling. Many clients either feel numb or are overwhelmed by their emotions, thus have problems naming their feelings (Chapman & Gratz, 2009). By getting them to check in, BPD clients may realise they need to use additional skills. For example, getting clients to use a DMHI to ground themselves in the present, if they are heading towards a crisis may be another useful area a DMHI could help with in times of heightened emotion.

Willingness - wilfulness dialectic

The study suggests that being willing to be mindful even when it is seen as boring or about something unpleasant indicates that mindfulness can be a life-encompassing practice for both good and bad experiences. This indicates an issue that might be very important in a DMHI for BPD. The *willingness - wilfulness* DBT dialectic is one which is frequently discussed.[3] This dialectic involves overcoming *wilfulness* to not practice DBT skills (i.e. knowing that a skill should be used, but choosing not to do it), by recognising that it is *wilfulness* and counteracting it using *willingness*, especially in the face of an unpleasant experience. This points to a difference between not noticing a lack of mindfulness because it falls from the mind when busy, and noticing not being mindful, but then wilfully choosing not to take time for it. The DMHI may help by talking about this dialectic or by giving reasons why practising *willingness* is helpful.

Time to show results

The results also imply that mindfulness takes time to show results, which is important to remind anyone learning mindfulness. This means that for clients in the early stages of learning DBT mindfulness, when it can take a long time for the results to show, it is very important to help the clients have faith that practice will lead to a result. This means a DMHI that emphasises the positive results and benefits that mindfulness will bring may be helpful.

Incorporating bodyscans

In addition, the DMHI should allow for the three different types of mindfulness meditation discussed by Singer & Engert (2019) to be practised. This would involve finding a way to allow DBT clients to experience bodyscans, perhaps focusing on particular parts of the body which would not trigger a reaction to past trauma. As this would lead to more bodily awareness, it may be preferable to incorporate this component into practices for more experienced DBT clients rather than integrating it into the practise of those new to DBT.

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[3] See Section 2.4.4 for a discussion of dialectics.

3.4.8 Answering the research questions

The knowledge gained from this study helps to answer the main thesis research question, firstly by supplying direct information to sub-question 1, *How do non-clinical practitioners and DBT patients achieve and maintain mindfulness skills and practice?* as it provides a direct answer to this question from the perspective of the non-clinical practitioners. All of the themes contribute to this, as they all help the non-clinical practitioners in building a mindful life. However, it is of particular interest to the DBT clients that a DMHI should: (a) support many short bursts of practice in relatively relaxed states; (b) emphasise self-compassion to counter the emergence of previously dampened negative voices, possibly incorporating the findings of Singer & Engert (2019); (c) include a morning practice, even if very short, may be extremely beneficial for setting the tone for the rest of the day; (d) acknowledge that mindfulness is difficult and takes practice, commitment and willingness.

This sub-question is further discussed in Section 4.8.1 in light of the answers in Study 2. The discussion includes: choosing to undertake mindfulness; learning and embedding mindfulness; compassion and self-compassion; and, being able to narrate the experience of, and constraints on, the mindfulness acquisition journey.

3.4.9 Reflexivity

My mindfulness practice had been inconsistent over the few years before the research started and in the early years of the research. However, I had a strong belief that mindfulness was able to help with mental health conditions like anxiety and depression, because it allowed an attitude of acceptance without trying to fight the condition. In running the study, this may have been a confounding factor due to my own biases and beliefs about the benefits of mindfulness practice, causing the extracts and themes to biased to my viewpoint.

However, having this knowledge, and using empathic UCD and a dialogical approach allowed me to ask more personal, in-depth questions to try to understand the emotions, experience and practice, and participants were very generous in sharing their experiences, which were often very personal, with me. This made me reflect on my own experience of learning. I tried to remain in the role of the researcher and be unbiased whilst I used my experience to ask pertinent questions. Thus, facilitating a deep discussion with some participants. In order to maintain internal validity in this study, I used rich verbatim extracts from my participants' diaries and interviews to allow the reader to judge whether the themes that I developed from analysing the participants' data are accurate (Noble & Smith, 2015).

I had an assumption before I started the research and the placement at the Tuke Centre that the results of a study on a population practising mindfulness without the "distraction" of a mental illness might be useful for a DBT-mindfulness DMHI. However, I had not realised how strongly the presentations of BPD affected the clients, the history of trauma and abuse they had lived with and the shame that these caused. My understanding of and attitude towards the two types of mindfulness has changed a lot during the course of this research. Having reflected on and understood the clients and their struggles with BPD better, I have realised that coping with BPD and undertaking DBT was not only the motivation to start and continue to use Mindfulness, but the client's life may in fact have depended on them undertaking DBT.

3.4.10 Confounds and limitations on validity

There are a number of confounds and limitations within this study which need to be addressed. The characteristics of the population may have had a confounding effect on the results. In terms of socioeconomic status, the participants were all employed, with 14/15 working in white-collar jobs (or on parental leave from such work) and the other being a builder who was running his own business. In addition, the participants overall had a high level of education, with most having attended university. This may not be reflective of mindfulness practitioners across the UK, and more diversity of socioeconomic and educational status is desirable in a further study, to reflect a more divergent population. In terms of gender, there was an almost even split between males and females (males = 7, females = 8); however, the participants were predominantly white. Whilst demographic data on mindfulness practitioners was difficult to find, extrapolating from reviews, there is an over-representation of well-educated, Caucasian women in the majority of mindfulness studies which was noted by for example, Baer et al. (2008), but which still seems to be the case today, (for example, Kriakous et al., 2021).

The study population of mainly white, well-educated, middle-class participants may have altered the results in terms of the types of stresses they encountered, the time they had available to practice mindfulness, and their attitudes in wanting to take part in my research. Future research should include a more socioeconomically, educationally and ethnically diverse population, as the results in terms of what helps and what hinders practice may have differed if the participants had been unemployed, retired or from different socioeconomic or ethnic backgrounds.

A qualitative study looks at a particular phenomenon in a particular setting and is therefore not generalisable in the way that quantitative work is (Merriam & Tisdell, 2015). However, the ability to apply the findings in similar contexts helps to give the findings external validity (Noble & Smith, 2015). It is acknowledged that using a non-clinical population to design for a clinical population is problematic, but evaluating some of the findings of this study in Studies 2 and 4 with the clients and clinicians may help to show that some of the findings are also relevant to a clinical population. In this regard, the population in this study matches in a number of aspects with the DBT clients I encountered on my placement at the Tuke Centre; whilst at the time of treatment, almost all of them were unemployed or on sickness pay due to the severity of their illness, they tended to be predominantly Caucasian, well-educated and had worked as nurses, paramedics, teachers and managers, previously, or were university students.

Another confound could have come from the bias inherent in this population. A number of them were working as either DBT mental health professionals or mindfulness teachers, which may have distorted the results as they would be expected to be committed to mindfulness practice and to "buy in" to mindfulness helping in their lives. The diary and interview methods rely on participants being honest in their answers, and can be subject to biases. Long-term practitioners, especially teachers of mindfulness, are aware of the expected benefits and effects of mindfulness, and this expectation may have influenced the diary entries and interview responses to be more positive. However, embedding mindfulness into daily life requires persistence, and it seems unlikely that participants would have maintained a practice over many years unless they were seeing substantial benefits. The participants were all committed to their mindfulness practice, which was one of the inclusion criteria for this study. They had all initially chosen to undertake a mindfulness course and then to continue with the practice, which was seen as a positive and helpful factor in their lives. However, in choosing to undertake the study, the participants may have realised they had to be consistent with their work "image", which is why they did not choose the *"No"* response as much as the "*Yes*" response. In future research it would be interesting to look at participants who were not so successful at maintaining a practice, and did not "buy in" to mindfulness being a helpful or useful practice, as well as participants who had practised mindfulness for a number of years, but had then given up.

Comparing mindfulness practitioners from different traditions and practices, both secular and religious, may have been a confound to the results. Although, as in this study, other studies strive for a mixed mindfulness background (for example, Lomas et al., 2015) in order to show a range of experiences, having such a range may not allow for meaningful comparisons between participants, as asserted by Ekici et al. (2020). This is due to the training, practices and experiences being too different. However, this study considered that the primary inclusion criteria for the mindfulness participants was to have an established mindfulness practice in their lives, and this was the same for all participants, regardless of any additional purpose mindfulness served. This may have affected the study because it gave some participants a framework and sustained support network to help them in maintaining their practice which others did not have access to. Again, having participants with lapsed practices to compare with may have given richer results.

A further limitation was that participants were recruited in two main areas, York and Colchester. Just under half (8/15) of the participants were from the greater York area, with other participants coming from London, Hull, Sheffield and Colchester. All but one participant lived in a city. Therefore, having a majority of participants from one area or predominantly urban areas may have limited the findings.

Limitations of using a non-clinical population in designing requirements for a DMHI for DBT

Whilst some of the participants reported mild-moderate mental and physical illnesses and conditions, for example, chronic pain, and anxiety, which they used mindfulness to alleviate, none of the participants had the life-threatening mental illness of the DBT clients. The clients are the end-users of a DMHI for DBT Mindfulness; therefore, whilst the information gained from this study is interesting *per se*, in terms of what we can learn about the practices of non-clinical long-term mindfulness practitioners, using a non-clinical population may be seen as limited in the value it will bring to a design project for a DMHI. However, understanding the experiences of mindfulness practice and its processes in these participants facilitates a discussion around the experiences of DBT Mindfulness training and practices developed from analysing the data in the client interviews.

As a task, Mindfulness is the key skill in DBT, but is also seen as the most difficult DBT skill. In answering the research question, determining the process of establishing a long-term mindfulness practice when not coping with a mental health disorder seemed an important research area. It might then be possible to see if it was in any way relevant to the end-users. In addition, whilst it was important to carry out research with the DBT client group, as participants they were difficult to access, requiring a long and complex ethical process. The depth of knowledge about mindfulness practise and state and trait mindfulness gained through the diary study would not have been possible with the client group, as I did not want to run a study that might be detrimental to them. Whilst the non-clinical practitioners are not the target end-users, in successfully embedding mindfulness in their lives, they had gained lived-experience of part of the process that the DBT clients are undergoing. Therefore, by looking at mindfulness in a non-clinical population, the initial study allowed me to derive possible ideas for a DMHI and feed forward potentially helpful tasks and features for the clients and clinicians to evaluate in Study 2 and Study 4. That being said, it is very important not to take the experience of these participants as the "correct one" or to *measure* the clients' experience against this, and care is taken not to do so in this case study. However, in using a non-clinical population for the first study, as well as discovering new knowledge about this user group, it brings a number of advantages in answering the research question:

1. Using qualitative techniques typically used in UCD to first gain knowledge about acquiring mindfulness in a non-clinical population allowed me to study a group who were easier to access, and for whom in-depth questions and questions about negative aspects of their practice would not be detrimental.
2. The findings give us a new in-depth understanding of long-term participants embedding mindfulness in their lives without also having to deal with a life-threatening mental health disorder.
3. Combined with the results from Study 2, which examines clients' DBT skills acquisition experience, including Mindfulness, comparisons can be made between the clinical and non-clinical populations' mindfulness acquisition experiences.
4. Whilst it is acknowledged that the participants are not the end-users of a DMHI, the findings from this study may contribute to our understanding of how mindfulness practice in different forms can lead to improved functioning for individuals living with a mental health condition.

3.5 Conclusion

The overall research question for this study was: How do long-term mindfulness practitioners achieve and maintain their practice? This question was answered using four themes which detailed the factors that assisted and constrained the practitioners in their practice; how the practitioners had integrated mindfulness into their life and maintained their practice, and what embedded, lived mindfulness might look like.

Through the analysis, several key themes were constructed from the data, including two contexts, which I termed *relaxed* and *purposeful* mindfulness. Relaxed mindfulness, practised without any other cognitive constraints, built up the mindfulness ability, which then allowed constraints on mindfulness like busyness, difficult thoughts and illness to be better addressed. Daily formal mindfulness meditation, as a typical form of relaxed mindfulness, laid down a baseline which participants could return to, as well as ingraining mindfulness as a habit. The study also examined how participants fitted mindfulness into busy lives by doing short mindfulness practises in between tasks, and how mindfulness helps in social situations, in particular those where listening and paying attention to others are important.

This study adds to the qualitative mindfulness literature on what the experience of long-term mindfulness practice looks like. As there is comparatively less literature on mindfulness practised long-term and integrated into a life over years, and very few using a diary study.

In addition, it set up knowledge to be tested in Study 2 around ideas about mindfulness acquisition; possible designs for a DMHI for clients acquiring DBT Mindfulness; and, to facilitate a discussion about using qualitative study methods with non-clinical populations and how such methods might need adjusting for a clinical population.

Finally, this study helped to scope the research, resulting in a DBT Mindfulness game and COTS mindfulness apps eventually being rejected as unsuitable for a clinical population. Thus, Study 1 helped to define the scope of the project in confirming that a tailored approach to DBT Mindfulness was needed and led to the research focus changing from a DBT game to an app during Study 2.

3.5.1 Looking ahead to the next chapter

Having seen how mindfulness works in a non-clinical population, the next step in the research is to look at a clinical population in the form of DBT clients attending DBT at the Tuke Centre. Therefore, the next chapter describes a study in which DBT clients and clinicians were interviewed about their experience of DBT skills training. The themes that I classified in this study proved useful in talking to the clinicians and clients in the interviews, informing some of the Mindfulness skills questions.

Chapter 4

How do DBT clients and clinicians experience DBT skills training?

4.1 Introduction

This research looks at gathering requirements for an adjunctive DMHI to support BPD clients in learning and using DBT. To carry out this work, I used a UCD approach, in which an understanding of DBT and the experiences of the skills training aspect of the therapy for the clients and the clinicians as stakeholders of the therapy was needed. It was necessary to understand the clients' perceptions, attitude and disposition from first attending DBT skills training, to becoming more proficient in using the skills, and finally using them in trauma processing[1] or to maintain wellness, as their attitude to skills training changed over time. It was also important to gain the clinicians' views as the clinical experts on DBT and working closely with patients with a BPD diagnosis, possibly recommending or even employing the DMHI in therapy sessions. Therefore, the study detailed in this chapter gathers this information.

This research would typically take place in the *Understanding* phase of the UCD process (Section 2.2.4). The Information found in this study is then used in the *Defining* stage to produce documents for inclusion in a User Requirements Document (URD), as done in Chapter 5). As well as producing research information, this study starts to detail how the "standard" UCD methods discussed in Section 2.2.6 needed to be adapted for a vulnerable clinical population. The full set of documents presenting the clients' requirements for a DMHI can be seen in Appendix I.

4.1.1 Study scope

Due to the risk of patients self-harming and the suicidality of people living with BPD, gaining NREC and Retreat ethical permission to run this study took 6 months; the research focus changed a lot over those 6 months due to running Study 1 and ethnographic observations made on placement at the Tuke Centre (see Section 1.3). See Section 1.3.2 for an overview of changes to the research focus.

Following Study 1, I had been considering the suitability of a game as the delivery medium for a DMHI. However, due to the considerable buy-in to a game from myself and the DBT group, the change in research focus, from a digital game to an adjunctive app, took some time to happen. The submitted ethics application and Interview Schedules, which had been prepared at the start of the research, were based on a digital game, as this was the focus at that point. The ethical clearance therefore related to game-focused questions, and as I was not 100% sure that I would change the DMHI delivery mode from a game, when I started Study 2, these were asked in the interviews

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[1] Part 2 of DBT; outside the scope of this thesis

conducted in this study (see Appendices A and B for the Interview Schedules). During analysis of the interviews, it became clear to me that a game might not be the most suitable delivery mode for a DMHI and I changed the research focus to an adjunctive app. Therefore, answers from the Games section of the Interview Schedule were not all written up, as they were beyond the scope of the final requirements.

At the start of the research, I considered that all four DBT skills modules were going to be included in a DMHI. The ethics application reflected this. It was known from the start of working with DBT, that Mindfulness, as the core skills module (Linehan, 1993, Section 2.4.3) would focus prominently in the intervention. However, as my knowledge of DBT developed, it became less clear whether any or all of the other three DBT skills modules would also be part of the initial design. Again, ethical permission covered questions on all four modules and this study asked questions about all four DBT skills modules, to gain a full picture of the DBT skills learning/training experience. After discussions with supervisors, I realised that as the focus of both clients and clinicians was on the Mindfulness skills module, it would be better to concentrate on one skills module at a time, starting with Mindfulness (though other skills could be added later). One of the benefits of understanding the user's wider journey and those involved in delivering it is that you can notice things that could be improved in later development phases, whilst concentrating on the most important issues first.

4.2 Methodology

4.2.1 Research question

The overall research question for this study was: How do clients and clinicians experience DBT skills training? This was split into 2 sub-questions:

- How do the clients experience learning and applying the skills?
- What is the clinicians' experience of delivering the skills in terms of clients' needs?

4.2.2 Aims

In order to answer the question, the objectives of this study were:

1. to understand the clients' experience of learning and using DBT skills.
2. to understand the clinicians' experience of teaching the skills and clients acquiring the skills.
3. to explore if and how clients overcame difficulties in learning the skills.
4. to explore the clinicians' experience of mechanisms that help or make it difficult for clients to acquire the skills.
5. to identity what clients might expect from a DBT DMHI and anything they did not want.

From understanding the clients' and clinicians' experience of learning and teaching the skills (Objectives 1 and 2), the answers from each group were synthesised to form discourses of experiencing DBT skills acquisition and training. This was then used to generate design considerations for requirements generation. Objectives 3 and 4 added further insights into helpful and less helpful strategies and components for the requirements generation stage of the process. Objective 5 helped to understand what components the clients would like/dislike in a DMHI to help in the design process discussed in Chapter 5.

4.2.3 Study design

I wanted to gain as detailed knowledge as possible, given the constraints of participants living with a mental health condition, so in order to achieve the study aims, several study designs were considered, including a diary study (Lazar et al., 2017), questionnaires (Sharp et al., 2019; Mathers et al., 1998) and interviews (Adams & Cox, 2008; Sharp et al., 2019).

I initially considered another diary study, but there were a number of disadvantages (Lazar et al., 2017; Goodman & Kuniavsky, 2012). The clients may not be aware of the details of their Mindfulness skills practice or the reasons for it, so they might struggle to log it in a diary entry. They may also forget to write or be unable to write sufficient entries. In addition, recruitment might have been difficult, as the study requires considerable time and effort commitment. Following discussions with the DBT clinicians about Study 2, it was clear that although the data collected *may* have been helpful (Goodman & Kuniavsky, 2012), I would not able to run a diary study with the clients, which I could then compare with Study 1. Firstly, the week-long format would have been too arduous for the participants; secondly, it would have been unethical asking BPD clients the same questions as I asked the non-clinical participants about when they were *not* mindful. These questions may have been perceived as intrusive and negative, potentially triggering negative thoughts leading to self-harm. Therefore, I amended my plans to replicate Study 1 in conducting Study 2.

I then considered a survey (Sharp et al., 2019; Mathers et al., 1998). Questionnaires would give participants a chance to reflect and report on their DBT skills learning experience (Mathers et al., 1998). This could could possibly be administered during a skills group session. However, this was rejected for a number of reasons. Firstly, methodologically a questionnaire might not capture fully what participants really thought (Sharp et al., 2019). Secondly, it was unlikely to get ethical clearance for administration during the group skills session, and after discussion with my supervisor I realised that without me being present when the survey was completed, there was a chance of questions being misunderstood by the client group, without a context in which they could ask about the study and clarify what was required. The motivations for being asked to complete a questionnaire also may not have been clear, causing the clients concern with no support for behavioural repercussions in place. BPD people tend to overthink (Linehan, 1993) and thus it would have been unethical to cause any negative reactions. The nature of the Tuke Centre client group and the disorder had to be taken into consideration. This client group can use self-harming behaviours when they are upset and there was a possibility of questions triggering thoughts of self-harm for clients; therefore, a study design which allowed clients to be asked explicitly how they were feeling at the end of the session, and to have help available immediately if necessary, was felt to be more appropriate.

Thus, to gain the knowledge to meet the aims of the study, a qualitative, semi-structured interview (Adams & Cox, 2008; Sharp et al., 2019) was chosen. This aligned with the dialogical approach, that participants contribute to the construction of meaning, rather than merely serving as passive sources of information, as can be the case with structured interviews (Edwards & Smith, 2014). In addition, interviews can give comprehensive data on a topic, which a questionnaire might not provide (Sharp et al., 2019), as it is a live conversation between the researcher and the participant, which unlike a general conversation, is structured and is motivated by a quest for research knowledge gained through the interviewee answering questions (Merriam & Tisdell, 2015). One of the advantages over a survey is that any questions or answers that are not understood can be immediately clarified. Interviews are good for gaining knowledge, because they allow in-depth investigation through immediately following up an answer with a question about the answer (Dexter, 1970), which a survey does not allow. I decided to conduct one-to-one interviews with the clients and to time these to take place immediately before their one-to-one therapy sessions at the Tuke Centre. Their therapists would know about the interview and would check their well-being in the session. The questions asked were carefully tailored to the research question to obtain the necessary information.

In designing this study, I spoke about it at length with my clinical supervisor,[2] Dr Julia Coakes, who was Team Leader of the DBT group. I was on a one year placement at the time, and had a lot of contact with Dr Coakes. We had extensive daily conversations about aspects of DBT and the clients. Our conversations frequently included her colleagues who were DBT clinicians and other qualified clinical psychologists, who were interested in my research and in helping me to understand DBT, the clients and the clinical context. Once I had decided on the methodology, given the clinical constraints, these conversations informed the clinical aspect of how this study was run. In addition, in applying for ethical clearance, the NHS IRAS (Integrated Research Application System) Exeter Research Ethics Committee, wanted strict assurances about the procedures I would use in conducting the interviews.

4.2.4 Interviewing technique

The research method used in this study was semi-structured interviews. In clinical psychology and psychiatry, interviews are the most widely used assessment and treatment tool (Kramer et al., 2019). Many guidelines used in psychiatric diagnostic interviews are similar to "standard" UCD interview guidelines: establish rapport, elicit specific information, ask if the patient has any questions (Waldinger & Jacobson, 2001, *inter alia*). Waldinger & Jacobson are talking about interviewing psychiatric patients for diagnosis, but many of the principles are also applicable in the UCD interview situation. For example, listening not only to *what* the client is saying, but to *how* they say it, as they may not be able to clearly articulate their meaning, due to the illness. This is one of the reasons that my research uses Discourse Analysis, to fully understand the *how* aspect of the interview.

Waldinger & Jacobson also advocate allowing the clients to present their knowledge in their own style and order. This means the interview should not be over-structured.

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[2] Dr Coakes supervised the clinical aspects of the EngD, during my placement at the Tuke Centre.

It also recalls Adams & Cox (2008)'s "letting off steam" technique. However, some structure is required to ensure all required data is acquired and to help clients who might struggle with presenting their ideas in order. Therefore, ideally a semi-structured approach should be taken, using open-ended and non-leading questions to encourage the client to speak (Dumas & Loring, 2008). Reflecting their words back to them, for example, if they use particular terms or phrases is also helpful, and can be used for gentle probing. However, there are also additional instructions to bear in mind in working in this context. Being aware of whether the client is becoming distressed is important, for example, through early changes in behaviour, such as getting up to pace, or a change in language or silence. Waldinger & Jacobson also mention threatening and violent behaviour in diagnostic interviews and setting boundaries. This was not an issue with the clients I interviewed, although there are examples in the literature. For example, Thieme et al. (2016) mentions being warned about a BPD inpatient client who pulled hair when doing participatory design. In these cases, having clinicians who are aware of issues who can tell you in advance is helpful.

4.2.5 Analysis method - Discourse Analysis

The original study design planned to use Thematic Analysis, as in the previous study. However, after reflecting on the interviews, it became clear that although all participants were asked the same questions, there were disharmonies between the spoken words and the attitudes of some of the participants. Transcribing the data revealed a further disconnect between clients' espousal of a positive view of DBT and an expression of negative feelings and resentments towards DBT and the DBT process at the Tuke Centre. In addition, there was a disconnect between the importance given to some of the skills by several of the clinicians and the indifference or apparent negative attitude to the same skills by some of the clients. Although the disconnect was quite subtle in some places, it was important to try to capture this. All this made *how* the participants were expressing themselves, in addition to what they were saying, important. To this end, I decided to use Discourse Analysis (DA: Gee, 2010, 2004) as an analysis method.

DA covers a number of tools and approaches used in analysing the use of language as a "sociocultural practice and social resource of a group" (Gee & Green, 1998, p.121). Approaches to DA vary from field to field, but generally, language and communication is seen as not only a means by which people say things, but also used to accomplish things. An example might be to build co-operation or show disdain for a person or group. DA asserts that the meanings of communications are situational, being "assembled 'on the spot', as we communicate in a given context" (*ibid*, 1998, p.122). The context may be denoted by verbal signals, such as words or grammatical constructions, but can also include tone, stress and pitch of the voice. However, prosodic features were not used in my analysis as they would have been difficult to analyse without a recording of the interview to refer back to. The seven areas used in the analysis and the questions Gee recommends asking are shown in Table 4.1.

Discussion of discourse analysis

DA has been widely used in healthcare research, including studies in a mental illness healthcare setting. Examples of such studies include discourses shaping mental health practitioners (Zeeman & Simons, 2011), in-patient eating disorders (Malson et al., 2004) and recovering heroin users (Nettleton et al., 2013). However, in the area of DBT, very few studies were found that used DA (Hazelton et al., 2006; Simons, 2010). The approach adopted in analysing this data is detailed in Gee (2004) (see Table 4.1), which sees language-in-use as always political, being about how social goods (things considered by a group as having worth, value, or giving power) are discussed and disseminated. In addition, it makes "discourses with which we are familiar strange, so that even if we are members of these Discourses we can see consciously how much effort goes into making them work and indeed seem normal, even right to their members" (Gee, 2004, p.102). This was useful, because having spent a year attending the weekly group skills sessions at the Tuke, and attending weekly Consultation meetings and chatting to clinicians, I had a familiarisation with the clinicians' approach to DBT in particular, which might lead to bias in the data analysis. DA allowed a distancing from the viewpoints of both groups of participants.

Area of reality being constructed	Questions to ask
Significance	How is this language being used to make certain things significant or not and in what ways?
Practices	What practice(s) (activity) is this language being used to enact? (i.e. get others to recognise as going on)? What socially recognised and institutionally or culturally supported endeavours are taking place?
Identities	What identity or identities is the language being used to enact (i.e. get others to recognise as operative)? What identity or identities is this piece of language attributing to others and how does this enact the speakers' identity?
Relationships	What sort of relationship(s) is this piece of language seeking to enact with others (present or not)?
Distribution of social goods	What perspective on social goods is this language communicating (i.e. what is being communicated as to what is taken to be normal, good, like me, appropriate, acceptable or the opposite)?
Connections	How does this piece of language connect or disconnect things? How does it make one thing relevant or irrelevant to another?
Sign Systems and Knowledge	How does this piece of language privilege or disprivilege specific sign systems or different ways of knowing and believing?

Table 4.1: Areas constructed through communication – from Gee (2004, pp.32-36)

Discourse mark up

The extracts in this chapter use a discourse mark up based on Gee (2004) (see Table 4.2).

/	short pause
//	long pause
...	hesitation
[ ]	language or punctuation inserted by me. For example, [...] would show where I had removed part of the extract. Also shows extralinguistic parts of speech like laughing

Table 4.2: Discourse mark up, based on Gee (2004)

Discourse analysis coding

Using DA fitted in with my view of how knowledge is constructed. I transcribed the data immediately as requested by the NREC. The recordings were transcribed, which helped me to have great familiarity with the recordings.

Coding was done synchronously with interviewing as these happened over a few weeks. I then read through the transcripts a number of times. The transcriptions were placed in a table with two columns. For each question that I asked each participant, I considered the answers and looked to see if they fitted one of the 7 discourses above. I started as Gee recommends by breaking the utterances down into small units like words or short phrases and then built these up. Sometimes more than one discourse could be constructed. I continually asked myself, 'what is the social good here and how are the discourses being used to construct it'? I wanted to remove BPD from the clinical diagnosis and understand it as the client's lived experience, using an empathic constructivist framing of what they said, constructed through the dialogue between myself and the clients. This gave more of a voice to clients about *how* BPD had affected their lives, what DBT had brought to them and how they experienced the skills training.

To minimise bias, the transcript coding was discussed with my University of York and Retreat supervisors. After coding a section, through the process of data interpretation given above, I discussed the codes that I had assigned with my York supervisor. We had extensive discussions around the coding and the meaning of some of the clients' and clinicians' phrases. In particular the beginner clients. Once all coding had been done, it was further discussed.

4.2.6 Context

This study took place at the Tuke Centre, the outpatient centre of The Retreat, York. At the time of the study, a DBT team which comprised eight clinical psychologists who were DBT-trained, including a DBT Team Leader and a Senior Psychiatrist were employed at The Tuke. Two of the team were part-time, only teaching the DBT skills groups. The team was a shared resource between the Tuke Centre and inpatients at The Retreat. There were two DBT skills groups per week, each lasting for two hours. These were run by two experienced DBT clinical psychologists or DBT trained nurses.

One group had between three and six clients, the other varied between five and eight clients over the year that I attended the Tuke Centre on placement. Thus, the number of DBT clients varied between 8 and 14. Clients were both NHS-funded and private. They were drawn from York and the wider Yorkshire NHS trust area including Leeds and Scarborough. Some private clients also came from further afield.

4.2.7 Participants

The number of DBT clients attending the Tuke Centre at any one time varied. In addition, it was not known how many of the clients would be willing to participate in the interviews. In light of this, to gain additional data and another perspective on DBT skills, I interviewed clinical staff as stakeholders involved in delivering DBT at the Tuke Centre and the Retreat about their experience of teaching skills, and the clients learning the skills.

Recruitment

Client recruitment was through personal therapists and was dictated by my ethical permission. It is discussed below in Section 4.3.

The clinicians in the DBT team were recruited by word of mouth. No financial incentives were offered as the Retreat Research Governance Group thought it inappropriate to offer these to staff, who were expected to take part in studies as part of their role.

Client demographics

Client participants (*n*=5) were DBT outpatients attending therapy sessions at the Tuke Centre. They were at various stages in the therapy (see Table 4.3 for a breakdown of client information). Ranges are used to show age and length of time in DBT to protect anonymity in a small participant group. All participants were women. Some were attending the skills group, others had finished the two-year skills learning stage and had moved on to the next stage of DBT, in which the trauma at the root of BPD is processed through one-to-one therapy. For many clients, this cannot be done before the skills have been learnt thoroughly, as this work can be very painful.

Study ID	Age range	Time in DBT
Rosie	18 – 30	< 6 months
Suzy	31 – 40	6 – 12 months
Emily	18 – 30	> 24 months
Maisy	18 – 30	> 24 months
Charlotte	31 – 40	> 24 months

Table 4.3: Client information (all names are pseudonyms)

Clinician demographics

Clinician participants (*n*=5) were mental healthcare professionals using DBT with outpatients at the Tuke Centre and/or with inpatients at the Retreat. They had been delivering DBT for between 1 and over 10 years (see Table 4.4 for a breakdown of clinicians' information). All of the clinician participants were women, as the DBT team are all female. Ranges are used for age and time working in DBT to protect anonymity in a small participant group.

Study ID	Age range	Time working with DBT
Eleanor	18 – 30	1 – 3 years
Catherine	31 – 40	1 – 3 years
Leah	18 – 30	3 – 6 years
Grace	31 – 40	6 – 9 years
Abbey	41 – 50	10+ years

Table 4.4: Clinician information (all names are pseudonyms)

4.2.8 Materials - clients

Information Sheet

The clients' Information Sheet explained to them the purpose of the study, who was running it, what would be required of them if they participated and that participants could withdraw at any time, without it affecting their medical treatment.

Consent Form

The Consent Form also reiterated that the interviews would be audio recorded, participation was voluntary and that participants could withdraw at any time, without it affecting their medical treatment.

Interview schedule

The client Interview Schedule went through several iterations due to the ethics procedure, discussed below. The final schedule comprised an Introduction, a section for each DBT skill, questions about technology use, questions about a DBT game and its aesthetics asking about look and feel ideas. The Client Interview Schedule can be found in Appendix A.

4.2.9 Materials – clinicians

Information Sheet

The clinicians' Information Sheet explained to clinicians the purpose of the study, who was running it, what would be required of them if they participated and what would happen to their data.

Consent Form

The clinicians' Consent Form informed clinicians that taking part in the study was voluntary and that they could withdraw at any time. It included that interviews would be audio-recorded and data would be used anonymously.

Interview schedule

The clinicians' Interview Schedule also underwent changes. The Retreat Research Governance Group suggested that the number and types of questions might take a long time. Therefore, questions on the therapeutic relationship and measuring of efficacy were removed. Some of the questions on Mindfulness were also removed. This made the interview shorter, whilst still retaining the overall theme. The Clinician Interview Schedule can be found in Appendix B.

4.2.10 Interview procedure - clinicians

The clinicians were interviewed at their place of work. Four participants were interviewed at the Tuke Centre and one at the Retreat.

1. Clinicians were met at their place of work. We went together to the interview room. The interview began by chatting to the participant about everyday things whilst the papers and recording device were set up. Clinicians were asked if they had read the Information Sheet (they were all sent a copy) and if they would like to look at it again. Several asked for the sheet and were given a copy and time to read it through.

2. The following was explained to the clinician participants: the reason for the interview, that they were free to leave at any time or to say they would prefer not to answer any of the questions, that their data would be treated anonymously and any references to things that might identify them would be redacted. They were asked if they had any questions for me about the study.

3. They were then asked to sign the Consent Form to say that they had understood the information given to them and were happy to proceed.

4. Once everything was ready, the recording device was switched on. Clinicians were identified by their number and asked on the recording if they were happy for the interview to be recorded.

5. The interviews took between 20 and 40 minutes, with most lasting around 30 minutes.

6. Participants were asked if they had any final questions. Once these were answered, participants were thanked for their time.

7. The interviews were transferred to an external hard drive for secure storage and the transcriptions were made as soon as possible. The recordings were then destroyed as stipulated by the Exeter Research Ethics Committee, as part of the NHS IRAS ethics application.

4.2.11 Interview procedure - clients

Client participants took part in a recorded semi-structured interview about their experience of learning and using DBT skills. Participants were also asked to discuss their experience of technology and digital games and their thoughts on what a game supporting their DBT skill learning might look like. As discussed in Section 4.2.3, the study had a lot of input from the clinical team at the Tuke in conducting the interviews; however, Waldinger & Jacobson (2001) was also recommenced by Dr Coakes and read prior to conducting the interviews. In the ethical section below I detail where and how the procedures for an interview (detailed in Section 2.2.6) were amended.

4.3 Ethical issues

Ethical considerations are very important when working with vulnerable people with a very high suicide rate. However, this meant that my study was strongly affected by other people, with two committees requesting changes to my questions. This made recruiting very difficult, limiting the number of participants The overall effect of this was probably not major, but it is something other researchers need to be aware of. This is discussed further in Chapter 7.

4.3.1 Data handling

The way the recordings were made and the way the recordings were stored was stipulated by the Exeter Research Ethics Committee. They did not want the recordings stored on a laptop, which was suggested by the Retreat Research Governance Group.

This meant that no one could listen to them, as is frequently done in design teams (personal knowledge through working as a user researcher). Therefore the models which were created in Study 3, based on this data, had to be completely representative, as they were the single source of truth for the project. This needs to to be bourne in mind by other researchers.

4.3.2 Adapting “standard” UCD for the setting

As seen in Section 2.2, working with end-users with a mental health disorder and other difficult to access vulnerable groups, can be challenging (Doherty et al., 2010; Neves et al., 2015; Thieme et al., 2016; Wärnestål et al., 2017, *inter alia*). However, I considered it important and worth the long and stringent ethical permission process necessary to talk to DBT clients. Care had to be taken to adapt the process to the context of research with vulnerable users, based on guidance in the sensitive HCI literature. Therefore, although it is a "standard" UCD method to interview participants about the process of what they do, the interview process from planning to recruitment, to triangulation had to be carefully considered in the best interests of the clients. In creating requirements for a DMHI to support BPD clients in learning and using DBT Mindfulness module skills, an understanding of DBT and emotional insights into the clients' lived experiences of the therapy and their life situation was needed, which was gained using using empathic UCD (1.1.3) in my approach to the study. In addition, a dialogical approach (1.1.4) helped me to try and engage with stakeholders as partners, appreciating their diverse perspectives and accommodating them in the requirements.

4.3.3 Participant recruitment

The recruitment process was removed from my direct control by the NHS IRAS (Integrated Research Application System) Exeter Research Ethics Committee, who would not allow me to approach the clients directly, as they were worried clients who knew me might feel pressured into being interviewed. Therefore, everything had to be done through the clinicians at the Tuke Centre.

Having spent a year at the Tuke observing the DBT skills groups, the Exeter Research Ethics Committee (responsible for the processing of my NHS IRAS ethics form) were concerned about my having undue influence on the clients in forcing them to be participants. They therefore stipulated that the recruitment of clients was done through a third party and there was no direct involvement, such as my talking to clients face-to-face about the study. All emails were sent via a third party, which was usually the individual therapist. In addition clients could not be offered financial incentives *a priori* (though *post hoc* was allowed). The clinicians therefore asked the clients if they were interested in being participants during group skills sessions or one-to-one sessions. Clients that showed an interest were emailed by the clinicians with the Information Sheet and Consent Form. The clinicians then arranged for the meeting to take place before the client's one-to-one therapy session, as part of the support mechanism for anything triggering coming up in the interview. Thus, a standard direct way of recruiting participants directly (for example, Lazar et al., 2017) could not be used and had to be adapted to comply with ethical concerns.

The original research planned to recruit former service users in addition to current service users. However, the Retreat Research Governance Group suggested this would not be ethical unless the former service users had given The Retreat permission to contact them. The paperwork to establish whether permission had been given or not had not been previously collected and was considered too time-consuming by the Tuke Centre administration team; therefore, this idea was abandoned.

4.3.4 Information sheet and consent forms

The Information Sheet, on the Exeter Research Ethics Committee's request, had to include a request for GP and individual therapist contact details. Therapists also had to be informed that the client was taking part in the interview. Clients had to be assured that saying no to the study or leaving the interview at any point would not affect their medical treatment in any way. I did not want the clients to think that they might be stigmatised by not taking part in the research (Waycott et al., 2015), so this was made clear in the Information Sheet.

The Consent Form, on the Exeter Research Ethics Committee's request, had to include GP and individual therapist contact details. They also had to be informed that the client was taking part in the interview. Clients had to be assured that saying no to the study or leaving the interview at any point would not affect their medical treatment in any way.

4.3.5 Interview schedule

The client Interview Schedule went through several iterations due to the ethics procedure, as the Retreat Ethics Committee requested changes to the original. The number of questions was reduced, with questions about the therapeutic relationship and dialectics of treatment removed. Some of the questions on Mindfulness were also removed. This made the interview shorter, whilst still retaining the overall theme. Questions about client wellness were also added at the end, to check the participants were not in any distress.

4.3.6 Client interviews

Planning The questions were initially drawn up around the themes I wanted to examine which were the four DBT skills groups and digital technology use. The Exeter REC and the Retreat wanted the questionnaires to be shorter, so these were reduced to take less time. The interview was at the more structured end of the semi-structured spectrum, with carefully constructed questions following the schedule quite tightly, although some probing was also done to expand answers where necessary.

As detailed above ethical clearance for this study took around 6 months, including obtaining an enhanced DBS,[3] with several re-submissions to the NHS REC. Retreat and University of York ethical permission also had to be sought

Johansson et al. (2015) assert that mental illness can lead to cognitive difficulties, for example in focusing, sustaining attention, dealing with stress and short-term memory, which can be caused by the mental illness or by medication. Dr Coakes and I had discussed this, so I took this into account when planning the interviews: it was important to be patient when awaiting an answer, but it might also be necessary to prompt or ask the question in a slightly different way.

In addition, a population with a mental health condition may also experience hypersensitivity to how a study is run, including last minute changes, and a perception of not dealing politely with the participant, an omission or error can result in the participants not wanting to be involved (Waycott et al., 2015). This is especially true of BPD clients, who often have strong affective reactions to small things. Therefore, protecting participants from being upset due to poor research implementation was very important and I paid extra close attention to details at the planning stage. Participants

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[3] An enhanced *Disclosure and Barring Services* check shows full details of a criminal record, such as cautions, spent and unspent convictions etc. The check also searches the DBS Children's Barred List and the DBS Vulnerable Adults list to ensure the applicant is not barred from working with either group.

need time to consider whether to take part in the interview study (Johansson et al., 2015). My participants were indirectly recruited via the clinicians. They were given a detailed Information Sheet and allowed time to understand what the interview subject was, where the interview would take place, how long it might last and who would hear the recordings.

The client participants were interviewed at the Tuke Centre. This was a place that they were familiar with, and they were also close to their therapists in the unlikely case that they because distressed by the interview. Therefore, it was a place that they could feel secure. Interviews were scheduled to take place immediately before their one-to-one therapy sessions.

Piloting The interview questions were piloted with Dr Coakes. Although she was not a member of the target group, there were only 5 client participants and I did not want to use one as a pilot. In addition, Dr Coakes was in the best position to spot any question which might trigger distress in the clients. The questionnaire was not changed after piloting.

Running the interview - Beginning Clients were greeted in the waiting room and asked if they would like a drink. They were then taken to the interview room. The interview began by chatting to the participant about everyday things whilst the papers and recording device were set up. Once everything was ready, I asked clients if they were happy to begin. The recording device was then switched on. Clients were identified by a random number and asked on the recording if they were happy for the interview to be recorded. Clients were asked if they had read the Information Sheet (they were all sent a copy) and if they would like to look at it again. Several asked for the sheet and were given a copy and time to read it through.

The reason for the interview was also verbally explained to the client participants. They were reminded that they were free to leave at any time or to say they would prefer not to answer any of the questions, that their data would be treated anonymously and any references to things that might identify them would be redacted. They were also reminded that this would not affect their medical treatment. They were asked if they had any questions for me about the study. They were then asked to sign the Consent Form to say that they had understood the information given to them and were happy to proceed.

Building a rapport with an interviewee, without becoming personally involved, has been long-known as important (Dexter, 1970; Dumas & Loring, 2008); when working with with people with a mental health disorder, who may be “experiencing complex emotional issues” (Waycott et al., 2015), this becomes more important and more difficult. In order to build a rapport I was friendly and relaxed in the interview with open body language. I started the interview gently by asking very general warm-up questions about how long they had been in DBT, to put them at ease.

Running the interview – Body The questions were presented in a logical order, asking about each skill group in turn with some probing to get more information if necessary. Due to the nature of the disorder, deep probing was not done. Sensitive questions, such as why they were in DBT or anything about their past history were not asked due to the nature of the disorder and its presentations. The interviews took between 20 and 40 minutes, with most lasting around 30 minutes. None of the clients asked to leave before the end or asked not to answer any questions.

Running the interview – Final stages The questions at the end of the interview asked about clients' use of computers and digital apps and games, to bring the interview to a gentle ending. Participants were asked if they had any final questions. Once these were answered, my final questions checked on participants' well-being. I reminded them that they could talk to their therapist or GP if they needed to. Protocols had been put in place in case any participants were disturbed by any questions. However, all participants said that they felt fine at the end of the interview and the protocols were not used. The interviewees were thanked for their time and given a £10 Amazon voucher to thank them for being willing to participate. They did not know about this previously and it was not used as an incentive, as stipulated by the Exeter NHS REC, as part of the NHS IRAS ethics application. To close the session the recorder was switched off.

Data Analysis The interviews were transferred to an external hard drive for secure storage and the transcriptions were made as soon as possible. The recordings were then destroyed as stipulated by the Exeter Research Ethics Committee. Feedback for participants from vulnerable groups is seen as particularly important (Johansson et al., 2015) so that participants can see their impact. Unfortunately, before I was able to give feedback, the DBT group at the Tuke was disbanded and I was not allowed to contact the clients to get comments.

Because future design teams would not have direct access to interviews, making sure that models were detailed and faithful representations of the clients and the context was then very important.

4.4 Results and discussion

This section examines how the language used in the client and clinician interviews functions to present discourses on identities, relationships and behaviours in the DBT skills training context.

4.4.1 Clients' discourse

The discourses discussed in this section are:

1. DBT as a reliable help for a better life, but not a panacea.
2. The process of learning DBT skills going from being "in a fog" to gaining confidence, becoming proficient and maintaining skills.
3. Mindfulness as strange, challenging and the foundation skill.

4.4.2 DBT – reliable help for a better life, but not a panacea

Client participants constructed a discourse in which DBT was seen as a positive influence, with each participant's interpretation of its value varying based on their individual experiences. In this discourse, clients talked about DBT as enabling them to gain the social good of a life in which they were able to cope with BPD. The idea of DBT being extremely important to manage and bring stability to their lives was dominant in the three experienced clients, and the expectation of this was present in the less experienced clients, which serves to make this the main social good in the DBT discourse. However, none of the clients constructed DBT as giving them lives free from the causes and symptoms of BPD and some of the problems associated with the disorder were still present, which clients constructed in different ways.

The experienced clients' discourse constructs an expectation of being able to manage the disorder, and confidence in their ability to use DBT to help them with life issues was strong. They constructed themselves as better able to manage the urges to self-harm and other life-threatening behaviours than before treatment. In addition they presented themselves as better able to recover from a crisis, as well as importantly, having the knowledge that they were able to use the skills to recover if things went wrong. Emily, an experienced client, described learning DBT skills as difficult, but presented life now as a great improvement on life pre-DBT. However, DBT is not seen as a panacea; Emily shaped a discourse on the limits of DBT, which has not cured the disorder and her life is not perfect. The skills are presented as a means to allow her to get over lesser issues, and to recover more easily after she has a crisis. In articulating this discourse, she uses a strong visual image of the disorder and the use of DBT.

> [progress and getting well] was slow // it took a long time // and still kind of / it it feels a bit like if you fell down a well / and then you had to carve steps out of the mud on the side / every single time with your fingernails // but like / you've done it before / so you can do it again // and you know what works and what doesn't work so. . . / each time you fall down / you can kind of just start / but each time you know how to do it / a little bit more and it makes it a little bit easier and a little bit easier // but like I don't think the falling in the well is ever going to stop // but at least I will know how to pull myself out [Emily] (4.1)

She constructs an identity of a person living with BPD who does not see a time when she will live without having issues due to BPD: *I don't think the falling in the well is ever going to stop*. However, in contrast to life before DBT, she now has a life worth climbing out of the well for. The simile she uses gives strong significance to the challenge of using the DBT skills for people with BPD, but also the huge difference they have made to help recover from a crisis. Iterating that process gives significance to the effort and repetition needed to use the skills, but with continual practice, confidence in her identity as a person who has the ability to use the skills builds.

Like Emily, Maisy also enacts an identity as a skilful DBT practitioner in her daily life (Extract 4.2). DBT skills are constructed as bringing order to Maisy's life, as she contrasts the time before DBT, in which life was chaotic, with the present, in which practical daily issues are handled well. Maisy presents herself as a person who can now cope with daily problems, which previously she would not have been able to manage. However, again, the discourse around the use of DBT is a measured one. She makes a distinction between DBT helping with her life in the present and DBT helping her to come to terms with issues in the past. She is reserved in her praise, using the word *quite* to qualify *useful*, presenting a tension between DBT leading to some social good, but it not being a perfect solution. She holds it accountable for not dealing with trauma in her past, without her doing further work in that area: *I don't think it necessarily deals with the past*.

> [DBT as a therapy] is quite useful // er I think it helps manage your day-to-day life / it makes a lot more sense than what it used to without it // so / it's good with dealing with practical day-to-day stuff / but I don't think it necessarily deals with the past [Maisy] (4.2)

The tension between DBT being effective, but not a complete cure, presented by Maisy and Emily was seen in other participants who also constructed DBT as *not* preventing problematic situations due to BPD. In Extract 4.3, Charlotte also presents herself as a skilled DBT user, who is now able to use the skills to manage difficult times.

> I don't draw on [my self-soothe box] as much as I used to / because I erm / feel like I can use my other skills to get through the situations a lot better now [Charlotte] (4.3)

Self-soothe is a Distress Tolerance skill, used when the client cannot access any of the other skills. Charlotte identifies as still having *situations*, which seems to be used as a euphemistic term for problems leading to self-harm urges, but using DBT skills means that instead of enacting dysfunctional behaviours, such as acting on self-harm urges or using Distress Tolerance to tolerate them, which she did as a beginner, she can now use other DBT skills to *process* negative affect and cognitive processes, to manage them in a more proactive way. She constructs DBT skills as helping her, although they do not remove the urges, but her identity is now presented as confident in using a range of skills to help.

By following DBT practices, Emily, Maisy and Charlotte have accessed the social good of a stable, manageable life, which they were unable to do before undertaking DBT. However, this is in contrast to clients at the start of DBT, whose discourse on DBT was framed by a tension between the significance given to belief in the efficacy of DBT and the skills practices they were able to achieve. In contrast to the more experienced clients, their discourse was inconsistent and less measured, with their initial discourses contradicted by later assertions in the interview.

For Rosie, a client new to DBT, the significance of DBT giving her the social good of a better life is strong and she constructs DBT as *magic*:

> [learning DBT skills has been] er really life changing // it's like magic // it's like something I've never... experienced before / it's like... / it's completely changed my life // it's er it's something that's really really awesome [Rosie] (4.4)

The repetition of the sentence structure, the use of words like *magic*, *awesome* and *life-changing* combine to attribute huge significance to the efficacy of DBT and the importance of using DBT to create the social good of a changed and better life. Rosie constructs all the agency in this change in her life as belonging to DBT. However, the construction of DBT being *like magic* works to create a separation between her lack of explanation of how the changes have been brought about and the experienced clients' discourse of the difficulty of learning the skills, their not understanding them at first and the length of time needed to fully grasp the skills.

As shown in Extract 4.5, when the *magic* discourse was explored with Rosie, by asking about use of specific skills, she gave significance to her expectations of DBT rather than her practice. She was unable to maintain a discourse of the ways in which DBT made a difference in her life, in the same way that the more experienced DBT clients could. For example, unlike Rosie, they were able to explain how they use a particular skill to improve an aspect of their life, whereas Rosie presented herself as the issue: "*I often forget... I don't do / like those skills that often you know?*" which works to maintain her construction of DBT as *magic*.

> Sam: Are you able to use *DEAR MAN*[a] and *GIVE*[b] in your daily life?
> Rosie: No, I often forget // the problem is that I need to have... the sheets in front of me // and er so if I'm not at home / I don't have it / and even if I'm at home / I would have to go to my file / open the file / find the correct sheet and... seeing that there are people out there that have put / a lot of effort into helping people like me [...] / [sighs] I feel really bad sometimes because I don't / when I'm at home I don't do / like those skills that often you know? [Rosie] (4.5)

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[a] DBT teaches a range of acronym-based Interpersonal Effectiveness skills (see Section 2.4.4 for DBT skills) for effective communication in different scenarios. "DEAR MAN" covers a set of skills, assisting with assertive communication and gaining one's objectives, e.g. resolving conflicts or making a request effectively (Linehan, 1993). Each letter represents a word or short phrase describing a sub-skill: **D**escribe, **E**xpress, **A**ssert, **R**einforce, (be) **M**indful, **A**ppear Confident, **N**egotiate. Using DEAR MAN as a mnemonic is asserted to help clients express their needs and wants in a way that is respectful to themselves and others (Linehan et al., 1993), and these skills are practised within group skills classes, for example in role-playing exercises. However, the acronym is long and complicated, and often difficult for clients to remember in a real-life situation, especially when first learning DBT.

[b] GIVE is another acronym-based Interpersonal Effectiveness skill, which concentrates on helping clients to gain and maintain relationships. The sub-skills are: (be) **G**entle, (act) **I**nterested, **V**alidate, (use an) **E**asy manner

Despite her initial discourse of DBT being *like magic*, when later asked about specific use of skills (Extract 4.5) Rosie is unable to maintain a consistent discourse that complex skills like *DEAR MAN* are acquired with ease. DEAR MAN requires the client to work out which skill is appropriate to apply in a given setting (for DEAR MAN, e.g. in a communication setting when a request needs to be made effectively), what the name of the acronym is (DEAR MAN), what the sub-skills that comprise the acronym are and how to apply those sub-skills in a logical order. In contrast to her earlier *magic* discourse, DBT skills are seen as requiring an expertise that she is not yet capable of bringing to them, even at the level of organising and remembering hand-out sheets. The function of this is to maintain the significance of DBT being *like magic* in helping to give her a better life, by presenting herself as the problem, not the complexity or difficulty of the therapy or the disorder being therapy-interfering.

4.4.3 Process of learning DBT skills

Being able to use DBT skills was presented as going through a process: from not understanding; to understanding, but being unable to chose the correct skill; to proficiency in selecting and using the skills. Significance was given to the time the process took, but clients finally built an identity as a person who could deal with the symptoms of BPD. The challenges of using DBT happened throughout the process. However, even after the clients understood the skills, becoming proficient was not easy. In addition, the significance of the process and the building of a new identity as a skilful person could only be seen at the end of the process.

Early stages - in a fog

In the early stages, the clients presented learning DBT as extremely difficult. Problems are constructed as due to personal failings, such as lack of understanding or being unable to practise. Although all clients identified Mindfulness as the most challenging skill, Rosie framed problems with Mindfulness as an individual failing:

> I really struggle with Mindfulness // but that's just personal [Rosie] (4.6)

This followed her initial assertion that DBT was *like magic* (Extract 1.4). To maintain a consistent discourse, she does not construct DBT as difficult or Mindfulness as a challenging skill to learn. Rosie sees her problems with Mindfulness as a personal failing. She uses *but* to introduce the second clause, which works to suggest she is saying something contrary to the first clause. She also qualifies *personal* with *just*, both of which work to reduce the difficulty of Mindfulness and construct the problem as being with herself, but also present Mindfulness as not difficult for others. *Just* also constructs her personal problems as less important. The contrast with Extract 4.4 frames another contradictory construction of DBT; for Rosie, in order for DBT to be *magic*, DBT cannot be challenging or Mindfulness a hard skill, which has to be worked at.

Using the skills in times of distress was constructed as particularly hard by beginners:

> Sam: What about / you know / if you're not feeling great / do you have certain skills that you go to or do you try different ones?
> Suzy: If I'm not feeling great I wouldn't use them. . . if I'm not feeling great I just avoid it [. . .] they are helpful // but as I say, you have to be in the right frame of mind to use the skills // [Suzy] (4.7)

Suzy presents herself as not able to use the skills when she is distressed. For Suzy, being in *the right frame of mind* meant feeling well, not feeling distressed and not under pressure. High affect and emotional dysfunction mean she is unable to use the skills. *I just avoid it* works to construct not using the skills as a personal flaw, rather than the disorder being therapy-interfering. The discourse here works to create a separation between the experienced clients who are able to use the skills in times of distress, as seen in the above section, and the new clients who were not able to access them. Suzy constructs the unstable mood and affect typical of untreated BPD, and which is interfering with the therapy, as her not being *in the right frame of mind*. As with Rosie, there is a contrast between acknowledging the benefit of the skills – *they are helpful* – and her inability to access their help. The switch to the generic *you* works to generalise her comment to other DBT clients, making it less of a personal failing, but applying to all early-stage clients.

All clients made the difficulty of understanding and learning DBT significant, especially at the start of therapy. Experienced clients were able to shape a discourse around how they overcame the initial difficulties. The discourse of DBT acquisition suggests that learning the skills requires more than following a set of instructions; rather, significance was given to following instructions in the context of a changing self-view.

> At first I found [DBT skills] really difficult to [. . .] grasp // especially the Mindfulness / to get my head round that // [Charlotte] (4.8)

The instructions have to be absorbed on a deeper level than, for example, following a set of exercise instructions. Charlotte's use of *grasp* and needing *to get my head round* suggest that DBT skills had not only to be learned, but also absorbed and integrated into her life. The effect of this is to construct the change process as embedded in the learning process, making the learning process more difficult, but also the changes more likely to last.

Similar to Charlotte, Emily's discourse about first learning the skills, gives significance to the early part of the process being challenging and arduous.

> [learning the skills at first was] really hard / it was really difficult to get them like cemented in / and like / I would say probably for like / the first five months at least of therapy / I was like this is pointless [pitch raise] / you're not going to get anywhere [pitch raise] // I'm never going to be able to use this [Emily] (4.9)

Like Charlotte, skills are constructed as elusive and not easily understood. Emily uses the term *cemented in* to show the skills cannot be learned by rote, but need to be assimilated on a deeper behavioural level, which works to suggest a stable foundation to learning is co-constructed. The discourse of beginners' difficulty is framed by describing DBT initially as *pointless*, emphasised by the pitch raise, to give significance to her doubt in her own ability to acquire the skills. The construction of herself as the problem, rather than the difficulty of the therapy, is again dominant: ***you're** not going to get anywhere*. Like Charlotte, Emily constructs acquiring skills as not about 'learning', but about skills bringing a change in her self-image and model of the world. This in turn meant she was able to learn the skills more easily, which works to create skill-learning, and behaviour and cognitive changes as codependent and iterative.

Gaining confidence

Gaining confidence was given significance in the client discourse of learning the skills. The construction of achieving progress in acquiring skills happened through a gradual appreciation that DBT worked and that the skills could help build a better life. This was framed as overcoming ineffectiveness. Again, this works to construct DBT skills acquisition as a process of mindfully changing an habitual response and engaging with a skilful response. Confidence was gained from seeing and experiencing that doing this brought about a better conclusion.

> In the beginning / it was hard training yourself to do something completely different // you're more used to reacting / and suddenly you're trying / you know to tell yourself to do something completely different / . . . and that was really hard to. . . get your head around // but then / eventually after doing it for a while / then you could see the benefits of it. . . // you would have made your situation worse if you hadn't've used those skills [Maisy] (4.10)

For Maisy the discourse of gaining confidence was centred around changing her thought processes. Gaining confidence is given significance in the learning process, overcoming difficulty and changing how she reacts in a situation, presenting herself as having the agency to make the changes: *it was hard training yourself*, "***you're** more used to reacting and suddenly **you're** trying you know to tell yourself to do something completely different*". *The benefits* (i.e. the social good) from DBT made her want to use the skills more. The confidence comes from seeing the results. As noted above, it was only after becoming proficient that she was able to construct the process of learning DBT. The use of the impersonal pronoun *you* throughout serves to make the discourse more impersonal (Kitagawa & Lehrer, 1990) and generalises the activity.

Emily also presented herself as taking time to build confidence. For her, following the steps as laid out in the DBT exercises was seen as significant:

> I think it took me quite a while / to kind of get the confidence to do what actually worked in this quite formulaic way [Emily] (4.11)

She needed to build *confidence* in order to change her behaviour. Doing the skills in a *formulaic way* constructs the strategy as risky, because she did not at that time trust the skills to give her the social good.

For Charlotte, understanding a difficult concept was framed as developing "with practice", with the amount of time this took being given significance in the developing skills discourse. Again, she constructs her lack of ability to understand as the issue, rather than the concept being complex.

> Looking at dialectics, I'd say that's improved over time and with practice // at first I didn't understand the whole concept of dialectics / but I understand a lot more now [Charlotte] (4.12)

Suzy's discourse in Extract 4.21 shows that although she presented herself as having learnt the skills, and intellectually understanding them, she was not prepared to practise them, preferring to stick with what she knew. This works to suggest that she did not have the confidence and trust in the skills to change her mental model of the world. She continued to use the old ways of dealing with thoughts, using a lot of distracting techniques.

Becoming proficient and maintaining skills

The next step was becoming proficient at using the right skills as required in the situation. The clients framed being able to remember the skills as an issue at this stage. There was a clear discourse of using the skills in bad times, which the more experienced DBT clients had, but the beginners did not have. For example, Emily who had been undertaking DBT for >3 years said:

> Sam: What makes you think to use the skills?
> Emily: It's when there is a particularly difficult situation that I can't seem to get through / like it I had a relationship with someone / where they weren't picking up / on what I would call / normal level social interaction cues // so I had to literally spell it out / as awkward things / like what I was trying to tell them // [Emily] (4.13)

Emily gives the DBT answer, then constructs her own version of using the skills. The association between being aware of an issue and using a skill is given significance. She is constructing an identity as a person who is able to use the skills to overcome a situation she would have found difficult in the past: *I had to literally spell it out / as awkward things*.

Charlotte identifies as a client who took a long time to develop the skills. She connects the length of time learning DBT with her ability to be able to use a more productive skill, Emotional Regulation. This skill helps to resolve issues, unlike Distress Tolerance which allows the client to recognise and cope with challenging emotions, but not necessarily to resolve the issues behind them. Making the skills comparison significant shows that proficiency of the more challenging skills is identified as a social good. Charlotte constructs becoming proficient at DBT as changing and stabilising her identity.

> I'd say the effects of using Emotional Regulation are more. . . er long lasting than say Distress Tolerance / that's much more short-lived // and again / it's taken me time / over five years of doing DBT / to erm build up those skills // because before / I just never used those skills very well [Charlotte] (4.14)

She also identifies as someone who found DBT challenging. Again, she does not overtly blame the illness, but she gives significance to the time the skills took her to learn and what happened before. Looking at the way the skills benefit her now, she can compare the effects of two skills modules taught in DBT, with the long-lasting skill constructed as more helpful. She presents herself as changing how she relates to the world and being able to think more long-term. Once the initial part of learning the skills has happened, building the use of the skills can take a long time. Again, as identified above, it is tied in with changing cognitive and behavioural processes.

DBT is also identified as something that has to be continually practised; the social good can only be maintained by using the skills every day. The clients identified this process, although not all were happy about it.

> So / yeah it is a lot more part of me / but I think / as time goes on and the further I get away from when I first initially used them / it's easier to just think / oh I need to use them // you forget that you need to keep training yourself // the practice never stops and / sometimes it would be nice if you think you could just stop // but it's always a work in progress and that can be quite erm // I guess that can be depressing sometimes / knowing that you'll never stop / you'll always evolve your skills at some point [Maisy] (4.15)

Maisy identifies a sadness in having to maintain skills to access the social good. Even though maintaining practice was constructed as important. The open-endedness of skills practice was also identified as *depressing* by Maisy. This works to show that Maisy does not identify DBT as curing BPD, but it is a way of managing it that has to be kept up to access the social good of a 'life worth living'.

4.4.4 Mindfulness as strange, challenging and the foundation skill

Client participants constructed a discourse in which Mindfulness was framed as being particularly hard and the skill which they found most difficult to understand to begin with. It was also interpreted as "strange" by many of the participants.

> Me and another friend // at the beginning we'd be like 'What the hell is this [Mindfulness]?' / we'd be sat there and we don't know what they were trying. . . / we didn't understand what they were trying to say and I think that is / I know I keep saying it / it is really. . . / it sounds really easy / but putting it into practice is hard [Maisy] (4.16)

The strangeness of Mindfulness was given significance by Maisy. She also brings in her friend having the same opinion, which works to add weight to her construction of the strangeness. As seen in Section 4.4.3 the clients framed the difficulties of learning as a problem with their own ability to understand what they were being asked to do or the way they were asked to practise the skills, rather than seeing the therapy interfering nature of the disorder or the difficulty of Mindfulness as the issue.

Emily also presented Mindfulness as an experience that initially did not make sense to her:

> I just didn't really get the get the point // I'm like why are we sitting here looking at a leaf very intently // okay / this is really weird [Emily] (4.17)

Initially, she could not see how the mechanics of Mindfulness would lead to the social good. It was either not explained well or she did not understand the explanation. She was expecting Mindfulness to have a point. However, the point is awareness, which is subtle, and in the beginning not easy to understand. Now that she has more confidence in DBT and realises that Mindfulness helps the other skills by being more aware of thought and feelings, and helps her assess how close to the *edge of the well* (Extract 4.1) she is, so she can now present Mindfulness as helpful.

> [Mindfulness is a] really easy concept / but really hard to get your head around // it sounds so easy / but actually doing it is a completely different ball game // so er I still do practise it every day now // it's much more a part of me // but I think because it's become so much a part of me / er I don't often realise when I'm using it or not / although I use it for the other skills [Maisy] (4.18)

> Really difficult at first // and then once I got the hang of it / I would never say it was easy to use / but because I've been doing it for quite a while now / it's maintaining or trying to maintain the skills [Maisy] (4.19)

The attitudes shown in these two Extracts from different places in the interview works to create a tension between how Maisy feels about the skills and in particular Mindfulness. Maisy again constructs learning Mindfulness as challenging, and even though she is experienced in the skills, she firstly identifies as a competent DBT client: *so er I still do practise it every day now*, but in the later extract, she identifies ongoing difficulties *I would never say it was easy to use*. As in Extract 4.15, Maisy constructs maintenance of Mindfulness as a thing she is *trying* to do, rather than a thing she is able to do.

Mindfulness takes a while to show benefits, and therefore, as shown in Section 4.3.5 with other skills, clients may not have confidence in it as a technique at first. Clients presented practising as one way to build up confidence in themselves and the therapy. Charlotte identified herself as a client who could use Mindfulness to work out which further skill was needed. She also constructed Mindfulness as not stopping her from needing help, but being beneficial in recognising that help was needed and which further skill she should use.

> Sam: Do you think that Mindfulness is helpful in learning and using the other DBT skills?
> Charlotte: I think you start to associate them them together // so I think I'll do the Mindfulness thing // and then I pick the skills that I need / to get out of wherever it is that I need some help with / so // I think yeah Mindfulness definitely supports all the others / because if you can't recognise your emotional state then you can't make an educated choice of what to do with it [Charlotte] (4.20)

Sometimes clients rejected Mindfulness. Suzy, a client with less than a year's DBT experience, presented herself as having learnt the skills and understanding them in Extract 4.21: *now I get it*. In this extract, Suzy constructs herself as a competent DBT client. However, there was a tension between this identity and her later answers, which revealed the skills had not been absorbed. For example, Mindfulness is framed as *dwelling*. In addition, Suzy presents herself as unwilling to practise Mindfulness, preferring to stick with habitual coping strategies: *I would use something different to me // that suits me personally*. The word *personally* works to present her strategy as helping because it is a coping mechanism she has developed individually. *I would use something different* suggests that although she presents herself as a competent DBT client *now I get it*, she has not been able to embed Mindfulness. This tension, and the words: *not skills learned here*, work to suggest that there is a reason that she is not willing to use Mindfulness, which may be a rejection of DBT and possibly the Tuke Centre:

> Sam: How did you find learning Mindfulness?
> Suzy: Hard // It took a long time to do that // but / now I get it //
> Sam: What helped you to erm get it?
> Suzy: Just keep doing it / practising //
> Sam: Is it something you use in daily life? (4.21)
> Suzy: Not skills learned here // I would use something different to me // that suits me personally / because I just don't have time to sit down and dwell for 2 minutes 3 minutes 4 minutes // because I have a busy lifestyle [Suzy]

Suzy constructs the problem as being the time that Mindfulness takes – *I have a busy lifestyle*. She identifies herself as being able to cope by using distraction techniques. For Suzy, because Mindfulness has not given her access to enough of the social good, she constructs the skill as not useful to her, rather than seeing it as something to be integrated into her life. Her construction of Mindfulness as a practice requiring her to *sit down and dwell* works to show the tension between her negative attitude to the practice and that she has not recognised the purpose or the training aspect of the short sitting Mindfulness meditation at the start of the DBT sessions. The short sitting session is to train the clients to use Mindfulness to focus awareness in situations of emotional dysregulation or dysfunctional thoughts, which then helps in using the other skills. Keeping busy can be a distract technique used by clients who do not want to acknowledge or deal with negative thoughts and is often seen in early stage clients. The discourse of not practising Mindfulness, because of her agency in choosing not to, continues through the discussion of Mindfulness and contrasts with the discourse of the more experienced clients who frame Mindfulness as a hard skill to learn in the beginning, which takes a lot of effort, but is worth mastering.

Rosie also struggled with Mindfulness skills:

> Sam: You said you found it quite difficult // is there anything that helps you erm to learn and use Mindfulness? //
> Rosie: [. . . Long pause while thinking] Just someone to do it with me //
> Sam: So / do you like it in the group sessions when everybody does it at the beginning? //
> Rosie: Well / yeah but no // because then you have to give feedback / and I find that. . . / it makes me really anxious because / I'm worried of the judgements / of the facilitators and the other participants [Rosie] (4.22)

On one hand Rosie identifies Mindfulness as a skill that is easy and straightforward, as the word *just* shows *you just bring yourself back*, but she cannot use the skill in moments of distress to help herself at the present time. This works to show the tensions in her discourse of DBT. Additionally, Rosie constructs the other clients and the facilitators as judging her; she does not trust the system or that the skill will help her. She further frames the problem as wanting help from a person, but tension can be seen in her rejecting help of this type in the form of the facilitators and the group. This is constructed as unhelpful: *it makes me really anxious*. Rosie is fearful of doing Mindfulness because she frames it as a skill which she must do correctly, if she gets it wrong, she fears being judged. Although she believes in DBT's ability to help her, she does not trust the situation or those involved. She clearly understands what is required and what the skills do, but she cannot do it herself. Her discourse is one of incompetence, passive acceptance, lack of confidence to try, and distrust.

4.5 Results and discussion – Clinicians

This section examines how the language used in the clinician interviews functions to present discourses on identities, relationships and behaviours in the DBT skills training context.

4.5.1 Clinicians' discourse

The clinicians constructed the following four discourses on DBT skills training:

1. Individualistic, compassionate guides to DBT skills- this involved an individual approach to each client, compassionately helping the clients with constant validation to building their skills and confidence.

2. Stages of learning
3. Why clients struggle
4. How clients can help themselves to acquire the skills

4.5.2 Clinicians' approach to DBT and the clients

Individually-focused

The construction of clients as individuals was dominant throughout the clinician interviews and clinicians resisted any attempt to describe the clients as an homogenous group. Abbey's response to a general question about clients illustrates a typical example of this discourse in use:

> Sam: In terms of clients / are there skills that they find easier or / more difficult to pick up? (4.23)
> Abbey: I think it depends on the individual [Abbey]

This serves to reinforce an individually-focused, humanistic stance towards the clients. Further, as Extract 4.24 shows, because clients are constructed as individuals, clinicians present themselves as consistently flexible in their approach to clients, shown by the use of *always*, customising DBT skills to suit the client, as each client responds differently to DBT and needs a different subset of skills.

> So I always try to say to clients 'try to find the ones which are best for you / and which are most effective for you as well' / so I think again having the range[. . .] of options and / different ones and / encouraging them to try everything // but not to hammer on / if for example *Describe*[a] doesn't work for a person [Leah] (4.24)

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[a] One of the DBT Mindfulness skills.

In Extract 4.24 *best* and *effective* have specific meanings. The skills are constructed as the key to accessing the social good of a better life by the clinicians, *best* therefore carries a meaning of the skills which allow this particular client to stay alive, stop self-harming behaviours and eventually to get better; *effective* presents the skills that fulfil those roles in the best way for the client. This shows Leah's concern for the clients to learn the skills (the mechanisms for acquiring the social good). The language also embodies validation in Leah's encouraging skills use, but stopping when it seems too much for the client: *not to hammer on*. The effect of this is to further construct the therapist as individually focused, balancing between pushing the client, and accepting and validating where they are in the treatment, given their history. This also constructs DBT as a pragmatic approach to the clients and their needs, with regard to the skills.

Compassionate guiding

As well as an individualistic discourse, clinicians constructed themselves as compassionate guides for the clients. Part of the clinician discourse was that, despite the trauma and challenges they faced, the clients' lives and keeping the clients alive were still social goods. They could not change what had happened to the clients, but they could help them to process it in a different way, so that they could have enjoyable lives in the future. They wanted to get the clients to see the social good in them being alive and in themselves. As a supplement to standard DBT, the Tuke DBT clinicians used Compassion Focused Therapy (CFT; Gilbert, 2009) to help with this. Self-compassion was something that clients found extremely difficult. In Extract 4.25, the phrase *raises a lot of debates* constructs an emotive group discussion, with the word *debates* giving significance to the fact that compassion is challenging for the clients, as they do not believe themselves and their lives have a social good, and do not think that they deserve self-compassion.

> so for example we we integrate compassion / into some of the Mindfulness // and that usually raises a lot of debates because / actually / most people doing the programme have spent their lifetime being very self-critical [Catherine] (4.25)

The clinicians presented the clients as struggling with DBT, especially at the beginning, due to their background and history. The clinicians constructed themselves as having an affectionate and compassionate attitude to the clients and their repeated struggles, failures and crises. They kept helping the clients every time they strayed from the DBT path, encouraging them to continue to build better understanding of and beliefs about what having a life worth living and keeping well meant. At the start of DBT, when the clients could not understand the skills or were anxious about using the skills, this happened very often, but even after years of practice clients still needed help.

Building confidence through validation

The clinicians' constructed a discourse of clients self-harming shaped by their knowledge that many clients had suffered prolonged or serious abuse and used self-harming behaviours as the only way to cope with the psychological repercussions of that. Part of the clinicians' construction of helping clients, was to make them feel safe, validated and confident, so that they could stop using old strategies, such as self-harming, and start trying to use the DBT skills. For example, Grace constructs clients' fear of trying to use the skills as a lack of trust in them working, which is why validation was framed as so important.

> Clients are often worried or frightened to try the skills because they do not trust that the skills will work. [Grace] (4.26)

Building confidence was also constructed in terms of validating the clients' emotions and behaviours. Mindfulness was then presented as helping to encourage self-validation.

> [Emotion Regulation] can be / tricky in terms of[…]being able to understand emotional regulation in a way that it doesn't become invalidating to their current emotion / and the intensity of their emotion / I think Mindfulness can underpin / teaching them how to validate themselves and their experiences and that current emotion [Grace] (4.27)

Validating the client illustrates the building confidence discourse in action. At the same time, the expectation of clients trying to *change*, whilst *accepting* how difficult that is, is a central dialectic of DBT, and is very important to the clinicians in dealing with this client group. Without the clients feeling understood and validated, they cannot trust the clinicians or the therapy, as skills can take a long time to show benefits, particularly in the case of Mindfulness.

The discourse for the clinicians was framed around clients needing to feel safe, validated and to have confidence in what the therapists were telling them, before they could start letting go of their old strategies, such as self-harming, and trying new skills. The process of building up the skills and integrating them into the clients' lives was constructed as a dialogue:

> The way that they can then think about it with their problems is that we accept you as you are / and if you don't want this life you're going to have to do something about it even though you didn't cause it // it really helps people to come unstuck // without the acceptance of where they are and how hard it's been for them and the validation of their struggles up to that point // you can put in all the change techniques or suggestions you like / but you're not going to get that far in the therapy. [Leah] (4.28)

Here, Leah presents the dialectical aspect of DBT as important in helping clients to change their view of the world, by validating their behaviour, given their history, while at the same time encouraging them to change. This discourse is shaped by Leah's belief that without clients accepting how awful their past experience has been, it is difficult for them to move forward in the therapeutic process. Leah begins by talking about clients in the third person, but changes to the first person halfway through the description of dialectics: *we accept you as you are*. This functions to include all clinicians and even the Tuke Centre. In addition, direct reported speech communicates authenticity or a commonly repeated utterance (Li, 1986), perhaps replaying a dialogue with one or more clients. This serves to construct the challenging side of DBT, but also shows that the framework is one of understanding.

4.5.3 Stages of learning

DBT skills learning was constructed by clinicians, like the clients, as having different stages. Clients at the start of the programme were seen as lacking in skills, as well as not knowing how and when to use the skills:

> These clients have got a skills deficit / and they need to erm learn the skills / but they also need to know how to apply the skills [Leah] (4.29)

As a formal, professional way of describing the clients' problems, the phrase *Skills deficit* identifies Leah as a clinician. She gives significance to the word *need* to show how important these tasks and the skills are. The *skills* in the first clause are probably general life skills. The second *skills* are DBT skills which are necessary to get through life and the mechanic underlying acquiring the social good. There are two stages: learning and applying. Learning is not enough; clients must also be able to apply the skills in the right place at the right time.

This involves changing their mental model of the world to some extent, as seen above with, for example, Radical Acceptance or the dialectics (see also Extract 3.36). This requires a lot of learning, as Grace narrates:

> I've had experience of working with a client / who had just been doing DBT skills group / and then had a negative experience of DBT // er because the client didn't know how to apply [the skills] [. . .] because if you're just learning skills / how do you know when to actually put them into practice? [Grace] (4.30)

Grace presents an early stage DBT client's problems caused by inexpertly applying one of the skills. This caused the client to reject using the skills. Grace constructs this as understandable for an early stage client. She uses direct reported speech to indicate what she would say to a client and to lend authority to the assertion '*how do you know when to actually put them into practice?*' The construction of clients as initially not understanding the skills or understanding the skills on an intellectual level, but not being able to apply them was dominant throughout the clinician interviews.

Sometimes acquiring the skills requires clients to make changes to beliefs about themselves or the world. Again, the mental models that required some adjustment changed throughout the therapy. Some clinicians presented this as clients being unable to apply the skills, particularly in the early stages of DBT. Skills were constructed as having a theoretical and a practical aspect. For clients further on in the DBT process, (Extract 4.31) Catherine describes how the patterns that clients had previously learnt as a coping strategy led them to find the Interpersonal Effectiveness and Emotion Regulation skills difficult, as they required '*a big change*' from the way clients had previously dealt with situations such as personal relationships.

> I think clients can / pick up the Interpersonal Effectiveness skills // whether they actually then / can translate that and use them / I think is more. . . difficult // because often people have had patterns in their life when they haven't been using those skills / so to actually then / start to use them is a big change [Catherine] (4.31)

Catherine highlights the discourse here by showing that it is not just about teaching the Interpersonal Effectiveness skills, but also helping the clients to make the transition into using the skills in their life and understanding that there are reasons why they are not immediately able to apply that skill. The reference to '*patterns in their life when they haven't been using those skills*' uses clinical language to discuss how the disorder has had a big effect on interactions with others. Relationships are often unstable, with clients using repeated, unhelpful behaviours, which are not planned or thought out. An example might be stormy personal relationships or expecting friends and relatives to know what they want or need and getting upset when they do not. This leads to the client not getting their needs fulfilled or getting what they want though using unhelpful strategies, which leaves others feeling resentful or relationships harmed. The use of '*whether they actually then / can translate that and use them*' works to suggest that there is a process beyond just understanding what is required. Clients have to be able to convert the knowledge into something meaningful, which they can use. This is not because they cannot understand the skill, but rather that, due to the illness and its manifestations, in order to use the skill regularly and well, the clients needs to change their mental model of the world and how they react to it. The word '*actually*' shows that the clinician has seen clients struggling with this and serves to construct herself as an empathetic and 'good' therapist.

The therapists gave significance to there being a big difference for all skills between the clients intellectually understanding them and being able to use them. It has already been noted that clients struggle with dialectics because of feelings of invalidation, and this can also be seen as understanding the concept, but not being able to apply it:

> I think. . . / people get the principle of [dialectics] // but when it comes to applying it to their own life and to certain. . . / situations // they find that hard // So, in the skills group we've er sometimes started having examples of emotion acceptance versus emotion regulation // think about where they are on the scale and what it might look like to move down a little bit / and what they'd be letting go of [. . .] I think they get the idea of it / and they can understand why it's helpful / but when it comes to applying it / that's when they find it harder [Abbey] (4.32)

Again, Abbey frames this dialectic using the difference between the concept and the application, with an example of how it is taught. The dialectic of '*emotion acceptance versus emotion regulation*' is taught using examples from the clients' lives, with them placing themselves on an imaginary dialectic line from one extreme to the other. The clients are encouraged to see how they can move towards the middle, but moving along the dialectic is presented as changing their mental model of the world; '*what it might look like to move down a little bit*' means: what would have to change in the client's mental model of the world for them to be able to accept that their emotion was justified, but needed to be regulated or to be expressed more appropriately? The clients are also constructed as having difficulty using dialectics outside the classroom or therapy situation.

4.5.4 Why clients struggle and why they should keep struggling

The clinicians constructed a discourse framed around the difficulty of disseminating and acquiring DBT skills. However, despite this, they presented a simultaneous discourse of why the skills were a social good to justify why the clients should try to learn them. Acquiring DBT skills was constructed using words associated with conflict or combat, such as *struggle*, *challenge* and *battling*, which worked to construct the extreme difficulties clients face in letting go of their old coping strategies and self-defeating behaviours to acquire and use the DBT skills. The clinicians' discourse included DBT being very difficult for the clients, with a number of different reasons being presented, including the disorder interfering with therapy and the difficulty of the therapy.

BPD is therapy interfering

Part of the clinicians' discourse about why the journey was so hard and why clients needed a lot of compassionate guiding was around the causes and manifestations of the disorder, which make it hard to learn and use DBT. A lot of the clinicians' language concerned the clients fighting to acquire the skills. Words like *challenge* and *battling*, were frequently used to signify that this client group find change and therapy difficult. They also serve to refer to them having to go through conflict to overcome both the manifestations of their illness and the disadvantages and mistreatment that they had experienced in life, which made acquiring the skills even harder. As shown in Section 2.1, people with a diagnosis of BPD were traditionally seen as treatment resistant, because of this. The disorder makes treatment harder, because clients are dealing with both the manifestations and the causes of the disorder; that is, the high emotions and self-harm urges and the trauma/abuse that may have led to the disorder.

Eleanor gives significance to clients at the start of DBT, who can be very difficult to help, due to the severity of the disorder and its behavioural manifestations:

> I think sometimes due to the difficulties experienced with / this population of people / sometimes they can feel like their whole life is just going from crisis to crisis to crisis [taps table to emphasise] // erm and I think there's something in the reality / when you first start working [small laugh/sigh] with someone / you probably are / fire-fighting quite a bit / and just keeping them safe / and alive er. . . [Eleanor] (4.33)

The fire-fighting analogy constructs the condition and its manifestations as complex; helping a client in one area does not mean the whole illness is dealt with, because it often finds another way to flare up and cause destruction and pain. Clients' lives have little space for learning skills or applying skills, because they are so ill, so it is a slow process in the early stages.

Clinicians constructed a discourse around the difficulty of acquiring and using the Emotion Regulation skills, shaped by clients being unable to recognise the emotions they are experiencing. The reasons for this were articulated as twofold. Firstly, due to the nature of the disorder, clients may experience either strong emotions, which take a long time to dissipate; or secondly, clients more rarely may block out all emotional responses, to such an extent that they cannot distinguish emotions or relate typical emotional responses to how they are feeling:

> Emotion Regulation is all about emotions and labelling emotions / which for a lot of our clients can be really really difficult / and often they don't get that or they can't relate that to themselves // with some [clients] / it's the reluctance for any kind of emotional aspect because of their interpretations and beliefs around feeling and expressing emotion / I've had clients say that they would rather operate in life with no emotions // if they could get them all cut out they would [Catherine] (4.34)

The difficulty can also come from clients' '*interpretations and beliefs around feeling and expressing emotion*'. This continues the discourse of difficulties in acquiring the skills being due to the disorder as therapy-interfering. This extract shows the clients' past experiences of emotions being invalidated, of being told not to show their emotions or being told their emotional responses are not acceptable. Catherine's extract follows a very common pattern in the clinicians, of using quite formal clinical language, then explaining or giving an example using more informal language. Here, the discourse is strengthened by giving an extreme example of a client's fear and abhorrence of their emotions, working to illustrate the severe difficulty some clients experience in facing their emotions, in order to learn the Emotion Regulation skills.

Black-and-white thinking

Another hindrance to learning the skills presented in the clinicians' discourses is the clients' adherence to rigid thinking patterns. This can lead on from abuse and invalidation in their early lives. Clinicians frequently constructed the clients as *black-and-white* in their thinking, especially when discussing the dialectical stance or skills which require a dialectical attitude, such as *Radical Acceptance*.

> Erm. . . // I think that often it can be quite a challenge to them to // when they're so focused on on. . . / on it being so black and white / and often there's a lot of grey areas in DBT // and they / you know want to perhaps // again I'm generalising / it to be black and white and to be sort of simplified [Abbey] (4.35)

This leads to difficulties in clients being able to change, because their clear cut view of the world is being challenged, which can be frightening and upsetting:

> Radical acceptance is a really hard one. That always brings up lots for people // erm that's quite a difficult skill to teach or for clients to understand // Erm. . . / that it's not the same as forgiving // it's not the same thing as okay // erm particularly for the client group with. . . // DBT is often used with // where they're quite black and white and quite rigid [Leah]

(4.36)

> The teaching and understanding of // I think [the dialectical stance] is also kind of fundamental to so many of. . . the difficulties / and challenges that this population face when they / they live in a world that they so desperately want to be black and white / it feels much safer if there is a right and a wrong and there's a good and a bad [Eleanor]

Extract 4.36 illustrates the clinicians' discourse of how difficult these skills are to teach, because of the clients' reactions, but it also explains their reactions. In Leah's quote, '*brings up*' works to suggest that it triggers memories, and emotional reactions to abuse and harmful situations in the clients' past, which makes the clients both emotional and resistant, and therefore much harder to teach. Leah uses informal language here to explain the types of words she would say to clients to reassure them about the Radical Acceptance skill, '*that it's not the same as forgiving // it's not the same thing as okay*'. In this use of informal language, in contrast to the name of the skill, she constructs herself as a caring and skilled clinician, who is reassuring the clients that their view about the seriousness of what happened is not invalid. However, they need to change their attitude to things that cannot be changed, and in the way they deal with these issues in the present, in order to gain the social good of 'a life worth living'.

Eleanor also discusses how clients want the world to be simple and certain. The use of colours to describe the clients' rigid thinking patterns and the *grey* reality that is being presented to clients is the language of DBT, constructing herself as a caring but professional clinician. The grey areas, where the truth is unclear, or where several conflicting beliefs have to be synthesised, are disruptive of the clients' mental model of the world. This makes the clients feel unsafe and therefore reluctant to try skills, as the words '*desperately want to be black and white*' show. The use of the word *desperately* works to both highlight the difficulty, but also to show her empathy for that difficulty. The danger is that by confronting the unhelpful mental model, the behaviours the clinicians are trying to prevent may be triggered, making learning DBT skills a slow process.

Mindfulness as a struggle

Mindfulness was presented as one of the most difficult skills for the clients, as their life experiences led them to particularly struggle with this skill. Clients are constructed as casualties of their past trauma, some of whom have spent years blocking out the traumatic events that happened to them, as well as the hurt, shame and anger they feel in reaction to that. Therefore, being asked to sit and observe the thoughts, without blocking them, even in a short Mindfulness exercise, is incredibly hard. The clinicians constructed Mindfulness as a concept which was easy to explain, but the skill was difficult for the clients to practise. Eleanor discusses one way in which this difficulty manifests in learning Mindfulness:

> To be able to separate yourself from your your experiences / that are at times so horrendous and so difficult to / kind of experience them / as more of an observer [using Mindfulness] / is really really difficult [Eleanor] (4.37)

Eleanor refers to events in the clients' past to explain why it is difficult for the clients to learn Mindfulness. If they are scared that the result of what they are being taught is going to make them face the thoughts they have spent years avoiding, then resistance and challenges are understandable and it is also understandable that they will not be very good at it. Her mix of clinical language here: *experience them as more of an observer*, with less formal language *so horrendous and so difficult*, again works to present her as an empathetic, but professional clinician.

> I think...probably the Mindfulness skills in some ways are the easiest / because ...they're not kind of complicated in themselves to explain // but then on the flipside actually / a lot of stuff comes out of Mindfulness / which is is sometimes quite difficult to explain / cause it is a kind of concept [Catherine] (4.38)

Mindfulness as a *concept* is constructed as challenging to teach and for the clients to acquire. Catherine presents the difference between the basic idea of mindfulness and its applications to BPD and in DBT. The things that cannot be written down and explained are the things that occur to the clients through actually doing the practice and integrating it into their lives. '*Comes out of Mindfulness*' means the rest of the therapy relies on Mindfulness, because clients need to know how they are feeling and thinking to be able to access the correct skill.

> [Mindfulness] would be the skill the clients find the hardest to understand and / in some ways then that can add a different dimension in terms of your ability to teach when / A: there can be a lot of resistance // or B: just a real kind of lack of understanding of the concept of Mindfulness [Leah] (4.39)

> Mindfulness I think are hard skills to teach / I think they only get it / only through a lot of practice [Catherine] (4.40)

The clients' life experiences of abuse lead to them struggle with the more abstract skills. Eleanor discusses how this manifests in learning Mindfulness:

> I think a lot of people actually don't really understand Mindfulness / so I think it kind of gets tied with meditation or kind of relaxation erm / and it's a really... in many ways quite an abstract concept erm // and again thinking of our quite concrete learners erm / that's really difficult and to be able to separate yourself from your experiences / [Eleanor] (4.41)

Eleanor constructs the clients' identity as '*quite concrete learners*'. This works to show the tension between clients not being able to easily understand abstract ideas and preferring to learn using examples, with DBT, which encompasses a number of concepts for clients to understand. As a quality of consciousness, mindfulness cannot be demonstrated, only discussed. Thus, it is framed as difficult for the clients to learn Mindfulness, as examples are not possible.

4.5.5 How clients can help themselves to acquire the skills

Self-compassion

> So far I think [self-compassion] has been a difficult one / because... I think [the clients] can recognise what's needed / but it feels so far away... // For those particularly those who are just joining the group // For those who are a bit further on / I've noticed that they're a bit more willing to consider [self-compassion] as a concept [Grace] (4.42)

Self-compassion is identified as a skill which can help clients in acquiring DBT. Although it is presented as initially difficult, clients were seen as able to engage with the skill differently after attending DBT for a while. For beginners, this skill *feels so far away*; for more experienced clients, *those who are a bit further on*, compassion becomes more possible. This serves to construct learning DBT as a journey during which which skills are learnt, but also during which the attitude of the clients changes, as their confidence in DBT and their own abilities grow.

Compassion is very important in giving clients access to the social good and also helps with the other DBT skills. Understanding compassion is not difficult, but applying self-compassion is very difficult for this client group. Grace is again framing the discourse in terms of the clients understanding what they have to do, but being unable to apply the skill. *[I]t feels so far away* works to present the beginner clients as feeling full of shame, worthless or undeserving. At first, they find it almost inconceivable to even attempt being self-compassionate. However, after a few months, clients start to gain confidence and are *a bit more willing* to try out some of the exercises or discuss how it might help with their individual therapist. This again gives significance to there being a large distance between the beginner clients and the social good. Before they can begin to access the mechanics, they must build up some confidence in themselves (this is explored in more depth below), with Grace's use of the word *work* suggesting that a lot of time and effort are needed.

How Mindfulness skills can help

Whilst Mindfulness was constructed as difficult for clients to learn initially, it was also seen as a vital part of the discourse in helping the clients to learn the skills. Significance was given to paying attention to the emotions, somatic feelings, thoughts and behaviours, to enable clients to determine whether a skill was needed, and if so which.

> S: What helps clients new to DBT to incorporate Mindfulness into their lives?
> I suppose it's really explaining why we use mindfulness // How we spend a lot of time in the past or worrying about the future[. . .] it's trying to explain / perhaps what's going on for them / it might help or give them a break from their ruminating about suicide // give give examples and also give them lots of opportunities to practice // lots of different ways of practising Mindfulness / because something might work for some but not for others. [Abbey] (4.43)

For Catherine, practising outside the group setting is seen as vital in clients' acquiring the skills.

> At the start of every group we practice a Mindfulness [exercise] and I think that's vital that / that's in every group and / and that forces people to practice[...] clients that pick it up the most and / and it's most useful to also are committed to practising out of session [S: Right] and you can really see the difference in clients that / practise out of session and the ones that don't // the more they practise the better that's key with it [Catherine] (4.44)

Further in the journey, the part Mindfulness plays in other skills is given significance:

> But then, the place where they actually start to recognise the value of it, is when you start to chain with clients / and they can really see, "this might be the place where actually if I'd been more mindful, at this point I might have noticed that I was getting quite stressed" / or "if I'd been more mindful I'd have noticed that this person. . . I was feeling irritated by them and then I could have chosen to do something differently in the situation" / or "I might have noticed and recognised the emotion and just accepted that moment."[Leah] (4.45)

Leah identifies the difference that Mindfulness can make to the clients. This works to construct Mindfulness as key to implementing the skills. In pointing out where it would have helped, she is constructing it as practically useful in helping clients to gain the social good of a better life.

> erm you know if a person / kind of can't stay present and have insight into the types of cognition and physical experiences that they are having / well how are you going to regulate your distress when you don't even. . . / you're not even connecting to the distress / how then can you recognise it in order to implement the skills to regulate it/ // if you're not in tune with your body how do you know what your body is wanting and needing? [Eleanor] (4.46)

Swapping from third person to second person by the clinicians in the interviews was very common and serves to make the discourse more impersonal and general Kitagawa & Lehrer (1990). In the dialogue above, Eleanor says the same thing twice in the last few lines, firstly using clinical language, then using more informal speech, employing language she might use with a client, reinforcing her identity as a clinician.

Grace gave significance to the use of Mindfulness to temper emotional reactions without repressing them. This works to construct emotional dysfunction as one of the problems clients are dealing with; it also reinforces that DBT does not want to stop emotional responses completely, rather it tries to teach clients how to lessen the affect slightly, so that they can respond appropriately to self-harm urges or other challenges.

> S: What helps the clients to overcome the invalidating aspect [of Emotion Regulation]?
> G: Mindfulness is really helpful in teaching them how to validate themselves and their experiences and emotions // and I kind of always really emphasise that we are taking the edge off it because at the moment it's too intense for you to think, in a way that's going to be kind of thinking / so we need to reduce the intensity / in order for you to then respond in a way that is going to be more helpful / because when any of our emotions are that intense we don't make wise decisions [Grace] (4.47)

Again, the discourse is around the expectation *not* of stopping or preventing the intense emotions, but training the client to manage the emotions and the responses, thereby allowing them to have a better life. This is another example of switching to first person: *so we need to reduce the intensity / in order for you to then respond in a way that is going to be more helpful.* The use of *we* works to show Eleanor's compassion and wanting to work with the client to help them (this is discussed below). *Taking the edge off* the emotion is an interesting use of idiom when many clients self-harm using sharp instruments.

4.6 Discussion

4.6.1 Research question

The overall research question for this study was: How do clients and clinicians experience DBT skills training?

This was split into 2 sub-questions:

- How do DBT clients experience learning and applying the four DBT skills?
- What is the clinicians' experience of delivering the four DBT skills in terms of clients' needs?

I give an overall answer to this and then examine it more closely through the constructed discourses. I then look at the design implications from the information arising from this study.

How do DBT clients experience learning and applying the four DBT skills?

The clients struggled a lot to understand DBT at first, and once understood, they struggled to integrate DBT skills into their lives. Once skills were acquired, maintenance was required to retain the skills and the benefits.

Clients in the early stages strongly believed the therapy would work, but they were unable to articulate their agency to bring this about and how they could move from not understanding and not being able to access the skills to DBT working for them. The clients' self-perceptions and discourses can hide the complexities of recovery, particularly in the early stages. Therefore, it is important to speak to clients at all stages in the therapeutic process, to understand the different requirements at each stage.

What is the clinicians' experience of delivering the four DBT skills in terms of clients' need?

Clinicians constructed themselves as compassionate guides to DBT skills training in terms of encouraging confidence and self-compassion in clients when using DBT. The clinicians saw BPD as a barrier to learning skills, as it is pervasive in clients' lives and causes therapy-interfering behaviours, which mean the therapy can take a long time to show results. Overall, there were differences in the client discourses and the clinician discourses. These were apparent when attributing agency to make changes, as well as in discussing some aspects of DBT that were seen as more important by the clinicians than by the clients, discussed in Section 4.6.5.

The results show that the experience of DBT skills training was not straightforward. DBT was constructed as a process in which change and acquiring skills were interwoven, with discourses of identities in flux and BPD making it more difficult for clients to acquire skills and make changes. Acquiring the Mindfulness skill, whilst challenging, was constructed as key to unlocking the social good of using the skills for a better life.

Although some new results emerged, my findings also some show similar discourses to those found in previous studies. For example, the impact of DBT on the clients' ability to manage their emotions was found in a lot of previous studies (Perseius et al., 2003; Cunningham et al., 2004; Tsakopoulou, 2009; McSherry et al., 2012; Barnicot et al., 2015). In addition, the change in attitude towards DBT that was seen, from being unsure to developing confidence in being able to use the skills to manage strong affect and a variety of difficult situations, then from that the gradual ingraining of the skills with practice, was reflected in a number of studies,for example, Barnicot et al. (2012).

DBT as life-changing was also reported in Cunningham et al. (2004), with the skills helping clients to better cope with life.

4.6.2 DBT as a process

In answering the overall research question, both client and clinician groups presented Mindfulness as the most challenging skill, but also, once understood, the skill that most helped to embed and use the other skills. Both also saw a lot of practice as the key to acquiring the skill.

Both the clients and clinicians framed DBT skills training as a process or journey, with different stages. The idea of DBT being a journey was also seen in Desperles (2010), with a similar optimism and confidence in clients' discourses around their ability to cope found at the end of the treatment, which was not present at the beginning. This shows that DBT is efficacious in helping clients, but that there are steps along the way which must be taken into account. Both clients and clinicians discussed DBT having different steps of understanding. These were broadly: gaining an intellectual understanding, gaining a conceptual understanding, becoming proficient at the skills and maintaining the skills. In terms of requirements, this means that reflecting a journey in the URD would be acceptable to end-users and stakeholders.

As seen in a number of previous studies (Cunningham et al., 2004; Hodgetts et al., 2007), there was a relationship between the amount of time undertaking DBT and the ability to use the skills. This developed along a number of dimensions, including confidence, ability to remember and recognising the skills' effectiveness. This is also similar to my findings from Study 1; however, the time the clients spent at each stage was something of a surprise. DBT produces results, but change is a slow process, needing a lot of caring reinforcement. DBT being a slow process and hard work was also seen in Perseius et al. (2003). This slow progress explains why it is recommended that DBT clients take part in the therapy for a minimum of a year, and two years if possible. At the beginning, clients discussed how difficult it was for them to understand what is being asked of them. In addition, as seen in Perseius et al. (2003) is very hard for the therapists in the early days, as no construction of a better life can happen when the client is constantly in crisis. As in this research, Cunningham et al. (2004) asserts that the early days of DBT focus on stabilising the client, gradually reducing the self-harm and starting to bring down the emotions. In addition moving from a theoretical understanding of the skills to being able to use them in daily life was also seen as problematic by clients.

In the first 12 months, as well as lacking confidence in the therapy, clients did not always understand what was being asked of them, particularly with the more conceptual skills, such as Mindfulness and taking a dialectical stance. As also found in Hodgetts et al. (2007) in the early stages, some clients took to DBT straight away, whilst others initially felt disbelief or distrust in the therapy, particularly Mindfulness skills, which were unfamiliar to them. Although DBT skills are explained step-by-step in the group workshops, at first they were seen as elusive by the clients. Most clients initially did not understand how the exercises connected to treatment of the disorder and found the exercises strange, particularly Mindfulness, as also seen in Hodgetts et al. (2007). The clients could then start to intellectually understand them, but the underlying concepts often take a long time to become fully embedded. The clinicians recognised that in the first 12 months learning the skills is a slow process and they need to work to help the clients build confidence and trust in the therapy and themselves. The clients' discourse highlighted that DBT was challenging, which made the process slow. However, despite the difficulty, for the most part, clients continued to try to acquire the skills, which suggests that the social good of the skills providing a better life for the clients was important enough for them to persevere.

4.6.3 Change and acquiring skills are interwoven

The clinicians and some of the clients articulated a discourse of acquiring DBT skills involving a shift in beliefs about themselves and the world. They gave significance to not being able to acquire the skills fully until they had changed in some way. They framed cognitive and behavioural changes at each stage in the process as making the skills easier to understand, acquire and use. In acquiring the skills, the clients went through a metamorphosis in their attitudes, self-belief and understanding of the world. Acquiring the skills is not like acquiring practical skills, like how to cook, for example. Clients were being asked to learn and absorb new ways of thinking about, experiencing and responding to the world around them.

4.6.4 Client discourse changes throughout DBT

The discourse shows a tension between the clients wanting the social good of a better life, which DBT is seen as providing, and being able to use the skills to gain it. The tension manifested in conflicting statements. For example, beginners asserting that skills had been learnt, with later statements revealing this was not the case. People with a diagnosis of BPD have an unstable self-image (Dimidjian & Linehan, 2003), which suggest that this aspect of the disorder could make the skills more difficult to learn. This leads to inconsistencies in the ability to describe how skills can be learnt, seen in the early stage clients, which masks the complexities and difficulties of learning the skills. Malson et al. (2004) found similar tensions and inconsistencies in anorexic patients discussing treatment. They suggest that this signifies that clients' self-perceptions can hide the challenges and nuances of recovery, as anorexia is another disorder where self-perception is often unstable.

The beginners' discourse has implications for the requirements for a DMHI. In the early stages, skills need to be very carefully explained and large amounts of validation are necessary. In acquiring the skills, the discourse of the more experienced clients, showed they were able to construct their progress through the therapy after some time undertaking DBT. Acquiring the skills was interwoven with a change in their mental model of the self, as seen above. Therefore, the experienced clients were able to articulate in a more consistent way how they had felt at different stages of the therapy. However, in the empathic, experience-centred UCD approach, all accounts are valid and using the dialogical approach, all points of view need to be respectfully considered. In not being able to fully narrate how they can access the ability to use the skills, the beginner clients' discourse revealed something important for the requirements, which needs to be supported.

In some more experienced clients there was a tension between being a competent skills user and finding practise difficult, boring or depressing, which suggests some clients were still at the stage where mindfulness was another thing to do. Unlike the non-clinical mindfulness practitioners, Mindfulness skills had not become fully integrated into their lives, even after years of doing DBT. This again reflects the severity of BPD and the effect it has on the lives of those with a diagnosis. Experienced clients finding that the disorder still made accessing skills challenging at certain points, was also found in experienced clients in Barnicot et al. (2015).

4.6.5 Differences in client and clinician discourses

There were some differences between the clinicians' and the clients' discourses, mainly in what was given significance. The clinicians' discourse framed the clients as having a very rigid approach to life, due to their past trauma, which made them resistant to change when learning DBT skills, and therefore learning the skills took a long time. Generally the clients did not have awareness of this rigid approach, rather they framed time taken to acquire skills as not understanding what was required of them.

In addressing this, clinicians saw dialectics as vital to address the black-and-white thinking found in people with BPD. However, clients did not consider dialectics to be very important. There was also a client discourse of not understanding dialectics until they were proficient in DBT, reflecting a change in mental model of the world allowing the ability to understand dialectics or be more open to a flexible approach. This was also seen in (Hodgetts et al., 2007).

Experienced clients looking back to when they began DBT articulated not being able to see the value of the DBT skills or what they were doing, which changed with experience. However, the clinicians could construct the bigger picture and understood that a life worth living was possible. They responded with compassionate, individualistic guiding of the clients to use the skills. In bringing about change, compassion was seen as very important by the clinicians, but the clients struggled with this. The clinicians discussed compassion as difficult for clients because of their history. Using skills like self-soothe (a Distress Tolerance skill requiring self-compassion) was difficult, as the clients did not identify themselves as worthy of the social good.

This serves to reinforce an individually focused, humanistic stance towards the clients. However, this conflicts with a UCD point of view, which looks for user groups and traits in users, which designers can focus on. This is further discussed in Chapter 5 and Chapter 7.

4.6.6 BPD - therapy interfering and masks progress

The clinicians attributed the challenges of disseminating and acquiring the skills to the nature of the disorder. The clients were more likely to see challenges in learning as a personal failing, with themselves as the issue in not understanding DBT, rather than having the clinicians' discourse of seeing the disorder, rather than the person's character, as therapy interfering and making the practice of DBT skills more difficult.

The clients' description of the difficulties they had had at the beginning of DBT, and the construction of this as a personal failing suggests that clients have a negative self-view. This is consistent with the literature which reports that individuals with BPD have a more negative self-view than other clinical populations and healthy controls (Vater et al., 2015). The less experienced clients blame themselves for not being able to understand or practise the skills, rather than being able to step back and see the skills or changing behaviours as inherently difficult or attributing problems to the manifestation of the disorder, especially in the early days. They find progress hard to see and validation and praise can be construed as trite or insincere

The effort of learning the new skills involves having the courage to give up old coping mechanisms, like self-harming, but this often means facing very painful and shame-inducing thoughts, which may lead to a relapse. Gradually, clients start to recognise their emotional, physical and mental states and understand that they are temporary, to help balance the longer term consequences of indulging in self-defeating behaviours, because they feel bad at the current time, by using the skills.

4.6.7 Mindfulness is the key

As the Background and the previous study showed, mindfulness is very good at *breaking automatic responses*, whether that is a strong emotional reaction, an urge to self-harm or dealing with an interaction. This is one of the reasons why Mindfulness is the core skill in DBT. It affords the clients some distance. However, for clients who use distract skills or keep constantly busy in order not to think about their abuse or mistreatment, sitting still and allowing thoughts to come into their head without judgement or trying to change them has the potential to be frightening and/or distressing.

One reason that Mindfulness was seen as more difficult was the strangeness of the practice to those who had not been exposed to meditation-type practices previously. Whereas the participants in Study 1 had taken up mindfulness deliberately, the clients had undertaken DBT because the symptoms of BPD were endangering them. They did not necessarily know the components of the therapy. The non-clinical participants' discussion of mindfulness (Study 1) revealed a much more consistent discourse about their practice, experience and enjoyment of mindfulness than was found in the clients' discourse, where there is a tension between practising mindfulness and enjoying the practice, even in the experienced clients.

Part of Mindfulness in DBT is acquiring wise-mind: a skill to help clients make the right choice, to use a combination of their emotions and their logical minds to make wise decisions (Linehan, 1993), such as using a skill to help them in a challenging situation. There is a discourse of Mindfulness as an enabling skill; the skill which allows clients to use and be able to us the other skills. Mindfulness is a very important skill to the clinicians and the clients, but also very hard for clients to learn and understand what is being asked of them. However, without Mindfulness, using the other skills becomes much more difficult, partly because the clients will not be checking their thoughts, feelings and emotions to pre-empt a difficult situation where a skill is needed (Linehan, 1993). In addition, the choice of which skill to use is aided by the objective viewpoint that Mindfulness brings.

Mindfulness as the DMHI focus

As discussed above, after the interviews were analysed, Mindfulness emerged as the key skill and the most difficult to learn. The clinicians thought that practise was one of the most important things to help the skill develop. Whilst the other skills are more practical in nature, Mindfulness as a concept and something which cannot be demonstrated, is much more challenging to acquire. After analysing and considering the data and discussions with my Tuke supervisor, it was decided to concentrate on Mindfulness as the main skill to be developed in a DMHI, as this was the core skill. If the clients could grasp Mindfulness, the other skills were then made a lot easier, as were the changes in their mental model of the world, which helped to lessen the self-defeating and therapy-interfering behaviours. In addition, DMHIs delivering skills to clinical populations were seen as better being split into a number of smaller apps by David Kavanagh (2016, *personal communication*).

4.6.8 Discourse analysis and thematic analysis

Thematic analysis (TA) as used in Study 1 is a more rigorous analysis method, as it has set steps for identifying codes and building them into themes or patterns in the data. The difference between a discourse and a theme is that a discourse is the direct utterances made by the participants and a theme is the categorisation of these utterances into a theme or sub-theme (Boyatzis, 1998). The two methods of analysis are complementary because they focus on different aspects in the data.

The view taken in this research is constructivist - speech is used to construct our versions of reality and our perceptions of reality are a product of socio-cultural processes. In producing requirements, I wanted to understand how the clients and clinicians were directly constructing their experience of DBT skills training with the words they used. So, using discourse analysis did allow me to get in depth knowledge about the clients experience. However, most qualitative methods should show an overlap in their findings, although they may be viewed form a slightly different perspective (Jaspal, 2020).

I did find some extra data, which I might not have been able to collect using TA, for example the subtleties of the different stages. The clients do not go from beginner to learning to learnt. The skills have different understandings at each stage, then the clients have to develop confidence, then the skills have to be absorbed and integrated into the clients' lives. The other discourse which might not have been so apparent was the inability to describe how skills could be learnt, seen in the early stage clients, masking the complexities of learning the skills. However, it did not take a lot more effort than TA, and now I have experience of doing this, which I can take to other projects.

4.7 Design considerations

In this section I set down some ideas for general guidelines for the design of a DMHI for DBT Mindfulness, at what might be called a 'pre-requirements' stage. By this I mean informally stating requirements and principles, as opposed to the detailed analysis and formal requirements generation and specification which these ideas form the basis of, found in Chapter 5.

From answering the research question, two of the thesis sub-questions can be addressed. Firstly, how Mindfulness is acquired, and secondly, What are the requirements for a DMHI. There were a number of implications for the design: DBT as a journey with stages, means that the app needs to adapt to the different stages, with not only different exercises, but different levels of support and different ways of expressing the *acceptance and change* dialectic. Other design considerations are discussed below.

4.7.1 BPD therapy interfering

In terms of the implications for a DMHI for DBT Mindfulness this would mean trying to give the clients considerable support, but also not over-burdening them with lengthy exercises at the beginning. Thirty seconds of mindfulness might be all they could manage. But this can be built up and lengthened.

4.7.2 Cognitive and behavioural changes are intertwined

Cognitive and behavioural changes, stopping behaviours and acquiring the skills were constructed as being intertwined, particularly by the clients, which suggests that the two build on each other and must both be supported in a DMHI.

4.7.3 Lack of trust of DBT

Clients may initially mistrust the therapy, even though they also have a strong desire for it to help them become well is an important thing to understand in designing a DMHI, as it means that the app will need to promote confidence, not only in the DMHI, but also in the therapy underlying the DMHI. It also means that support from clinicians may be very important in early stage clients using the app.

4.7.4 Useful but needs to account for difficulty

The implications of this are that a DMHI to help deliver skills would be a useful addition to the clients' and clinicians toolkit, but that any DMHI needs to take into account how difficult it is to make progress for the clients.

4.7.5 Tracking progress

In Study 1 and Study 2, participants asserted that seeing the benefits of doing mindfulness helped them want to continue to practise. Adding a tracker to a DMHI would allow clients to note effects and times when Mindfulness was beneficial. This is very important to the clients in helping them to keep practising and develop confidence and trust in DBT Mindfulness. A diary function may help clients to keep track of advances they make and show them that they are making progress, rather than a function which showed times or amount of time when they had been mindful, which might trigger clients' shame at their lack of practice.

4.7.6 Short activities

Study 2 showed that the DBT clients struggle, particularly at the beginning of the therapy, when the old ways of coping are being discouraged and the new ways are not yet embedded. Therefore, it is very important to support the clients as much as possible, particularly in the initial stages of learning DBT. One way to do this is to break down the Mindfulness exercises in the DMHI into as short a time as possible, in particular for beginners, offering very short-length activities. These short mindfulness exercises could possibly be added together to form longer exercises, as seen in the EMOTEO app (Prada et al., 2017), if the client felt able to continue.

4.7.7 Taking account of place in the process

Study 2 revealed that with practice, confidence in DBT skills' use grows. Thus, a DMHI will need to give a lot of support to beginners, including their expectations. However, experienced users may also still need support, as their confidence in their ability to use the skills grows they may take on more personal challenges, such as longer mindfulness exercises or different types of exercise, with prompting for these. Therefore, supporting more experienced clients will take a different form from supporting beginners. At the more experienced stage, reminders to keep practising, perhaps using a tracker may be introduced. Again using a diary for clients to record sessions and their progress, in terms of where Mindfulness was helpful, could be a useful addition.

4.7.8 Explain why DBT and Mindfulness are helpful

Both Studies 1 and 2 saw that mindfulness skills and mindfulness benefits increased with practice. In addition, Singer & Engert (2019) revealed that the types of mindfulness training has a bearing on physiology and behaviour. Therefore, a DMHI may needs to explain the benefits of Mindfulness the importance of practice and the time spent doing it, and information about the types of practice. This could take different formats. The Pocket Skills app (Schroeder et al., 2018) used *eMarsha* for this purpose. This is a conversation agent modelled on DBT founder, Marsha Linehan. However, some clients in Study 2 voiced strong opinions about not having any human or even non-human avatars present in a DMHI. A possible way to add explanations, without clients having to read lengthy text, but without too much human presence could be to use a voice to give explanations. Another option may be to include interviews with more experienced users for beginner clients to watch if they wanted more information.

4.7.9 Reminders to practice

Clients may need a lot of reminding to practice. They may also benefit from being reminded *why* they are doing DBT. A DMHI should try to give the clients agency. However, at the beginning, as seen in Study 2, clients feel very muddled. A DMHI should not add any more stress to what is already a very stressful process. Therefore, this would need careful consideration.

4.7.10 Access to Crisis Plan

As well as having short, easy exercises, clients should be able to add their Crisis Plan to the app so that it is easily accessible if they feel strong self-harm urges. A Crisis Plan contains phone numbers and contact details for doctors, hospitals, therapists, and other people offering support, as well as a plan for the client to follow in a crisis. This is often helpful as the client may not be able to think clearly when they hit a crisis point. The crisis plan may also suggest helpful activities, such as listening to a piece of music which helps calm the client or doing another activity. Crisis Plans are individual and each one is different.

4.7.11 Validation

Study 2 highlighted that validation is important throughout the DBT journey. A DMHI should therefore give validation to the more advanced clients as well as beginners, reminding them that they are doing a good job and encouraging them when they are not mindful. However, too much praise may be unhelpful, if it is seen as condescending.

4.7.12 Stages

A DMHI needs to recognise that there is a skills learning process with stages, as seen in Study 2. The differences in clients' construction of identities and activities depends on where they are in the process. A DMHI needs to cater for where people are in the process, because they have very different experiences and understandings of what is being asked.

4.7.13 Non-judgementality

In addition to encouraging practice, A DMHI should encourage non-judgementality, to make clear that boredom is just a thought, dislike is just an emotion. Clients do not have to like the practice, they just have to do it. This may help with tolerating stronger distressing thoughts and developing better emotional regulation (the goal of DBT).

4.8 Conclusion

This chapter details a study to gather information to inform the design of a DMHI to deliver DBT skills to clients with a diagnosis of BPD. In the study, DBT clients and clinicians were interviewed about their experience of DBT skills training. The data was analysed using Discourse Analysis (Gee, 2004, 2010).

In the DBT Service at the Tuke Centre and the Retreat, reducing or stopping self-defeating behaviours and being well enough to have to have a chance at a good life are seen as the main social good by the clinicians and the clients. The clients begin DBT having developed attitudes, values and strategies to get them through a life which has faced considerable trauma. The attitudes and strategies discussed in both clinicians' and clients' discourses include being reactive to a situation because of not being able to plan or see long-term outcomes, rigid thinking and having an unstable self-view. This often leads to harmful behaviours which, rather than helping them, often make things worse. These included self-harming, drug and alcohol abuse and other behaviours which endangered them. The skills they have at the start are ineffective or have limited effectiveness. However, they do not know how to do things in a better way or which skills would help in which situation. The clients' and clinicians' discourses around agency, confidence, learning the skills and BPD being therapy-interfering show that acquiring DBT skills goes hand-in-hand with recovery and managing the disorder. This includes clients changing and stabilising their self-image and acquiring a mental model of their own abilities and agency in using the skills, before and after a crisis.

The clients needed to work with the clinicians to construct themselves as well people, as well as to construct what their behaviours will be; how they see themselves; how they react in new and old situations; how they understand the disorder and its presentation in the form of unacceptable behaviours; and, what being well means for them. This may mean that occasionally the clients still struggle, but less frequently, and having developed the skills to know how to cope and the confidence that they are able to recover. The clients' discourse was about gaining agency, but they also had to learn to think about the world in a different way, changing their values and self image.

4.8.1 Answering the research questions

The knowledge gained from this study helps to answer all four of the sub-questions to the main research question which are set out in Section 1.4.

The main sub-question it helps to answer is *How do non-clinical practitioners and DBT patients achieve and maintain mindfulness skills and practice?* There are a number of issues which help to answer this question and they are further discussed in Section 7.3.1. The main points are that firstly, non-clinical practitioners had chosen to undertake mindfulness and they knew what to expect when they started the course or started their practice. Secondly, as the non-clinical practitioners were learning and embedding mindfulness into their lives, without also having to deal with a severe mental health disorder, they developed mindfulness skills fairly quickly. This can also be contrasted with the clients' experiences of acquiring Mindfulness skills taking a very long time. Thirdly, on the whole, the non-clinical practitioners were able to be compassionate and especially self-compassionate. This is important in times when the inner voice is self-critical or harsh, or when mindfulness is not used or not practised.

The second sub-question asks *What are client requirements for a DMHI supporting mindfulness skill acquisition as part of DBT?* In the next chapter the data from this study (Study 2), including the ramifications described in Section 4.7, feed into constructing a User Requirements Document (URD). This details the user requirements and the reasons behind them, including using adjusted UCD methods and models. The material generated in this study, supplemented with material from Study 1, directly answer the research gap in using UCD to design mindfulness-based DMHIs for people with severe mental illness as documented in Study 3.

4.8.2 Looking ahead to the next chapter

In the next chapter, the results of this study supplemented with material from Study 1 are used to construct a URD which a design and development team could use to construct a DMHI for DBT Mindfulness. The design approach is given in detail followed by a discussion of how the UCD method was adapted for this case study and what was successful or not in the techniques used.

Chapter 5

Designing a User Requirements Document

5.1 Introduction

The *Understand* step of the UCD process (Section 2.2) carried out a systematic exploration and understanding of user and stakeholder context, experiences and behaviours. This was done in Study 1 (Chapter 3), which highlighted some of the helpful techniques and difficulties in acquiring mindfulness in a secondary proxy non-clinical population, and Study 2 (Chapter 4), which revealed how the clients and clinicians experience the delivery and practice of DBT skills training, and made some suggestions about how this might translate into a DMHI for DBT Mindfulness skills. In this study, I move onto the next step in the UCD process, *Define*. In this step, the research data is synthesised and analysed to identify patterns and insights into user behaviour to inform the design process. Thus, in this chapter, I detail the translation of the results obtained in the previous two studies into a User Requirements Document (URD) for an adjunctive DMHI to help deliver DBT Mindfulness skills. In this chapter this translates into models of the end-users and the context, as well as user requirements which the DMHI design / development team should take into account.

This chapter starts by defining the nature of requirements. It then looks at the creation process for the design artefacts I produced. Finally, I reflect on using UCD as a process in this context.

5.1.1 Requirements approach

A URD is used to specify the requirements the user has for the product which is being developed. It identifies user expectations about the product and how it should perform (Gulliksen et al., 2003). A URD often contains UCD documents such as personas (Cooper, 2004), user experience maps (Kalbach, 2016) and scenarios (Rosson et al., 2002) (personal experience through work as a senior user researcher). These are tools which can be useful in bridging the gap between researchers, designers and software developers, helping them to understand the context from which the user requirements flow and how they might be implemented in the *Design* stage of the UCD process (Section 2.2.4).

I produced design artefacts in the form of personas, user journeys and user scenarios, which help to specify the context of use and the requirements. In the *Design* step, the URD can then be used by a design team to produce a DMHI design which will support the user requirements in a way that users, stakeholders, designers and developers can understand, agree on and work with. Therefore, a set of stable requirements from the identified needs, which can be used as the foundation for a design, should be produced. The URD also gives requirements which can be tested against in the *Evaluation* stage.

The requirements are not a collection of inflexible directions, but rather guidelines which ensure that the DMHI remains consistent (Rogers et al., 2012) in the prototyping and development stages. Requirements should be clear, precise, and unambiguous (Rogers et al., 2012). For complex users and complex interventions, such as those found in this research, simply listing requirements without a context would be too abstract. For example, the designer would not have an insight into the underlying psychological needs of users living with a mental health disorder or the practical constraints which could adversely affect the users' mental health and the use of the DMHI, if not taken into account. Also in a mental health setting, it is important to have requirements which can be used to state the desired therapeutic outcomes of the system (Doherty et al., 2010), as well as the users' goals for and experience with the therapy. Having therapeutic outcomes as a requirement also helps in setting some of the metrics against which the system will be tested. These are not listed here, but could be added into the URD by clinicians.

Requirements analysis is a skill of judging, interpreting and balancing. In practise, generating requirements would most likely be done iteratively with some of the design, development and evaluation. However, working with the DBT clients precluded that option, as obtaining ethical permission for each iteration would not have been possible in the time scale of the EngD. In addition, focusing on the requirements generation process in isolation facilitates a discussion of the research questions and the wider implications of this research. In particular, the amount of methodological work that was necessary, such as the time commitment needed when doing UCD in this context and the necessary adaptions to the UCD process which were carried out, which other researchers in this or similar contexts may find useful (see Chapter 7).

5.1.2 Description of DMHI

The DMHI requested by the DBT group was a game to digitally deliver DBT skills alongside the therapy programme. Although initially a DBT skills game was considered, the focus was changed to an adjunctive app to deliver DBT skills, during Study 2 analysis. As discussed above, following Study 2 analysis, this changed into an app to deliver the Mindfulness skills module.[1]

The DMHI will be used by patients and clients who are following a DBT programme, at all stages of the therapy, and will help them to use and embed the Mindfulness module skills. It will be adjunctive to the therapy like the apps in Section 2.3 (Suñol et al., 2017; Schroeder et al., 2018, *inter alia*), will help them to practice Mindfulness exercises and may remind them of why Mindfulness skills are helpful. It will be tailorable to suit the different stages of learning DBT outlined in Chapter 4, and the differing levels of exercise and support needed at each level. An adjunctive DMHI to deliver DBT Mindfulness module needs to support and help to sustain behaviour change in those learning the skills taught as part of DBT, whilst recognising the trauma and indicators of BPD.

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[1] Possible adding the other skills modules at a later date, which is outside the scope of this research.

5.2 Personas

5.2.1 Introduction

Although the idea of personas is a simple one, considerable work must be done to generate and refine personas into accurate representations of the target users (Adlin & Pruitt, 2010). To be believable, the persona must include personal details, as well as representing the presentations and challenges caused by the disorder, which might be relevant to how users would interact with a digital intervention. The personas were developed based on the interview data as far as possible and supplemented by incorporating knowledge of people with BPD gained from spending a year on placement with the DBT group at the Tuke Centre and on Acorn Ward at the Retreat.

Personas should adequately represent the population, rather than trying to be diverse (Cooper, 2004); because of this there are more female than male personas. This reflects the fact that more females with a diagnosis of BPD are treated with DBT than males (Gunderson, 2014) (see Section 2.4.1), and females were generally more prevalent in DBT treatment (personal communication with Tuke Centre clinicians). In addition, all characteristics of the personas should be traceable to the data they were generated from (Matthews et al., 2012). As the target user population has a diagnosis of BPD, the causes and manifestations of BPD were a large part of all personas. As shown in Chapter 2, BPD can manifest in a number of different ways, and this spectrum is represented by the different personas. However, it is also important to ensure that any one user's personal idiosyncrasies are avoided, if they do not reflect the users as a whole (Cooper, 2004).

5.2.2 Adapting UCD processes

Standard UCD models needed to be adapted in this work. The personas were made more explicit than is usual, and I saw my early attempts at persona creation as extreme compared to, for example, the customer personas presented in Adlin & Pruitt (2010), because of the details they included about self-harming and abuse. However, I realised that this was because the client group has a mental health disorder, and this type of persona is not typically found in the persona literature. I felt that it was important to represent these aspects of the clients in the design process to ensure that any DMHI design reflected the level of support and validation that was needed by these types of clients. Many clients had experienced trauma in their early years, facing issues such as sexual and physical abuse and emotional neglect. In addition, clients with BPD have life-threatening presentations, such as eating disorders; self-harm, most commonly in the forms of cutting or taking an overdose; over-spending; promiscuous behaviour; and suicide attempts. This can make the personas difficult to read, although they do not contain any graphic details of abuse or self-harm.

In addition, the tension between the individualistic stance of the clinicians towards the clients, seen in Chapter 4, and using UCD to develop personas which represent a group of clients needed to be addressed; thus there are personas representing each of the different stages and the requirements include recommendations for a lot of tailoring. The necessary adaptations made to UCD methods is one of the contributions of the thesis and is discussed in the Discussion and Section 7.3.4.

5.2.3 Persona creation method

Persona creation is an iterative process based on summarising, synthesising and analysing the collected data, with the creation and evaluation of each persona undergoing several iterations of the steps involved, until the final personas are finished. The procedure used for persona creation in this case study is based on the *Six-step Conception and Gestation Process* (A&P; Adlin & Pruitt, 2010). This is a robust process grounded in research and experience. Adlin & Pruitt (2010) was written mainly for commercial use. However, as the steps were clear and it was a well-written step-by-step guide, it was adapted to fit the research context in which I was working. This section describes how I applied the process to the DBT client context, detailing how I adapted the process and where I deviated from it. The full A&P persona creation method is detailed in Appendix H.

In Step 1 of their process, A&P suggest rapidly developing assumption personas. These can help find categories for data processing in Step 2 of the process, allow inexperienced teams to practise making personas, and, more importantly for this research, bring up any biases and unvalidated assumptions about users to ensure that they can then be checked for validity using real data, including whether the user types which are initially generated are correct.

Assumption personas allow an initial attempt at a quick persona design. They are based on the available data and knowledge, boosted by assumptions made about the users. The benefits of assumption personas include them being quick to create and helping to focus thinking on a written set of ideas. The risks are that the creation team forgets or ignores the fact they are only assumption personas, which cannot be used for guiding the design process, as they have not been evaluated or validated with real client data. Data gathering and analysis, which is used to validate the assumptions, is done in Step 2.

The following sections detail how I created the data-driven personas, showing where the A&P process steps were followed and where they were not.

Step 1 - Creating assumption personas

In Step 1, a slightly reduced version of the A&P process was followed. I was, of course, not working in a team. However, the personas at all stages were discussed with my Tuke supervisor in our fortnightly supervisions and aspects of them informally with members of the DBT clinician team on many occasions.

Just before the data from Study 2 (Chapter 4) was collected and analysed, I created a number of assumption personas. As this point I had been at the Tuke for a year and wanted to prepare for what to do with the data from the study once ethical permission came through. As recommended by A&P, I wanted to bring out any underlying assumptions I had formed about the clients, as well as having some initial persona categories. The assumption personas were based on several sources: observing DBT clients and discussions with DBT clinicians whilst on placement on Acorn Ward at the Retreat; observations of the DBT skills group at the Tuke Centre; and, the literature, for example Linehan (1993).

I began by generating initial client types, as suggested by A&P, starting with the types of client I had encountered. I distinguished three main types of client:

1. Distractor. This type of client always keeps busy, so that they do not have to stop and process how they are feeling.
2. Emotional. This type of client has low affective control, they act impulsively.
3. Emotional repressor. This type of client has their emotions tightly controlled.

Rather than producing a lot of data which might not be representative and affinity sorting that, which A&P recommend at the stage, I expanded the assumption personas a little to make discussing them with the clinicians easier. I gave the assumption personas names, adding in categories like their comorbidities, their medical presentation and their interaction with DBT. However, as suggested by A&P, they are still very broad without many personal details or a photograph.

Around ten different assumption personas were created. These were discussed with my Tuke Centre supervisor in supervision meetings and in conversations in the staff room with other clinicians and underwent different changes based on the discussions. Three of these are presented here (Figures 5.1, **??** and 5.3) and discussed.

Background/DBT

The DBT and Background headings were judged to be important and were early additions to the basic assumption personas which just had the type of client. To model these types of user, based on the Tuke Centre DBT group placement observations, the following were addded:

Time in DBT

The assumption personas are all in the first year of DBT, and find it challenging. The assumption personas show a clear difference between clients after 3 months, 5 months and 9 months of DBT. However, this was one of the assumptions that proved to be inaccurate, as the client interview data (Section 4.2.10) shows that often integration of skills into the clients' lives happens over a much longer timescale and is a continuing process after formal DBT training has ended.

Nadia Jones

Discussions with the DBT team saw Nadia Jones (Figure 5.1) as being typical of a certain type of client who was always busy, distracting themselves from their thoughts and emotional responses. Several of her co-morbidities (the eating disorder and the self-harming) were reused in the final Catriona Desouza persona, as these are very common comorbidities seen with the DBT clients. However the other comorbidities were not taken forward, as being dissociative, whilst sometimes seen, is not typical of a DBT client. Some of Nadia's background was reused in the Gayle Foster persona.

Nadia Jones

Aged 24.

Employment: Administrator.

User type

Keeps busy, distractor, co-morbid eating disorder, self-harm, prescription drug abuse, dissociative, risk-averse.

Goals

Wants to become more familiar with DBT skills, try to work out which skills to use when. Wants to be able to cope with her self-harming and eating disorder.

Background/Presentation

Diagnosed with Borderline Personality Disorder a year ago, following a suicide attempt with sleeping medication after her husband left her. Had a history of taking overdoses. She is funding the treatment from her savings, and she gets frustrated that she is not getting better more quickly. She likes her therapist, although she finds being challenged about her eating difficult. She wants to be able to get better quickly and move on with life.

DBT

Three months DBT. She is struggling with DBT, finding mindfulness particularly difficult. She quite likes the DBT skills group, although the compassion–focused therapy is very challenging. Remembering the skills and acronyms is hard.

Figure 5.1: Nadia Jones

Trevor Foster

Following discussion, the Trevor persona (Figure **??**) was not carried forward, although some aspects of this persona were re-used. Although he was seen as representative of a minority of clients, he was considered to be fairly hostile to DBT and therefore not very relevant to the app. Following the advice of Cooper (2004, p.126) to design for people who love your product (the product in this case is the DMHI), personas of clients who considered DBT not right for them, for a number of reasons, as opposed to clients who found DBT extremely hard going but stuck with it, were rejected. However, reaching this type of client might be interesting for future research because of the challenges the disorder causes clients in undertaking DBT.

Trevor Foster.

Aged 40.

Employment: Electrician

User type

Impulsive, emotional, self-harming, therapy interfering, blames others when things don't work.

Goals

Wants to make his life better, but isn't sure how. Wants to stop drinking and taking drugs. Doesn't think DBT will help.

Background/Presentation

He had a neglectful childhood – physical/verbal abuse. Misuses drugs and alcohol to feel calmer, although he's trying to stop, but is finding this difficult. He's very emotional and gets into arguments frequently. He's easily swayed by people and changes his personality based on who he's with.

DBT

Five months DBT. He often fails to attend group sessions. Finds DBT hard to understand and doesn't get mindfulness. Shows some progress, but blames not making better headway on the staff not liking him because he drinks.

Figure 5.2: Trevor Foster

Eve Pemberton

Eve (Figure 5.3) is a persona of an older female client, reflecting that the Tuke and Retreat DBT client groups included people of all ages, from 18 to over 70. After the initial Eve persona was completed and following discussion with a DBT clinician, I realised Eve was trying to cover too many client attributes in one persona and some of Eve's attributes were distributed amongst other personas. The reference to a previous diagnosis of Bipolar Disorder was removed, as not relevant to Eve's current goals, and outside the research scope. The relationship with her mother was reused and expanded slightly, as an invalidating childhood environment and *parenting-of-parents* is often found in those with a diagnosis of BPD. Likewise the relationship with her partner was reused in Russell Jones, one of the final personas, as it gives a good idea of the trust issues and other effects that the challenges of BPD can have on personal relationships. Eve's job and self-harming behaviours were also re-used in final persona, Catriona.

Eve Pemberton

Age 52.

Employment: Ceramic artist.

User type

Emotional repressor, finds emotions hard to separate, worried about being seen to get it wrong.

Goals

Wants to understand her emotions better. Wants to do the exercises and mindfulness perfectly.

Background/Presentation

Eve was abused by an uncle as a teenager. She started using self-harm and food restriction as an escape from the intense pain and self-loathing she often felt. She found relationships and trust very difficult, often causing arguments then begging her partners not to abandon her. She'd had a number of hospital admissions to psychiatric wards, followed by several suicide attempts, often involving alcohol abuse. She was diagnosed as Bipolar in her 20s, and was given medication. About 5 years ago, following the death of her parents and several close friends, Eve's depression and self-harming urges started to spiral. She started keeping razors and other self-harming equipment in her studio. She began to severely calorie-restrict and started cutting herself. Her wife persuaded her to seek help and she was diagnosed with BPD.

DBT

Nine months DBT. Improving considerably with DBT. She thinks she isn't very good at learning, but doesn't like admitting when she doesn't know something. Wants DBT to help recognise her feelings and address the shame she feels.

Figure 5.3: Eve Pemberton

Co-morbidities

Figure 5.1 reflects that eating disorders are a common co-morbidity in people with a diagnosis of BPD. In addition, taking non-lethal overdoses is a very common method of self-harming among DBT clients. Discussions with my Tuke Centre supervisor of the assumption personas showed that the comorbidities were a realistic aspect of these personas and they were incorporated into later personas.

Step 2 – Processing the data

Rejection of assumption persona client types

With the assumption personas in place, in Step 2 the data from the transcribed DBT client interviews was processed. In this Step, I followed the A&P method closely.

I went through each interview transcript a number of times and identified individual pieces of data, writing each important data point (factoids) on a separate post-it note. (Post-it notes are a convenient way to easily merge, split and re-sort data points into different categories). I then used the category labels used for the sections within the assumption personas generated in Step 1 as focuses to sort the factoids, and used affinity diagramming to try to group and filter the data for points of significance.

When I first tried the affinity diagramming, I was using the following category labels, which were taken from the assumption personas, as focuses to sort the factoids:

- User types
- Goals
- Attitudes to DBT
- Personal information
- Areas of contradiction
- Use of technology, both hardware and software

As there was a lot of data (I had around 200 post-it notes), I started by sorting a subset of the post-it notes, taken from the two interviewees with the least and most DBT experience to test the appropriateness of the categories listed above (taken from the assumption personas). After attempting to sort the post-it notes into the assumption persona categories, these categories were rejected as inappropriate, as the data on the post-it notes did not fit into them well. The assumption persona categories were not precise or fine-grained enough and did not reflect the different approaches to learning and experiencing DBT.

In addition, care must be taken when reducing personas to a title or label which references a single feature to capture the category of users, which is frequently done in UCD, since in a medical context clients could be adversely affected (Deber et al., 2005). When the label is positive, for example *Museum regular* or *Keen beginner*, the development team will almost certainly not be adversely affected (Smith & Passik, 2008). However, when the label describes personal challenges, the effects on designers, developers, healthcare professionals and others coming into contact with the persona may cause inferences that stigmatise the individual, which may result in care being impaired (Smith & Passik, 2008, p.12). As an example, the assumption persona Nadia Jones was described using the labels: *distractor, has co-morbid eating* *disorder, self-harms, prescription drug abuser, dissociative, risk-averse*. People with BPD are often not well understood, including by mental healthcare professionals who have not worked with this group (Sulzer, 2015). They are frequently seen as difficult and attention-seeking; therefore, I realised that avoiding anything which might have a further deleterious effect on this group of users was imperative.

For the reasons outlined above, the following assumption persona categories and other possible categories were rejected as unsuitable for classifying user types:

Comorbidities of illnesses and disorders, such as drug and alcohol dependency, eating disorders and post-traumatic stress disorder are common in people with BPD (Roepke et al., 2013; Rizvi et al., 2011). However, co-morbidities are outside the scope of this thesis. Whilst they are retained as a realistic part of some of the personas, they are not used for classification.

Self-harming is a very common presentation of BPD. This was quickly rejected as a category, but retained as an important part of a realistic persona with BPD.

Difficult interpersonal relationships are often found in clients (see Section 2.4.1). Therefore, again this was kept as part of some personas, but was not used as a category.

Emotion dysregulation has two broad manifestations: clients who are overwhelmed by their emotions, and clients who repress their emotions. The initial personas try to represent these two types of client. However, the emotional repressive client is seen less frequently and therefore this was not used as a category, but is retained as an aspect of one of the final personas, Gayle Foster.

Dissociating is found in some DBT clients. After discussion with my clinical supervisor, this aspect of clients was removed as beyond the scope of this research.

Attitude to DBT was not retained as a category as the client relationship to DBT is complex and changing, as shown in Section 4.4.1 and may reflect other less obvious attitudes and emotions. Hostility to DBT, as seen in Trevor Foster (Figure **??**), was rejected and was not used for further persona development. This may be of interest for further investigation in future research.

Rejecting the assumption persona categories showed that the assumption personas were not wholly appropriate for complex personas of people living with a mental health condition. Therefore, a new way to generate personas based on end-user types was needed.

Although I rejected the categories used in the assumption personas as the basis for making full personas, some components of the assumption personas were retained and incorporated into the full personas. Examples are where they contained information that I could not get from the interviews, but had discussed with clinical staff, such as history of abuse.

The assumption personas had been a useful focus of discussion with DBT staff to develop my understanding of the clients, BPD and DBT. Following the A&P method, if the assumption persona categories are not accurate, they should be rejected and new categories based on the data should be generated into which the client types can be sorted.

Identifying new categories for sorting client types

The results from Study 2 (Chapter 4) revealed a client discourse of acquiring DBT as a process and there was a significant difference in clients' attitudes towards DBT depending on where in the DBT process they were. For this reason new categories based on the interview data and using *stages of learning*, rather than the assumption persona categories, were used in affinity diagramming. The new categories were: Entrant, Beginner, Intermediate, Competent, Proficient. These were seen as falling under three umbrella terms: *In a fog/life is chaotic*, encompassing the Beginner and Entrant personas; *Gaining confidence* with the Intermediate and Competent stages falling here; and *Becoming experienced*, which covered the proficient clients.

The rejection of the assumption persona categories and these new categories based on stages found in the client interview data were discussed with my supervisor at the Tuke. We had extensive discussions about categorising the DBT process as a journey, including how clients would feel about the stages, the non-linearity of the process for some clients who would go backwards and forwards along the path, and the separate stages. He was encouraging of this conceptualisation of the process. The difference between the Entrants and the Beginners was agreed on without contention. We had considerable discussion about the differences between the Intermediate and Competent clients. Although this seemed to be in my data, my supervisor saw this as a longer more flexible phase. The categories remained for this stage in the analysis. However, after some reflection, for the final personas the Intermediate and Competent stages are merged into one persona to represent the *Gaining confidence* stage.

Unlike my initial assumption of changes in DBT clients happening over a few months, the categories of stages in the journey correlated very broadly with the length of time clients had been in DBT, but the time needed to progress from stage to stage could be considerable (in the order of years rather than months), reflecting the complexity of the disorder and the time needed to develop confidence and ability to use the Mindfulness skills. Therefore, whilst time in months has been added to the categories, this is very flexible and highly dependent on the individual client. In Study 4, this was seen as unhelpful by the clinicians and possibly stigmatising and was removed after Round 1.

The final categories based on the discourses seen in the client and clinicians' interview data (Section 4.4.1, p.167) were as follows, with a client quote from the interviews for each stage, to illustrate typical things the clients might say at this stage:

1 In a fog/life is chaotic (around 1-9 months but especially first 3 months):
  - Entrant - "This is rubbish, it's never going to work" (1-12+ months).
  - Beginner - "It's hard to be mindful when I'm having difficult thoughts or problems" (6-12+ months).

2 Gaining confidence (around 6-18+ months, but can be years):
  - Intermediate - "I need to stop glamourising my illness and get better" (6-11+ months).
  - Competent - "I followed the steps in the exercise and it worked" (12-36+ months).

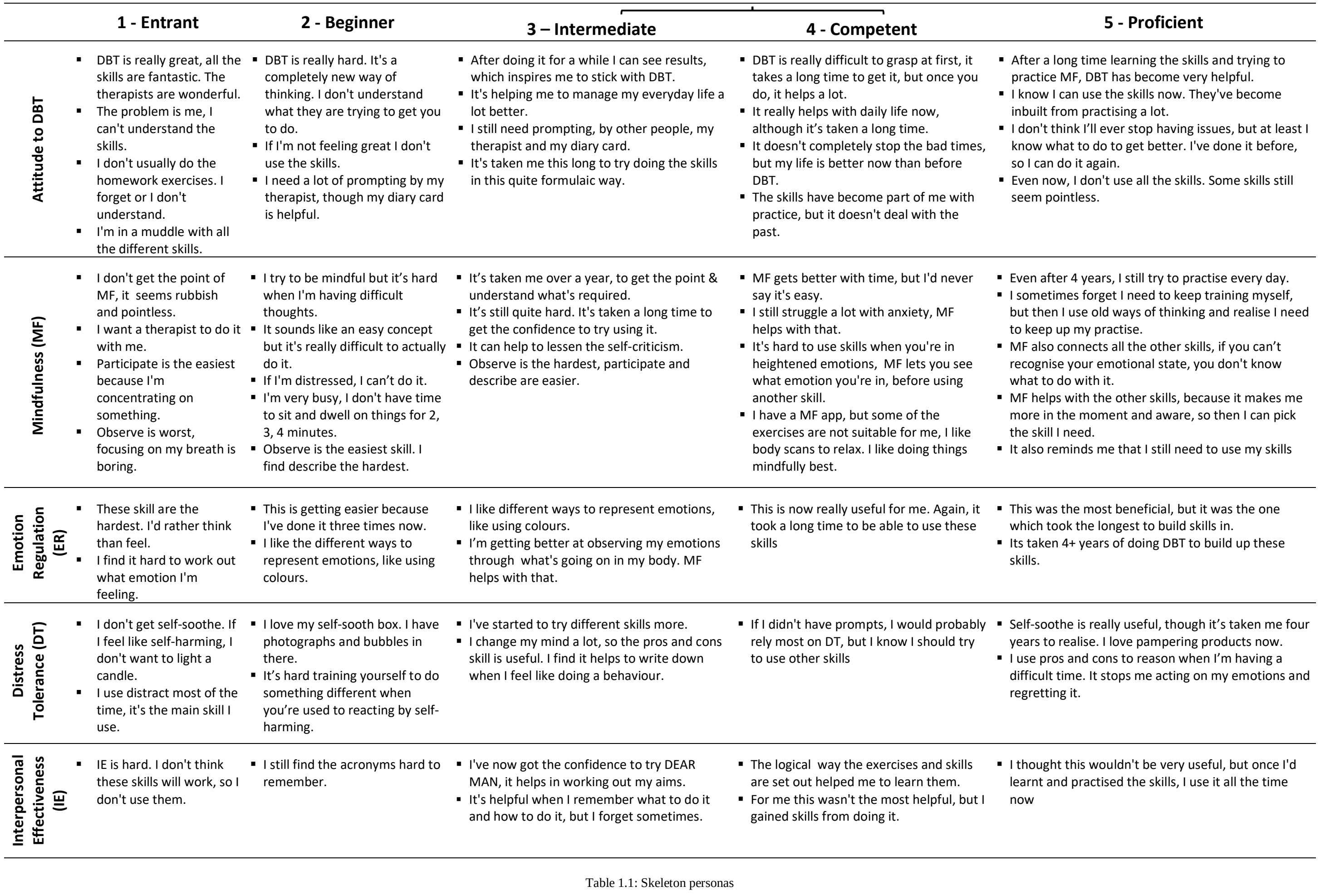
3 Becoming experienced (around 36 - 60+ months):
  - Proficient - "The practice never stops".

Using the new categories, based on stages in the DBT journey, affinity diagramming was used to cluster the 200 data points of quotes from the interviews. I found this was a much more effective way of affinity-sorting the data. The data points, in the form of post-it notes, were sorted into one of five stages. Some rearranging then took place. Finally, the stages and the corresponding data points were discussed with my clinical supervisor, adding to the co-creation process, and then used to produce the skeleton personas in the next stage.

Step 3 - Create skeleton personas

The A&P process was broadly followed in this step. From the sorted data points, five skeleton personas were developed, representing the stages in the DBT skills learning journey of Entrant, Beginner, Intermediate, Competent and Proficient. Skeleton personas represent *possible* categories of persona. The data points on DBT as a whole and the four DBT skills modules from the client interviews were then added into the skeleton personas. Typically, personas include information on competence and attitude to technology. The initial personas included this information, based on data from the interviews. However, this information has been extracted here, and in later personas, in order to streamline the personas and minimise the length, as they are longer than standard commercial personas. The information could be added back into a final URD, to give the full view of the personas.

Table 5.1: Skeleton personas



	1 - Entrant	2 - Beginner	3 – Intermediate	4 - Competent	5 - Proficient
Attitude to DBT	▪ DBT is really great, all the skills are fantastic. The therapists are wonderful. ▪ The problem is me, I can't understand the skills. ▪ I don't usually do the homework exercises. I forget or I don't understand. ▪ I'm in a muddle with all the different skills.	▪ DBT is really hard. It's a completely new way of thinking. I don't understand what they are trying to get you to do. ▪ If I'm not feeling great I don't use the skills. ▪ I need a lot of prompting by my therapist, though my diary card is helpful.	▪ After doing it for a while I can see results, which inspires me to stick with DBT. ▪ It's helping me to manage my everyday life a lot better. ▪ I still need prompting, by other people, my therapist and my diary card. ▪ It's taken me this long to try doing the skills in this quite formulaic way.	▪ DBT is really difficult to grasp at first, it takes a long time to get it, but once you do, it helps a lot. ▪ It really helps with daily life now, although it’s taken a long time. ▪ It doesn't completely stop the bad times, but my life is better now than before DBT. ▪ The skills have become part of me with practice, but it doesn't deal with the past.	▪ After a long time learning the skills and trying to practice MF, DBT has become very helpful. ▪ I know I can use the skills now. They've become inbuilt from practising a lot. ▪ I don't think I’ll ever stop having issues, but at least I know what to do to get better. I've done it before, so I can do it again. ▪ Even now, I don't use all the skills. Some skills still seem pointless.
Mindfulness (MF)	▪ I don't get the point of MF, it seems rubbish and pointless. ▪ I want a therapist to do it with me. ▪ Participate is the easiest because I'm concentrating on something. ▪ Observe is worst, focusing on my breath is boring.	▪ I try to be mindful but it’s hard when I'm having difficult thoughts. ▪ It sounds like an easy concept but it's really difficult to actually do it. ▪ If I'm distressed, I can’t do it. ▪ I'm very busy, I don't have time to sit and dwell on things for 2, 3, 4 minutes. ▪ Observe is the easiest skill. I find describe the hardest.	▪ It’s taken me over a year, to get the point & understand what's required. ▪ It’s still quite hard. It's taken a long time to get the confidence to try using it. ▪ It can help to lessen the self-criticism. ▪ Observe is the hardest, participate and describe are easier.	▪ MF gets better with time, but I'd never say it's easy. ▪ I still struggle a lot with anxiety, MF helps with that. ▪ It's hard to use skills when you're in heightened emotions, MF lets you see what emotion you're in, before using another skill. ▪ I have a MF app, but some of the exercises are not suitable for me, I like body scans to relax. I like doing things mindfully best.	▪ Even after 4 years, I still try to practise every day. ▪ I sometimes forget I need to keep training myself, but then I use old ways of thinking and realise I need to keep up my practise. ▪ MF also connects all the other skills, if you can’t recognise your emotional state, you don't know what to do with it. ▪ MF helps with the other skills, because it makes me more in the moment and aware, so then I can pick the skill I need. ▪ It also reminds me that I still need to use my skills
Emotion Regulation (ER)	▪ These skill are the hardest. I'd rather think than feel. ▪ I find it hard to work out what emotion I'm feeling.	▪ This is getting easier because I've done it three times now. ▪ I like the different ways to represent emotions, like using colours.	▪ I like different ways to represent emotions, like using colours. ▪ I’m getting better at observing my emotions through what's going on in my body. MF helps with that.	▪ This is now really useful for me. Again, it took a long time to be able to use these skills	▪ This was the most beneficial, but it was the one which took the longest to build skills in. ▪ Its taken 4+ years of doing DBT to build up these skills.
Distress Tolerance (DT)	▪ I don't get self-soothe. If I feel like self-harming, I don't want to light a candle. ▪ I use distract most of the time, it's the main skill I use.	▪ I love my self-sooth box. I have photographs and bubbles in there. ▪ It’s hard training yourself to do something different when you’re used to reacting by self-harming.	▪ I've started to try different skills more. ▪ I change my mind a lot, so the pros and cons skill is useful. I find it helps to write down when I feel like doing a behaviour.	▪ If I didn't have prompts, I would probably rely most on DT, but I know I should try to use other skills	▪ Self-soothe is really useful, though it’s taken me four years to realise. I love pampering products now. ▪ I use pros and cons to reason when I’m having a difficult time. It stops me acting on my emotions and regretting it.
Interpersonal Effectiveness (IE)	▪ IE is hard. I don't think these skills will work, so I don't use them.	▪ I still find the acronyms hard to remember.	▪ I've now got the confidence to try DEAR MAN, it helps in working out my aims. ▪ It's helpful when I remember what to do it and how to do it, but I forget sometimes.	▪ The logical way the exercises and skills are set out helped me to learn them. ▪ For me this wasn't the most helpful, but I gained skills from doing it.	▪ I thought this wouldn't be very useful, but once I'd learnt and practised the skills, I use it all the time now

Table 1.1: Skeleton personas

Step 4 - Evaluate and prioritise the skeleton personas

In Step 4, the five skeleton personas were considered, based on stages in the DBT acquisition journey (see Table 5.1). Skeleton personas do not have personal details, but they reflect the sorted data points from the interviews, so that all the bullet points are direct quotes from the client interviews.

- Skeleton 1 represents *Entrants*, who have just joined DBT and are generally confused and unsure.

- Skeleton 2 represents *Beginners*. At this stage, the clients have started to understand what DBT is, but are still far from being able to acquire or access and use the mindfulness skill. They may still be using old strategies, because they do not have confidence in DBT and cannot understand what is being asked of them.

- Skeleton 3 represents those who are at the *Intermediate* stage. They are starting to gain confidence now. They are probably coming towards the end of their DBT training and they are seeing improvements in their mental health, due to having more confidence in their ability to use the mindfulness skills. They may still have considerable challenges in practising Mindfulness skills when under stress, but they are no longer in a complete fog.

- Skeleton 4 represents clients becoming *Competent*. These clients are able to practise mindfulness and have a mental model of Mindfulness skills and when they should be used. However, there will still be times when they forget to use mindfulness or are unable to use it due to the effects of the disorder.

- Skeleton 5 represents *Proficient* clients who have been through the DBT programme and are now fully conversant with all the skills. These clients are not cured of BPD; they still face challenges, but they now know what to do to get themselves back on track. They use the skills on a daily basis. They understand how mindfulness enables them to step back and assess their emotions rather than just acting on them.

As Study 2 showed, over the course of the therapy the needs of the users changes at different stages. Whilst the therapy remains the same, the clients' attitude and abilities change quite drastically, which is reflected in the final personas. On examining the five skeleton personas, reflecting on the interview data, and discussing with my Tuke supervisor, I considered that clients would not sit neatly into each category, but would vacillate somewhat between the categories, whilst gradually progressing. In particular, as asserted by my Tuke supervisor, a client might occupy the middle categories of the high level class *Gaining Confidence* comprising *Intermediate* and *Competent*, see-sawing between the two for some time. Therefore, I decided to create a persona which sat over both these categories. Thus, reducing the original five skeleton personas to four. In modelling the process of DBT, showing all stages in a *user journey map*, it should be emphasised that the clients' progress would oscillate between the proficiency categories.

Step 5 - Develop the selected skeleton personas into full personas

After developing the skeleton personas, in this step, I extended these to produce four full personas that incorporate the individualist approach taken by the clinicians, into tools which could be helpfully used by a design team. For example, having client personas at different stages with different needs, reflecting the emotions and experience found in the research, incorporating the triggers and factors that facilitated and impeded their progress in acquiring DBT Mindfulness and other skills, and reflecting the hardest parts of the DBT experience. This gave a voice to clients at different stages about how BPD had affected their lives and how they experienced DBT skills training. In using the empathic, dialogical approach, I was open to learning from the clients and the clinicians. As the designer, through a dialogue with the participants in Study 2, I was able to shape and develop requirements. I used empathic UCD (Section 1.1.3) to understand the emotions and experiences of clients, the challenges and the improvements that DBT had brought to them and how they experienced the skills training, as well as the experiences of clinicians as stakeholders, using the dialogical approach (Section 1.1.4) to take all views into account in developing the full personas.

Cooper (2004) states that designing should be about making one key persona ecstatically happy, which will then make a broad population satisfied. Normally there would be a key persona, but here, there were four key personas representing clients at different stages of the DBT process. Each of these personas has different needs. Therefore, rather than a key persona, a number of personas were developed from the skeleton personas, to reflect the different types of users of the system (Adlin & Pruitt, 2010).

In addition, I designed the most challenging personas at each stage, as I hypothesised following Cooper et al. (2014) that in designing for DBT end-users who are facing the most challenges, those users with less challenging etiologies, who take less time to acquire Mindfulness, will be covered. The Entrant and Beginner personas need the most support. In the *Design* phase, the DMHI could start by designing with these early stages and expand and build on these for the other personas later. It is envisaged that the rest of the DMHI would build up in stages from the Entrant stage. However, this would be decided by the design team.

1. India Birch – Entrant
2. Russell Jones – Beginner
3. Catriona Desouza – Gaining confidence - Intermediate / Competent
4. Gayle Foster – Proficient

Some of the contents in the personas came from discussions with the clinicians and personal experience on placement at the Tuke Centre; for example, DBT clients tend to be well-educated and articulate, so the personas reflect this. At the same time, a diagnosis of BPD means the clients face a lot of challenges, as seen in the data. At this stage the personas needed to capture how the clients saw themselves. In addition, as the interviews revealed, they did not always have a stable self-image and were not always consistent in their evaluation of learning DBT, especially in the early stages. This also needed to be captured. Therefore, the final personas speak in the first person. After an extensive search of the literature it was not possible to find any other research using first person personas. I used first person voices to make the personas more realistic and

India Birch

"If you don't know what mindfulness is about, you don't know what you're trying to achieve"

- 22 years old.
- Single. No children.
- Studying foundation course at FE college.
- History of self-harm, and overdoses.
- Diagnosed with Borderline personality disorder (BPD) 18 months ago.
- Five months DBT.

Goals:

1. To cut down self-harming to less than 3 times a week.
2. To stand up to my mum better.
3. To get good marks in my foundation course.

Fears:

1. I'll never get better.
2. I'm too stupid to do DBT.
3. I won't be able to cope away from my parents at university.

Aspirations:

1. To stop feeling my emotions so strongly.
2. To be able to live with the effects of BPD.
3. To get a place to study Psychology at university.

Background

I'm doing a foundation course and I work part-time in a shop. I attend DBT skills and therapy sessions weekly. I was lucky to get NHS funding after being in hospital, after I took another overdose of my prescription medication. I was really shy and anxious at school and got badly bullied. My parents told me to just ignore it, but I used to get really upset and skipped a lot of school, which is why I'm going back to college now. I live at home with my parents, I was diagnosed with Borderline Personality Disorder recently, but I've seen quite a few therapists over the last few years.

I started self-harming when I was a teenager. I pull out my hair and cut myself. I usually hide my arms, but sometimes I show my mum because it makes her want to take care of me for a bit. I think she's scared I'll accidentally kill myself.

I'm quite shy and don't like people noticing me really. I find it hard to stand up for myself. My mum is very controlling and still tries to tell me what to do. She wants me to leave college & get a full-time job. I want to go to university, but my parents don't want me to live away, as they worry about what might happen. I have friends at college, but we're not very close and none of them know about the BPD. I get really ashamed of self-harming, all my faults, my illness and making my parents so upset. I get frustrated and upset with myself and my faults.

DBT

I've been going to DBT for 3 months. It's great, really helpful. I appreciate the time the therapists take, but I'm not very good at it. I almost never do the homework and I feel really guilty about that, but I forget. To be honest, often I don't understand the skill and there's so many skills, it's overwhelming. When I feel like cutting myself or other self-defeating behaviours as my therapist calls them, I'm just too flooded with feelings to use the skills or work out what to do. Maybe one day I will, but not at the moment. I know I need to be better in order to go to university, but on bad days I feel so depressed and exhausted. I just want to make it stop. I hope that DBT will help and stop the suicidal thoughts, although I'm not sure what giving up suicide as an option would mean.

Mindfulness

I don't get the point of mindfulness. It just seems really silly and a bit rubbish and pointless. I just don't understand what they are trying to teach us or why we have to do it every time. We sit and look at a leaf and I just think, this is weird, what's the point of doing this? I don't look forward to the group mindfulness exercise because it makes me anxious, I think they're going to judge me, judge what I say about the exercise, so I think about what I'm going to say rather than doing the mindfulness. I think it's me, I'm not very good at learning new things. Also, I'm very busy. I don't really have time to sit and dwell for 2 or 3 minutes. I like the participate ones, it's easier when you're doing something. The worst is observe, I especially hate focusing on my breath, it's so boring. What I really want is someone to help me, someone who knows what they're doing, not the group, like a therapist.

Figure 5.4: India Birch – Entrant

therefore, I hypothesise, more empathetic to a design team. This aspect of the personas is one of the questions covered in Study 4, Chapter 6. Using personas who introduce themselves and their stories in the first person also allowed the inability to work out how to use the skills, seen in both the clients' and the clinicians' interview data come through in their narrative, making the personas more personal and, it is hypothesised, their stories more compelling to a design team. In addition, by using first person personas it was hoped to avoid the negativity seen by (Smith & Passik, 2008), as the personas address some of their concerns about making these types of users more sympathetic to clinicians, design teams, developers and other stakeholders. Whilst mindfulness is the focus of the DMHI, DBT as a general category is included in the personas. Mindfulness exists in DBT to support the other skills, so the wider context within which Mindfulness skills are practised should be represented.

5.2.4 Final personas

Persona 1 - India Birch

The final Entrant persona, India Birch, can be seen in Figure 5.4. India mainly incorporates elements from Skeleton Persona 1 with some of Skeleton Persona 2, as well as other interview details. As a number of clients were educated to HE level or involved in education, she is studying. This reflects several of the interviewees and a number of younger DBT clients. She is receiving NHS funding, which can be difficult to access. In order to get this level of funding, clients have often been hospitalised a number of times and had multiple suicide attempts.

She discusses self-harming, which is complicated and has a number of functions (Edmondson et al., 2016). As well as helping clients to manage their emotional dysfunction (Terzi et al., 2017), it can also have an occupational aspect, which can become more hidden over time. The care and nurturing aspect of having wounds tended to and healed may be the only compassion and kindness that clients experience, so can be very powerful. However, clients also feel a great shame around this, as they do about many of their self-harming behaviours, and hide them from friends and other acquaintances. Self-harming can take many forms, India uses some of the more common ones.

India is based on several of the shyer clients that were encountered in the interviews and skills groups. This type of client is reluctant to speak and feels that their opinion is not important. Due to her shyness, reticence and lack of self-confidence in using DBT, India cannot yet imagine herself using the skills to get the results she wants out of a situation where she needs to communicate her needs effectively. India was developed iteratively after discussion with my Tuke supervisor. Her relationship with her mother was expanded, as an invalidating childhood environment is often found in those with a diagnosis of BPD. She has a difficult relationship with her mother, who sometimes lacks empathy, and thinks she knows what is best for India. This was seen on a number of occasions when on placement and reported in the clinician interviews.

India has intense shame about her illness, self-harm and the negative things that have happened in her life. Consequently she hides her illness even from close friends. She also gets frustrated with herself when she does not learn or get better as quickly as she wants to. She blames herself for not being able to do mindfulness, reflecting interview data. She feels a lot of shame about her self-harming behaviours, but also realises that it makes her mother more caring towards her and sometimes shows her mother what she has done, in order to get sympathy and care. India's attitude to her illness and behaviour shows a major characteristic typical of those with BPD: self-blaming when unable to understand or use DBT in the beginner stages. This was witnessed in group sessions and in the interview data. She has great faith in DBT, as shown in the interview data, and reports its helpfulness, but cannot yet produce mindfulness, showing a tension in her narrative about the treatment.

India cannot understand why mindfulness is being taught. She has not yet understood what is required in mindfulness – a very common finding – and she is not able to try being mindful when she is feeling intense emotions. India finds mindfulness difficult, a very common phenomenon reported by all the interviewees. In the interviews, several clients discussed anxieties around reporting back to the group, both for mindfulness and other activities, which is reflected here. India reflects clients who like to distract themselves by keeping busy. The mindfulness *Participate* skill was seen as the easiest, because she was focused on a task. However, she may have been using the *distract* skill rather than participating mindfully.

Persona 2 - Russell Jones

Russell is a young male *Beginner* stage persona. He is based on Skeleton Persona 2, and a number of clients, both male and female, from the Tuke Centre. Like India and the other personas, Russell Jones, the *Beginner*, was developed iteratively in discussion with the Retreat supervisor. Like India, he is fairly new to DBT and is really struggling to understand the therapy. Like almost all clients, Russell has struggled with a mental illness and it has affected all aspects of his life, including work. This is an issue that clients frequently discuss. When they are very ill, clients are often unable to work, with all the other issues that this brings such as lack of money, social isolation and erosion of self-esteem. For Russell this is another frustration.

Details about Russell's mood swings were added, as described in the interviews and observed in some of the clients attending the skills sessions. A history of sexual abuse and starting to self-harm at a young age are recurring themes in DBT clients with BPD. Russell has a lot of anger issues. The anger in BPD often appears in response to perceived rejection (Berenson et al., 2011). The anger and emotional outbursts comes from observing this type of client in the skills groups. Male clients, whilst not unknown, are less common than female. However, anger issues, whilst a possible symptom of BPD, are not typical, with anger more likely to be internalised as self-criticism or self-harm than reflected outwards, especially in female clients. Self-harming can often start with an accidental injury when the client is upset. This part of Russell comes from a discussion with the Retreat supervisor. Many clients have seen a number of therapists and tried different therapies which were not helpful before they find DBT. Russell's father not being understanding about his son's ongoing trauma is based on reported incidents from the Tuke and the Retreat.

Figure 5.5: Russell Jones – Beginner

Russell Jones

"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."

- 21 years old
- In a relationship - no children
- 5 GCSEs
- Finished mechanic apprenticeship
- Recently diagnosed with Borderline Personality Disorder (BPD)
- Six months DBT
- Anger, depression, emotional outbursts & suicidality
- Risk-taking behaviours, self-harm

Goals

1. Complete the DBT course
2. Handle my emotions better
3. Dampen suicide/dangerous behaviour urges
4. Get a job as a mechanic

Fears

1. My girlfriend will leave me.
2. I'll never get better.
3. I'm too stupid to do DBT.
4. My emotions feel so over-whelming, I'm scared of losing control.

Aspirations:

1. To have a life without any self-harm urges.
2. To be able to live with BPD
3. To have my own motorbike business.

Background

I recently finished a mechanic apprenticeship. I'm a good mechanic, but they let me go because of poor attendance. I've had lots of time off because of being depressed, but I didn't want to tell them. I'm also moody & get upset and angry over small things. I feel irritable and agitated a lot of the time. I've seen a few therapists over the last few years, but I was diagnosed with BPD about nine months ago. My girlfriend, Maddie broke up with me after a row I threatened to kill myself if she left and she said if I didn't get help she would. Maddie is my main reason for doing DBT.

When I was 10, my dad's friend started taking me fishing; it was an excuse for him to abuse me. It lasted about a year until I told my parents. I was an emotional child, who got upset easily, and I was completely traumatised by what happened. My dad doesn't understand why I still get upset about the abuse though.

I started self-harming when I was a teenager. I fell off my bike after a row with my dad & the pain helped. I'd hit things and burn myself. Physical pain helps when I feel really bad. When I'm angry, I drive my motorbike too fast and put myself in danger. I don't care if I crash. I'm always falling out with my mates. I seem to get close to a mate and then they do something to annoy me & we fall out big time and stop talking. When I'm angry I bang my head on walls and punch myself.

I know I don't always treat Maddie well. I go between being very loving and pushing her away. I get really jealous. We've rowed a few times because I'm scared she'll leave me. I wanted to know where she'd been and grabbed her phone to see who'd called her. I'd never hurt her, but I get so angry, I'm scared I might lose control. She tried to break up with me after our last row. I punched a hole in the door. I told her I'd crash the bike and kill myself if she left me. Sometimes I think we'd both be better off if I were dead.

DBT

I've been going to DBT for six months. It's really helpful, but I still feel in a fog with it a lot of the time. I appreciate the time the therapists take, but I'm not very good at it. I almost never do the homework and I feel really guilty about that, but I forget. To be honest, often I don't understand the skills, and there's so many of them, it's overwhelming. When I feel like hurting myself, I get overcome with emotion & can't work out what else to do or use the skills. Maybe one day I will, but not at the moment. I know I need to be better for Maddie, but on bad days I feel so angry & depressed; I just want to make it stop. I hope DBT will help and stop the suicidal thoughts.

Mindfulness

I can't understand what mindfulness is supposed to be about. We sit and look at a leaf and I just think, this is a waste of time, what's the point of doing this? I don't really understand what they're trying to teach us or why we have to do it every time, but they keep going on about it, so I guess it's important. I think it's me, I'm not good at learning new things.

I never really know what I'm supposed to be doing in the mindfulness practice at the start of each class. I try to be mindful, but it's hard, especially when I'm having difficult thoughts or problems. When they explain it, it sounds like an easy concept but it's really difficult to get your head around it and actually do it. I think I'm starting to understand it, but if I'm upset, I just can't do it.

In terms of Russell's relationship, many clients want to be able to have better relationships with people, as evidenced by the interviews. The Interpersonal Effectiveness skill helps clients to be assertive in communicating their needs to others without becoming overly emotional. Russell's *Goals* came from the interview data and the observations. His *Fears* came from observation of clients – many people with BPD have a huge fear of the power of their emotions, especially the negative ones. Moreover, in relationships, people with BPD may cause fights because they have feelings for partners that rapidly cycle between adoration and extreme dislike. They instigate arguments but when the partner tries to leave they frantically try to avoid being abandoned.

Russell also exhibits risk-taking behaviours, in the form of driving at speed. He also self-harms through head-banging and self-hitting, all acts that were discussed during the DBT placement. As with the other personas, DBT is often about getting people to reduce the number of times they self-harm or engage in self-defeating behaviours, rather than getting them to stop altogether, especially in the early stages of DBT.

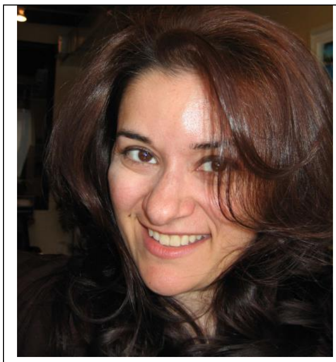
Clients in the interviews reported struggling a lot with the skills during the first six months to a year. Clients often discussed therapy-interfering behaviour caused by the manifestations of BPD. This is reflected in Persona 2 by Russell not completing the homework he is assigned. Russell's attitude to mindfulness was derived from the interview data: clients discussed not seeing the point of mindfulness at first. The attitude to homework was inspired by several participants who reported not doing the homework, but felt regret and guilt about not doing it.

Persona 3 - Catriona Desouza

Catriona Desouza represents clients at the *Gaining confidence* stage. Catriona is based on Skeleton Personas 3 and 4 and went through a number of iterations following discussions with my Retreat supervisor. Her *Goals* derived mainly from the interview data and *Fears* from clients from the placement observations. Catriona's *Aspirations* were inspired by the interview data and information revealed in the DBT skills groups.

People with BPD often have very dramatic lives and have often had a number of terrible things happen to them, which can seem unrealistic or excessive when modelled using personas. Discussing the personas with my Retreat supervisor helped to ensure they were grounded in realistic client-type experiences.

Many clients have experienced numerous hospitalisations, often for extended periods. This part of the persona is based on experiences related by clients and clinicians. Parenting-of-parents, included in Catriona to show an invalidating childhood environment is often found in those with a diagnosis of BPD. Several sections were added to the final version. Many of the clients had been brought up to be 'good girls', becoming distressed when they fail to meet unreachable perfectionist standards.



Catriona Desouza

"DBT really helps me with my daily life now, the practical stuff, but it doesn't deal with the past."

- 38 years old
- Divorced, no children
- Fine Art degree
- Ceramic artist
- Diagnosed with Borderline Personality Disorder (BPD) 5 years ago
- 2.5 years DBT, 1 year CBT
- Self-harm, suicidality – much reduced
- Alcohol use disorder

Goals:

1. Use DBT skills to work through past trauma
2. Reduce my urges completely
3. Have less crises

Fears:

1. If I'm more assertive people won't like me.
2. My personality is set in stone and I can't change
3. I'll never be completely well

Aspirations:

1. Work through my trauma
2. Stop all self-defeating behaviour
3. Help people with BPD through art therapy one day

Background

I'm a ceramic artist. I have a small studio with a kiln in the garden I sell things mainly online. I find work therapeutic, but I also get frustrated if it isn't perfect. I've destroyed pieces I've spent days on over minor imperfections. I'm having CBT now; I attended DBT for 2.5 years before that and still use the skills on a daily basis. About 5 years ago, the business wasn't doing well and my mother died. I ended up in hospital a number of times due to attempted suicide. I was eventually diagnosed with BPD, but it took a while to start DBT.

My home life when I was young was pretty bad. My dad used to drink and had an awful temper. He was physically and verbally abusive to me and my mum. I was taught to be good, quiet, polite and helpful, but nothing was ever good enough. I always felt responsible for my mother; she had a lot of mental health problems. After my dad left when I was 13, I looked after her from then really.

I've self-harmed since my teens. I started using self-harm as an escape from the painful situation and self-loathing. I didn't have friends because I daren't bring them home, so it was an escape. I used to drink a lot, that started with mum's sherry, but I've stopped completely now. Since starting DBT, I've managed to really cut down on the amount of self-harming I do and I haven't attempted suicide for about 18 months, but I still keep razors hidden in the studio. I go to A&E now if I'm feeling really bad and can't use the skills, but that's quite rare.

I find relationships and trust very difficult, I split up from my husband about 7 years ago, I know I can be passive aggressive. When I was married, I'd often take overdoses. I still have a lot of self-blame and bitterness about what happened. I still think that everything was my fault.

DBT

DBT is really difficult to grasp at first, especially mindfulness. It's taken a long time to get it, over 3 years, but once you do, it helps a lot. It's taken me a long while to get the confidence to actually try doing some of the skills, but it does work. After doing it for a while, I'm now seeing the benefits, which inspires me to carry on doing it. DBT has really helped me to understand my emotions better. I still need prompting sometimes though when I forget to use mindfulness and the other skills. I have posters in the studio and the kitchen to remind me and the skills are gradually becoming inbuilt in me, with a lot of practice. Sometimes I'm a bit disappointed that it doesn't completely stop the bad times or all the urges, but my life is so much better now than before DBT. I can get frustrated that I have to keep practising mindfulness and the other skills, and even then, I still have really bad times. So, I don't think I'll ever stop having issues, but after a crisis, at least I now know what to do to get better in terms of using the skills, and that I've used the skills to do it before, so I'll be able to do it again.

Mindfulness

It's taken me a long time, to understand what's required from mindfulness. It's still hard. At first, I thought it was nonsense, because it's so hard to use the skills when you're in a heightened emotional mood, but mindfulness connects all the other skills. It makes me more in the moment and aware, so I get some objectivity; then I can pick the skill I need. If you can't recognise your emotional state, you don't know what to do with it. It also reminds me that I still need to use my skills. It definitely helps to lessen the self-criticism. I struggle a lot with anxiety and it's helping with that too. But mainly, mindfulness helps me to be able to use the other skills.

In terms of the *What* skills, I prefer participating, *observe* is my least favourite. I like to be doing something whilst I'm practising, even if it's just making a cup of tea. I have a mindfulness app, but I don't think some of the exercises arenot veru suitable for me. I need some better mindfulness exercises. I quite like using body scans to relax, but I prefer doing an action mindfully. I still need reminding to use mindfulness now and again, because sometimes I forget for a couple of days, then old ways of thinking come back.

Figure 5.6: Catriona – Gaining Confidence

Gayle Foster

“Even after 4 years, I try to practise DBT every day”

- 31 years old
- Single - divorced, no children
- MSc maths / PGCE
- FE college maths teacher
- Diagnosed with BPD 4 years ago
- Multiple overdoses, promiscuity
- 2.5 years DBT
- 1.5 years Trauma processing

Goals

1. Reduce my urges completely
2. Have less crises
3. Retrain for a new career, running my own gardening business

Fears

1. I’ll never be completely well
2. I’ll feel so bad I’ll kill myself either accidently or intentionally.
3. I’ll never meet someone who gets me and can love the real me

Aspirations

1. To have a healthy relationship with a new partner and a child.
2. Practice mindfulness and be more self-compassionate
3. Keep using skills

Background

I’m a maths teacher at an FE college. I married my university boyfriend when we were 22. The marriage was happy at first, but my ex got frustrated with my coolness and inconsistency of feelings towards him. I was very insecure. I always thought he’d leave me, although I was desperate for him not to. Eventually he left. It was awful and I had a complete breakdown, I lost the house and my job and became really depressed and suicidal. I had a lot of partners. I just wanted to feel something. After the breakdown, I got a proper diagnosis and I did a couple of years of DBT. Now I have therapy for trauma processing once a week.

My parents were reserved and unaffectionate. I was bright, swotty and encouraged to be well-behaved. When I was walking home from school one day, I was seriously sexually assaulted. I didn’t tell my parents or anyone else what had happened for years afterwards. I thought it was my fault. I just closed down. As I got older, I realised that I didn't feel emotions like other people. Friends would describe intense emotions about the things they loved or hated, but I often felt very empty inside or found it hard to know what I was feeling.

I had first started self-harming as a result of being bullied, but it got a lot worse after the assault. I started by burning myself and taking more than the recommended amount of painkillers. I controlled my marriage by threatening and taking overdoses. I still have a lot of self-blame and bitterness about what happened. I think that everything was my fault.

DBT

After a long time learning the skills and trying to practice mindfulness, DBT has become very helpful. DBT has helped me to understand my emotions better.I know I can use the skills now and they’ve become inbuilt from practising over and again. I don’t think I’ll ever stop having issues, but at least I know what to do to get better, in terms of using the skills and that I’ve done it before so I am able to do it again. It makes me quite sad that I have to keep doing mindfulness and the skills. I still have really bad times. But now I know I can use the skills to get better.

Mindfulness

Even after 4 years, I still try to do this every day. I sometimes forget I need to keep training myself, even though it’s built in, but then I use old ways of thinking and realise I need to keep up my practise. I find the grounding aspect of mindfulness really helpful if I start to dissociate. Mindfulness also connects all the other skills, if you can’t recognise your emotional state, you don’t know what to do with it. I find it also helps me to get more in touch with my body and how it feels and what I’m thinking. Compassion can still be very hard, I try to be more self-compassionate and that helps with my critical voice. It’s still not always easy. Mindfulness really helps with the other skills, because it makes me more in the moment and aware, so I get some objectivity. Then I can pick the skill I need. It also reminds me that I still need to use my skills. Sometimes, I keep myself very busy, rather than being mindful or trying to work out which emotion I’m feeling. Once I realise what I’m doing I take a step back and use my mindfulness to see if it’s an appropriate response to the situation.

Figure 5.7: Gayle Foster – Proficient

Mental health often gets worse at times when life is very difficult. In those with BPD, self-harming at such times is used as a way of replacing mental pain with physical pain (Dr Mark McFetridge, personal communication). Regarding self-harm, as with India and Russell, DBT is often about getting people to gradually reduce the number of times they self-harm or engage in other therapy-interfering behaviours, rather than getting them to stop altogether, which may be too difficult. This also shows one of the dialectics which is inherent within DBT: that the therapy-interfering and self-harming behaviours are understandable given the client’s background, but that clients are nevertheless encouraged to reduce or stop the behaviours.

Difficulty in personal relationships, especially provoking partners into leaving through passive-aggressive behaviour, then begging them not to go, is seen as typical behaviour of a person with BPD (Linehan, 1993; *inter alia*). Likewise, Catriona's relationship with her partner gives a better idea of the trust issues and other effects that emotional issues can have in personal relationships.

Catriona's attitude and engagement with DBT, the slow learning and trying out of skills came from the interviews. Several clients said it took a long time to understand and start using the skills properly. Catriona has been in DBT for several years, which is not atypical. Although she has been undertaking DBT for 2.5 years, she struggled to understand Mindfulness for some time. This reflects the interview data, with clients saying they found understanding and practising Mindfulness difficult for over a year.

Persona 4 - Gayle Foster

Gayle Foster can be seen in Figure 5.7. In the final version of Gayle, the use of DBT and mindfulness skills comes from the interview data. The overall aim of DBT is giving clients who perceive their lives as painful and not worth living a chance to develop the necessary skills to solve the problems that cause them deep distress. Ultimately, by gaining experience in the skills, suicide is no longer one of the options considered by the client in deciding how to deal with a problem (Linehan, 1993). Gayle has reached this stage, having been in DBT for 4 years, which again, is not atypical. Clients who are competent/proficient have often been using DBT for a long time. However, an intervention can still help these clients as they still face challenges from time to time, need to be reminded to practise sometimes, or may want to try different mindfulness exercises or skills that they dismissed when they were in the early stages of DBT.

Gayle was based mainly on interview data, as well as observing skills group discussions. Like the assumption persona, Eve (Figure 5.3), Gayle is a client who represses their emotions rather than being overly emotional. Gayle also reflects that many people with a diagnosis of BPD only attend DBT after a breakdown in their mental health, as described by a number of the study participants.

However, as shown in the DBT skills groups, self-compassion is extremely difficult for most clients, who have often experienced an invalidating environment in their childhood, and Gayle still struggles with practising this skill. DBT is a long-term therapy and some clients can get frustrated with the time it takes to learn the skills, the slowness of recovery and their relapses. For clinicians, this is where a dialectical stance can help. Whilst clients did not discuss the dialectical element of DBT, they talked about not liking being challenged in the beginning.

Step 6 – Validation of personas

The final personas were validated in Study 4 (Chapter 6). Following the completion of the final personas, the personas were re-checked against the interview data to ensure they were a faithful reflection of the data. Unfortunately time constraints did not allow the validation of all four personas (see Chapter 6). In a design process, all four personas could be used to discuss design points relevant to the stage of the DBT journey they were at.

5.3 User experience map

5.3.1 Introduction

As Chapter 4 showed, the process of moving from an Entrant to a Proficient user of DBT skills is a long and difficult one. This section looks at representing this process, focusing on the Mindfulness skill, in a user experience (UX) map. A UX map is a type of alignment diagram (Kalbach, 2016). This is a UCD tool which shows how users interact with an organisation or service over time. It captures users' experiences and the processes and contributions of a product or service, showing the interaction between the two. It depicts both the user experience and the development and contributions of the system. In this research, the UX map is used to show an archetypal journey of a client interacting with DBT skills, with a focus on Mindfulness, using data captured in Study 2 (Chapter 4). They also show a beginner client using Mindfulness over 24 hours. UX maps are useful because they are powerful illustrations of complex data in one visualisation, rather than having to read a multi-page report.

Two experience maps were created:

1. An example 24 hours of India Birch using mindfulness.
2. The learning cycle for DBT mindfulness and other skills for an archetypal DBT client.

Number 1 examines how mindfulness might be used over a day in the life of a new DBT client. Number 2 is expanded on in the scenarios and examines the path of a client learning DBT Mindfulness and other skills.

5.3.2 UX map creation method

Getting the data in the experience maps accurate and presented so that it speaks for itself is a craft skill and took numerous iterations before it looked and felt right. The method used follows Kalbach (2016). The goal of mapping is to find, understand and address UCD challenges (Kalbach, 2016, p.27). Before beginning the map design, I considered the issues raised in the data from Studies 1 and 2 and the personas.

Framing

How the experience is framed is important. User journeys are archetypes; therefore, things are left out, truncated or conflated into a shorter time period, but they must still reflect the overall journey, as for example, the London underground map does so well. They are experience-based, which suits the data from Studies 1 and 2. Study 1 data describes the personal experiences of embedding mindfulness in the participants' lives and Study 2 data shows clients' experience of acquiring DBT skills.

Circumstances drive experience, but in acquiring both mindfulness and DBT Mindfulness, the acquisition changes the way the person experiences the circumstances. Thus, at *Entrant* level the client's circumstances are not in a good place. The client may have been hospitalised a number of times for suicide attempts or they may have a very poor quality of life in other ways. For the non-clinical mindfulness practitioners, often ill-health or difficult life situations led them to take up mindfulness. For both sets of users, the circumstances of their lives may have changed over time, or they may be the same, but the attitude, processing and reaction to the circumstances changes, making the experience different. The DBT client, as an Entrant, goes from one crisis to another, with the therapist fire-fighting. As they gain confidence and abilities, circumstances may still be bad, they may still want to self-harm, but the skills allow them to react better, so their experience changes. Even if they do a therapy-interfering behaviour, they know they can still find a way back using the skills. This experience change must be brought out in the UX map.

Point of view

In the UX map the journey point of view is that of an archetypal client going from Entrant to becoming Proficient. Alternatively, it can be seen as a number of archetypes at different stages in the DBT journey. For the 24-hour UX map, India Birch, an Entrant level client was chosen, as she has very extreme reactions to situations caused by the presentations of the BPD.

Scope

The scope of the journeys is broad in 2, covering a roughly five-year period, and very narrow in 1 which covers a day. The DBT acquisition journey shows the stages and the categories of *in a fog*, *gaining confidence* and *seeing progress*. For the mindfulness practitioners, the stages were about the length of time they were able to maintain mindfulness, using *purposeful mindfulness*, using mindfulness when under cognitive and time constraints and whether they had both a formal and informal practice. For the *day in a life*, the scope is narrow and focuses on time periods around waking and sleeping, meals and other daily occurrences.

Focus

The UX maps' design used the data to focus on a number of areas:

1. Thoughts – how do they see mindfulness and themselves?
    - DBT mindfulness – Initially, identities in flux, with chaotic thoughts, ambivalence and contradiction. Ability to use skills develops with confidence in the skills and their ability – it's a virtuous circle. Entrants and Beginners do not understand a lot of skills especially the more conceptual ones like mindfulness and dialectics.
    - Mindfulness – Understand and want mindfulness from the start, understand themselves and are used to knowing what emotions and somatic feelings are like. They have more access to self-compassion and non-judgementality than the clients.
2. Feelings – How are they feeling? What is their state-of-mind?
    - DBT mindfulness – Entrants + beginners are in a fog, confused, feeling like mindfulness is pointless, self-blaming, feeling very bad about themselves, anxiety, low self-esteem. Have to be able to recognise thoughts, somatic feelings and different emotions before they can start using the skills. Gaining confidence – becoming more confident, but still many challenges and desires to do self-defeating behaviours. Proficient – strong expectations of

being able to use skills to manage the disorder and challenges. Knowledge they can recover is very important.
    - Mindfulness – generally positive throughout the experience with some frustration at the beginning, until the results started to show. Experience varies over time in a different way as different things come to the fore. Eventually very happy with a mindful life.
3. Learning challenges – what are the constraints and barriers to learning?
    - DBT mindfulness – Many constraints, BPD and their history makes it hard, self-doubt, self-harming (and comorbidities) and other self-defeating behaviours. Mindfulness is extra challenging. They do not want to let in the dreadful thoughts of what happened to them or thoughts about themselves or about self-harming. Very hard to sit with those thoughts. DBT does not cure BPD. DBT does not deal with trauma in the past.
    - Mindfulness – Early on, questioning if they are doing it correctly. Later, trying to integrate it more, facing time & cognitive constraints. Using purposeful mindfulness at first. Adding informal to formal mindfulness.
4. Learning tasks – How do they learn the skills?
    - DBT mindfulness – attending skills sessions, doing 2 minutes mindfulness every session, discussing homework, skills lesson, contributing; homework; completing diary card, attending therapy, trying to be mindful.
    - Mindfulness – going to MBSR/MBCT etc, starting to practice with guided meditations and exercises, initially some short sitting mindfulness and short informal mindfulness of daily activities. These get longer and more frequent with practice; remembering mindfulness; integrating mindfulness becomes a habit often based on daily activities and triggered by a morning formal mindfulness

5.3.3 Final UX maps

As discussed, the UX maps are chronologically based, as the users' experience and activities change over time. Once the planning and design stage was over, the maps were initially designed and then iterated over, using the categories above and filling in data from the studies, until they were complete.

24-hour DBT UX map

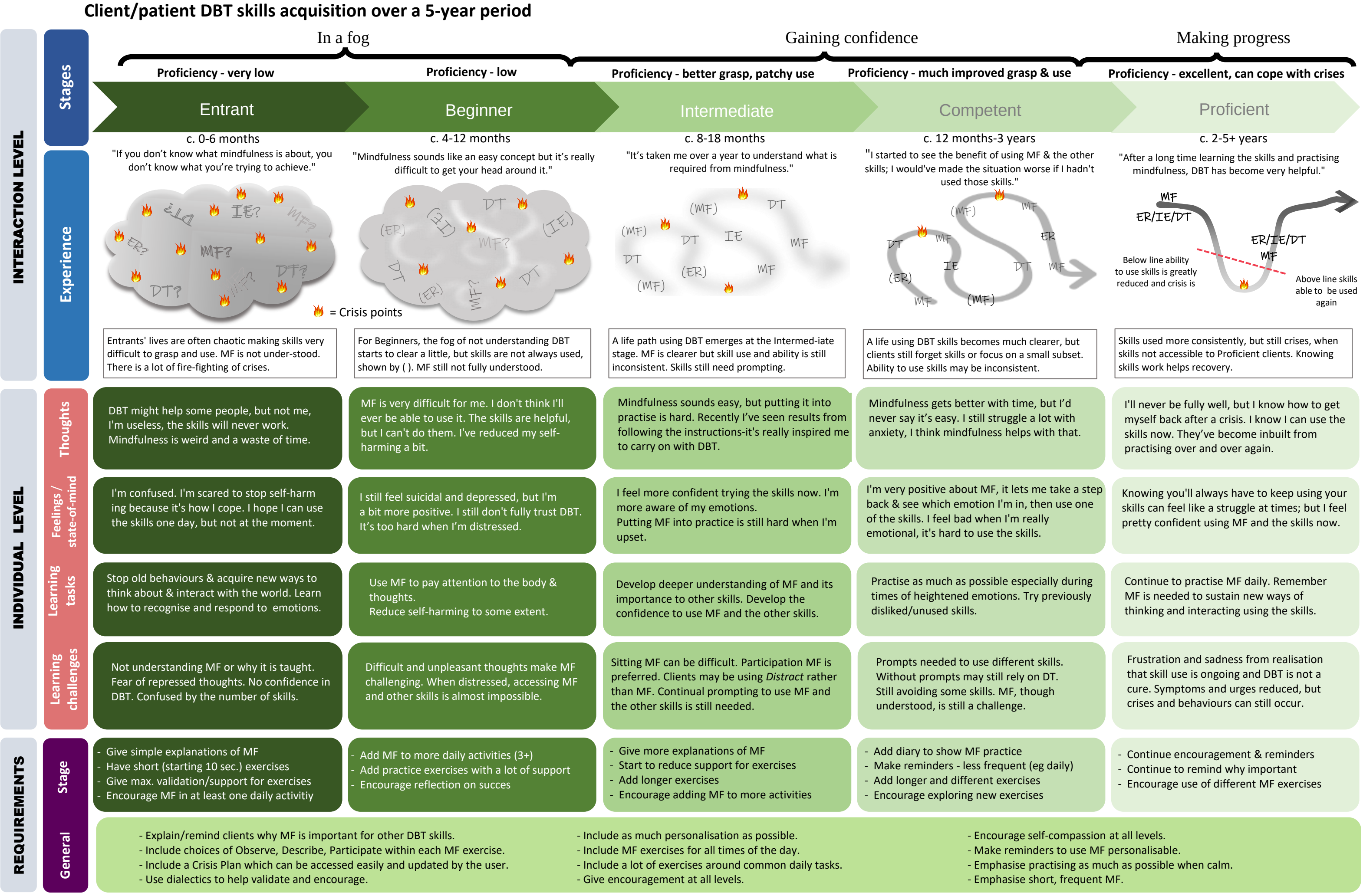
The 24-hour DBT UX map was the first map to be constructed (Figure 5.2), as 24 hours was considered a more straightforward experience to model than the five-years of DBT mindfulness learning. The 24-hour map is based on a day in India's life. It was not necessarily intended to be included in the URD, but was helpful as a first attempt at modelling a UX journey and as a starting point for India's scenario. It is necessarily different from the longer-term map, as the learning challenge is the same throughout, so is not explicitly modelled. Therefore, this map focuses on where in the day the mindfulness skill would be helpful. The headings are for the time of day, with a brief overview of what is happening at that time, India's thoughts and feelings towards what is happening, how she can use DBT to address the challenge, and dropping out of this, some possible requirements.

Table 5.2: Map of twenty-four hours in India's life

Stage	Waking	Breakfast/ leaving	Morning	Lunch	Afternoon	Hometime/ Dinner	Evening	Bedtime	Sleep
Overview	Not looking forward to the day ahead. Realised she hadn't done her DBT homework.	Travelling to DBT. The bus is crowded and the driver grumpy. It's a difficult journey.	DBT Group followed by a break to chat to other clients. One-to-one therapy.	Meeting Alex, a friend, for lunch, who is very late and doesn't see how upset India is.	College-catch up work and lecture. She decided to miss college because she felt so awful.	At home with her parents having dinner.	Discussion with parents about going to university next year. They want her to get a job and stay at home.	Exhausted and crying, after another row. She goes to bed early.	Ruminating about the day's events, it is difficult to sleep.
Thoughts	I don't understand DBT, I'm so bad at it. I couldn't do the homework. Why am I so useless?	Why can't I find my stuff? I can't do anything right. I'm pathetic, I do everything wrong. The driver hates me.	It's good to see people I know. I wish we didn't have to discuss the MF exercise. I get so nervous.	I don't want to eat much. I'm too fat. Alex is late, she always is. She doesn't care about me	Alex hates me I want to cut/ burn myself When I'm dead they'll be sorry	I hope we don't have another row about how much I eat or something else I've done wrong.	DBT will make me better. My parents don't understand I'll be fine on my own	I just want to go to sleep and never	My parents & everyone hates me. I'm an awful person. I'd be better dead
Feelings	Worried about DBT homework Scared friends at college will find out about the disorder.	Stressed and depressed. Anxious. Self-loathing. confused and unsure.	Happy, anxious, useless, hopeful, unsure exactly what she's feeling.	Angry, anxious, upset, dreading college, A mixture of emotions that are hard to name.	Very angry and upset with Alex for being late and herself for not saying anything when Alex arrived.	Anger at herself, her friend & her parents. Self-hate and self-blame.	Anger at her friend and at her parents. Very upset and tearful Self-hate. Self-blame.	Wants to self-harm, feels sad, lonely, depressed. A mixture of emotions that are hard to name.	Doesn't want to wake up. Overwhelmed by emotion.
Challenges	Try to address/ challenge feelings of fear and anxiety about things.	Try to bring down affect & address negative thoughts.	Practice mindfulness at home, so it's easier to discuss MF exercises when in group.	Use mindfulness to address thoughts and situation objectively.	Use mindfulness to recogise her emotions and thoughts.	Use mindfulness to access Interpersonal Effectiveness skills.	Use mindfulness to access Interpersonal Effectiveness skills.	Use mindfulness to process strong emotions and thoughts.	Use mindfulness to process strong emotions and thoughts.
Requirements	SET UP FOR DAY Before/shortly after rising do a short MF exercise. Acknowledge thoughts and feelings.	Helpful reminders of why DBT is so important. Short grounding MF exercise.	Discussion of the function of DBT MF at start of session. MF exercises to do while travelling.	Quick 2 minutes mindfulness to recognise when ruminating. May need help with finding other skill.	Help to recognise thoughts & feelings using MF. May then bring in other skills.	Reminder to stay grounded using MF. Use MF to help with other skills (e.g. Interpersonal Effectiveness here).	Grounding MF exercises. Crisis plan easily accessible.	Notice and stop ruminating exercises and reminders. Crisis Plan easily accessible.	Night-time MF exercise to help ruminating and bring down affect. Add relaxing and self-compassion.

Figure 1.8: UX map - 24 hours in India Birch's (Entrant) life

Table 5.3: UX Map of DBT clients' journey learning DBT skills



Client/patient DBT skills acquisition over a 5-year period

		In a fog		Gaining confidence		Making progress
		Proficiency - very low	Proficiency - low	Proficiency - better grasp, patchy use	Proficiency - much improved grasp & use	Proficiency - excellent, can cope with crises
INTERACTION LEVEL	Stages	Entrant	Beginner	Intermediate	Competent	Proficient
		c. 0-6 months	c. 4-12 months	c. 8-18 months	c. 12 months-3 years	c. 2-5+ years
	Experience	"If you don't know what mindfulness is about, you don't know what you're trying to achieve."	"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."	"It's taken me over a year to understand what is required from mindfulness."	"I started to see the benefit of using MF & the other skills; I would've made the situation worse if I hadn't used those skills."	"After a long time learning the skills and practising mindfulness, DBT has become very helpful."
		🔥 = Crisis points				
		Entrants' lives are often chaotic making skills very difficult to grasp and use. MF is not under-stood. There is a lot of fire-fighting of crises.	For Beginners, the fog of not understanding DBT starts to clear a little, but skills are not always used, shown by ( ). MF still not fully understood.	A life path using DBT emerges at the Intermed-iate stage. MF is clearer but skill use and ability is still inconsistent. Skills still need prompting.	A life using DBT skills becomes much clearer, but clients still forget skills or focus on a small subset. Ability to use skills may be inconsistent.	Skills used more consistently, but still crises, when skills not accessible to Proficient clients. Knowing skills work helps recovery.
INDIVIDUAL LEVEL	Thoughts	DBT might help some people, but not me, I'm useless, the skills will never work. Mindfulness is weird and a waste of time.	MF is very difficult for me. I don't think I'll ever be able to use it. The skills are helpful, but I can't do them. I've reduced my self-harming a bit.	Mindfulness sounds easy, but putting it into practise is hard. Recently I've seen results from following the instructions-it's really inspired me to carry on with DBT.	Mindfulness gets better with time, but I'd never say it's easy. I still struggle a lot with anxiety, I think mindfulness helps with that.	I'll never be fully well, but I know how to get myself back after a crisis. I know I can use the skills now. They've become inbuilt from practising over and over again.
	Feelings / state-of-mind	I'm confused. I'm scared to stop self-harm ing because it's how I cope. I hope I can use the skills one day, but not at the moment.	I still feel suicidal and depressed, but I'm a bit more positive. I still don't fully trust DBT. It's too hard when I'm distressed.	I feel more confident trying the skills now. I'm more aware of my emotions. Putting MF into practice is still hard when I'm upset.	I'm very positive about MF, it lets me take a step back & see which emotion I'm in, then use one of the skills. I feel bad when I'm really emotional, it's hard to use the skills.	Knowing you'll always have to keep using your skills can feel like a struggle at times; but I feel pretty confident using MF and the skills now.
	Learning tasks	Stop old behaviours & acquire new ways to think about & interact with the world. Learn how to recognise and respond to emotions.	Use MF to pay attention to the body & thoughts. Reduce self-harming to some extent.	Develop deeper understanding of MF and its importance to other skills. Develop the confidence to use MF and the other skills.	Practise as much as possible especially during times of heightened emotions. Try previously disliked/unused skills.	Continue to practise MF daily. Remember MF is needed to sustain new ways of thinking and interacting using the skills.
	Learning challenges	Not understanding MF or why it is taught. Fear of repressed thoughts. No confidence in DBT. Confused by the number of skills.	Difficult and unpleasant thoughts make MF challenging. When distressed, accessing MF and other skills is almost impossible.	Sitting MF can be difficult. Participation MF is preferred. Clients may be using *Distract* rather than MF. Continual prompting to use MF and the other skills is still needed.	Prompts needed to use different skills. Without prompts may still rely on DT. Still avoiding some skills. MF, though understood, is still a challenge.	Frustration and sadness from realisation that skill use is ongoing and DBT is not a cure. Symptoms and urges reduced, but crises and behaviours can still occur.
REQUIREMENTS	Stage	- Give simple explanations of MF - Have short (starting 10 sec.) exercises - Give max. validation/support for exercises - Encourage MF in at least one daily activitiy	- Add MF to more daily activities (3+) - Add practice exercises with a lot of support - Encourage reflection on succes	- Give more explanations of MF - Start to reduce support for exercises - Add longer exercises - Encourage adding MF to more activities	- Add diary to show MF practice - Make reminders - less frequent (eg daily) - Add longer and different exercises - Encourage exploring new exercises	- Continue encouragement & reminders - Continue to remind why important - Encourage use of different MF exercises
	General	- Explain/remind clients why MF is important for other DBT skills. - Include choices of Observe, Describe, Participate within each MF exercise. - Include a Crisis Plan which can be accessed easily and updated by the user. - Use dialectics to help validate and encourage.	- Include as much personalisation as possible. - Include MF exercises for all times of the day. - Include a lot of exercises around common daily tasks. - Give encouragement at all levels.		- Encourage self-compassion at all levels. - Make reminders to use MF personalisable. - Emphasise practising as much as possible when calm. - Emphasise short, frequent MF.	

LEGEND: MF - Mindfulness IE - Interpersonal Effectiveness ER - Emotion Regulation DT - Distress Tolerance

Five-year DBT mindfulness UX map

The five-year DBT mindfulness UX map (Figure 5.3) shows the stages in the DBT acquisition process, based on the stages which were found when creating the personas (Section 5.2.3). Within the stages, the high-level overview is also given, as well as the skill proficiency level and a rough estimate of the time each stage takes. There is also a quotation from one of the client interviews, to sum up each stage. In the experience level, the UX is summarised graphically. Starting with the *in a fog* metaphor, for the Entrant level client, a cloud of swirling unclear skills and crises are shown whirling around. As they progress and start to embed the skills, a path through life using the skills emerges. However, as the final graphic shows, even proficient clients face challenges when the skills are no longer available and they may hit a crisis point. Thoughts and feelings are given in the client's voice and many are direct quotations. The learning tasks and learning challenges come from the client and clinician interviews.

At the bottom of the map, from all the information above, the requirements drop out. First for the individual stage level, and then some general requirements for the whole DMHI. The requirements are expanded and explained below, for inclusion in the URD.

5.3.4 Expanded General Requirements

The requirements came from the interviews, the User Experience Maps and the Personas. This is supplemented by findings from a previous study on non-clinical participants acquiring a mindfulness practice. All assumptions need to be tested in prototyping in the *Define* phase.

Explain/remind users why Mindfulness is so important in DBT

In the interviews, clients at all levels identified the difficulty of learning and maintaining Mindfulness skills. They did not understand mindfulness or why they were doing it initially and this continued for a long time into therapy. All experienced interviewees reported that it was 12+ months before they "got" mindfulness and often longer before they had the confidence to use it.

Include choices of *Observe*, *Describe*, *Participate* within each Mindfulness exercise

In the interviews all clients expressed a preference for one of the *What* types of Mindfulness skills, and quite often a strong dislike of another one. However, by including a choice of all three for the same exercise, once clients feel comfortable using *Observe* for example, they could then expand their experience and try *Describe* or *Participate* for the same type of exercise, perhaps with gentle encouragement. Prototyping would show if encouragement to try another skill was helpful here.

Include a Crisis Plan which can be accessed easily and updated by the user

The clients have a written plan for when they are in a crisis and have urges to self-harm or attempt suicide. The Plan should be easy to add to the app by the client and easy to edit when necessary. It should be easily accessible, perhaps by a Crisis button on the app's home screen. A crisis plan was also added to the MedTep app (Suñol et al., 2017), although its use was not recorded. The Plan can include:

- Contact details for therapists/GPs/etc – useful information
- Individual crisis plan details, e.g. things/skills that help

Include a self-soothe area which can be accessed easily and updated by the user

The inpatients and *The Retreat* and some of the outpatients had self-soothe boxes. These contained items which were safe for the person and helped to calm and soothe them when they were thinking about traumatic situations and considering self-harming. In a DMHI, these could include digital objects like photographs, music, sounds etc.

Use dialectics to help validate and encourage

The clinician interviews showed that dialectics are an important part of DBT. The key dialectic of DBT is the need for the client to accept themselves as they are in the moment and the need for them to change. Thus, clients need validation and compassion if they have not used the app for a few days, but also need to be reminded to be mindful to help or maintain change.

Include as much personalisation as possible

Clients expressed a lot of differences when asked about colours and backgrounds for the app. Clients may be triggered by a range of things, allowing customisation can help to lessen this. As well as the exercises being very flexible and giving the client a lot of choice in how they do them, the look of the app should also be customisable for voices/colours/pictures etc. to account for different tastes and triggers. This should include, but not be limited to:

- A choice of verbal or written instructions
- Choice of voices – male, female, different accents
- Choice of timings and extendable timings for each exercise
- Exercises include choice of movement or being stationary

Include Mindfulness exercises which can be used at all times of the day and with many common daily tasks

Again, this was a finding from both the non-clinical mindfulness study and the client study. Mindfulness is easier to learn if practised first thing in the morning. Almost all of the long-term mindfulness practitioners had a morning practice. Building in an optional formal meditation practice or morning mindfulness ritual may be helpful. But, if the morning is a difficult time, the DMHI should have DBT practices for all times of day. Also, as many of the participants favoured Participate Mindfulness, Mindfulness based around daily tasks, which the client can manage, should be an option. Study 1 found that when mindfulness is done at the same time or with the same activity every day, it starts to build a habit. This can be encouraged at all stages, but should not be mandatory. The chosen activities and time of day may change both within stage and from stage to stage.

Give encouragement at all levels

It is important to validate clients with BPD. Standard Cheerleading phrases (a DBT skill) will be extended by customisable/client added phrases. Metrics (positive only) for time using app or Mindfulness exercises completed may be added if prototyping shows they are a liked feature.

Encourage self-compassion and being non-judgemental at all levels

Encouraging self-compassion is part of the *How* Mindfulness skills, and is very important as this client group often struggle with self-compassion. Being non-judgemental is another of the *How* skills of DBT mindfulness.

The non-clinical participants had chosen to undertake mindfulness and understood what the practice entailed and what was expected of them. Whereas, the DBT clients had not, which meant some found it extremely strange at first, and did not know what was expected or how to achieve it. DBT Entrants and Beginners need a lot of support when facing thoughts they have been trying to suppress, as well as dealing with the fear of feeling their emotions, which Mindfulness can bring. Some of the Proficient clients still saw Mindfulness skills practice as a chore, but they also understood it was important that they continued to do it. Therefore, it is very important that the app encourages self-compassion at all stages. The app should also remind users that self-compassion is very important in dealing with the thoughts and emotions that arise during mindfulness, as well as the times when they are not mindful.

Make reminders to use Mindfulness personalisable

Clients at all stages said that they forget to practice mindfulness, so reminders are may help. Phones do not get bored of saying the same thing over and again, so are good at reminding people to do tasks. However, the client should be able to chose the time and wording of the reminder, so that the reminder does not make them feel worse. Setting an intention or making a commitment to be mindful was found to be helpful to some participants. Reminders can be linked to times of day/places/activities which the clients finds difficult or triggering, or which give them a calmer place and space to practice.

Emphasise practising as much as possible when calm

Mindfulness is much easier to practise when not in crisis. Therefore, the DMHI should emphasise practising as much as possible when calm. Both the non-clinical mindfulness study and the clients study reported mindfulness being much easier when calm (*relaxed mindfulness*). Clients should be encouraged to do very short mindfulness practices when they feel calm. DBT clients may associate mindfulness only with difficult situations, but practising when not overwhelmed is very important.

Emphasise short, frequent mindfulness practice

Regular practice is the best way to learn and maintain mindfulness. Short regular practice is more beneficial than longer but less frequent practice, so even very short (30 seconds - 2 minutes) but frequent mindfulness is a good way to build up the practice. At the beginning of DBT this may be all that is possible and as clients progress they may still find very short exercises to be helpful at times.

Do not include human representation or communication

Clients were very clear that they did not want an app in which they could communicate with other people. Neither were they keen on having representations of humans or any animate objects like animals in the app.

Make the levels an underlying concept

This would need further testing at the lo-fi prototyping stage. However, the levels are a concept for DBT skills acquisition, rather than something that is built into DBT. If the app overtly named the stages, there is a danger that clients would use lack of progress from one stage to another to castigate themselves.

One design idea which would need further testing with clients is for the DMHI to show progress along a path. The metaphor for the system, which might be seen graphically in the DMHI is a labyrinth (in the original sense of a single, non-branching path, which leads to a centre). As well as giving steps along the way (without overtly naming the steps), the labyrinth is a traditional meditation symbol relating to wholeness. Like that of the clients in acquiring the skills, the labyrinth is a meandering but purposeful path. However, whether this is an overt or a covert feature of the DMHI would need further user-testing.

5.4 Scenarios

Scenarios are short narratives which allow the requirements to be specified in terms of what the end-users will do with the system to achieve their goals (Rosson et al., 2002; Carroll & Rosson, 1990). Scenarios discuss tasks, actions and processes, without committing to how they will be implemented, allowing a good exploration of the design space without any actual designs, and are particularly useful for discussing complex interactions in a domain.

Each scenario consist of a set of *Goals* for the scenario; a *Problem Scenario* which shows the existing state of affairs with current practices and thoughts, without using the DMHI. This includes a set of *Claims* about the current system, with the claims being analysed into positive and negative aspects of the claim. The claims are then used to inform the *Activity Scenario*, which shows how the same narrative might look if the proposed system were used to address the negative claims about the current system. The key activities and goals are replicated and aided by the proposed system. The activity scenario also includes a set of claims, which can be used to further inform the design.

The high-level vision for the system was using a DMHI to help deliver DBT mindfulness skills, initially (with the possibility of expanding the DMHI to include the other skill modules at a later date). The direct stakeholders, who will be using the system, are the DBT clients. The indirect stakeholders are the clinicians, partners, parents and significant others of the clients. They have an interest in the system, and in the system being used, but do not use the system themselves. The scenarios are based on the personas, the UX maps and the interview data, and supplemented with incidents which arose in the group skills sessions, as well as the findings from Study 1.

5.4.1 India Birch

Scenario 1 – Unhelpful thought processes

The starting point for the first scenario was the following interview data:

> One of the skills is judgementalness. I don't suffer with that so much [now] because I've learned not to criticise myself if I'm having judgemental thoughts. So yeah it is a lot more part of me, but I think as time goes on... it's easier to just think "Oh I need to use [the skills]." [Maisy]

As the quotation illustrates, both being self-judgemental and struggling to use the skills are very common among clients, especially during the first six months.

In the 24-hour UX map, India was anxious all day due to rushing and having DBT. This scenario uses the India Birch persona, and the scenario expands on an incident from the 24-hour UX map, with the basic rationale being that India is self-judgemental and self-critical, does not challenge these thoughts or remember to practice mindfulness or self-compassion. This leads to her becoming overwhelmed by her thoughts and emotions. A DMHI which would help to remind her to use the mindfulness skill and aid her in acquiring the habit of using DBT mindfulness could help to overcome the feelings of confusion and being overwhelmed which an entrant level client feels when first learning DBT mindfulness skills.

Scenario 1 – Problem scenario

Scenario 1 – Problem scenario goals

India's goals for this scenario are mainly about having a better internal dialogue and coping better with her emotional state, which might apply to a number of different situations.

1. Be able to go to college to do some work.
2. Stop having overwhelming thoughts.
3. Go out without too much anxiety.
4. Notice when negative thoughts start to spiral down and intervene to stop them.

The problem scenario shows India's current practices and thoughts.

Scenario 1 – Problem Scenario

> India was feeling anxious, she didn't want to go out, but she needed to go to college to do some work. She got up already feeling awful and dreading the day ahead.
>
> She managed to get dressed and put her make-up on, but walking to the bus stop she felt awful. Her thoughts ran on about how she looked stupid, her clothes were old and ugly, she was ugly, she was wearing too much make-up, her hair was a mess, everyone was thinking how awful she looked.
>
> On the bus, she didn't have the right change and the driver snapped at her, making her feel even worse. In tears she went to find a seat to hide in. Why was she so soft? She was useless. This was a terrible idea, she should never have left her room to go into college. She would leave, because she couldn't keep doing this. Her thoughts turned to self-harming and pulling out her hair.
>
> Her judgemental thoughts continued: I'm useless, I can't even catch a bus, I have no nice clothes, because I have no money, because I'm wasting my time at college, I'll never be able to go to university. I have a shit job because I'm useless at everything and no one else would employ me. I'll never get anywhere or be anyone. Lenny left me because I'm such a mess and ill all the time. I would be better off dead. Over and over the thoughts ran, becoming nastier and more self-critical.
>
> As the bus drove slowly through the morning traffic, she vaguely knew she should be using her DBT skills but didn't know where to start. Her negative emotions became stronger. She'd been told by her therapist that she could use mindfulness to anchor herself to the moment, but she didn't understand what that meant. It sounded so easy when they explained it in the skills group and everyone seemed to get it, although her friend Charlotte had told her that she didn't understand it either. Stupid mindfulness, thought India, I'm never going to get better, DBT is a waste of time. She tried to stop the thoughts, but she couldn't clear her mind, it was too busy and there were too many people on this bus distracting her to try to practice mindfulness. A child was crying and screaming. Some older kids were laughing. They were probably laughing at her.
>
> She shrank down into her seat. Her heart was racing, her mouth felt really dry. She couldn't move. Her thoughts were overwhelming and led in a downwards spiral. India wasn't able to break the thought train or stop the negative, critical voice. She decided to get off the bus and just walk home without going to college. She pressed the bell to stop, feeling more guilty and depressed because she still hadn't caught up the work she had missed.

Scenario 1 – Claims analysis for problem scenario

A claims analysis shows the features of the problem scenario which have important outcomes for the persona's knowledge and practice (Rosson & Carrol, 2002, p.13).

The claim is followed by positive and negative analyses.

Having a negative outlook from the start of the day

+ Negative thoughts are a way of signalling possible danger in the environment.
- An unchallenged negative outlook makes doing daily tasks harder.
- India has no way to stop the negative thoughts.
- India has no way to challenge the thoughts.

Time alone whilst walking allows thinking space

+ India has some time alone to think.
- India is not using this time to practise mindfulness and other DBT skills.
- India's thoughts are increasingly negative.
- Allowing rumination to continue, India's negative affect deepens.

External factors and reactions can have a powerful effect

+ Sometimes people's reactions are based on an action that should be reflected on.
- India is not questioning whether the external factors are reasonable.
- India is not challenging her thoughts and reactions.
- The strong affect is leading to thoughts of self-harm and self-defeating behaviours.

Rumination spirals into thoughts of self-harm and suicide

- Unchecked rumination does not easily revert to more helpful thoughts, without challenge.
- Unchecked rumination is dangerous for India's health and well-being.

Low affect prevents normal daily activities and goals from being met

+ Avoidance means India is protected from more perceived low affect in the short-term.
- However, India is not going to college where she could speak to someone who could help.
- In the long-term India feels worse because she may do a behaviour, and she is not living the life she wants.

Further explanation of Scenario 1

Interpretation of the world

This scenario shows that India's interpretation of the world is not necessarily realistic or helpful for her. India is finding it very difficult to stand back from her mental processes and see them as passing thoughts. Mindfulness can help to challenge skewed views of reality and would help with this, allowing India to remind herself that thoughts are not real, but only comments on reality and not truths about the world.

Coping with everyday tasks

Clients often struggle with everyday tasks, for example, going to college, because they feel overwhelmed by negative thoughts. India is strongly affected by external worry. She is feeling anxious about going to college. It may be reasonable to feel a little bit worried as she has missed some work, but India's negative feelings spiral into negative thoughts about how she looks, making herself feel a lot worse. Another external incident which upsets India is the bus driver's attitude. She takes the driver being rude as proof that she is bad, rather than being able to rationalise about the bus driver's attitude, or about people being grumpy in general. She uses this incident to turn her distress back in on herself.

Misunderstanding mindfulness

As an entrant level client, India is unsure of how to begin using mindfulness. The scenario shows that India incorrectly thinks that mindfulness means clearing the mind of all thoughts. She is unable to do this, but as the *Nonclinical Practitioners Mindfulness Study* showed, using mindfulness in a difficult situation (i.e. *purposeful mindfulness*) is challenging, unless it has been practised in a relaxed situation first. India has not been practising mindfulness very much, so in this scenario, she is not able to access it.

Scenario 1 – Unhelpful thought processes – Activity Scenario

The design scenario shows how the proposed system could help India in the scenario environment. It reproduces the activities that India was trying to accomplish, to go into college and catch up on work, but also to recognise and deal with difficult emotional states and thoughts. The activity scenario shows how the app could support India in achieving her goals by addressing the claims made about the problem scenario.

S1 Activity Scenario – Helping India's unhelpful thought processes

> India was feeling anxious, she didn't want to go out, but she needed to go to college to do some work. She had set the reminder on her DBT mindfulness app for an early morning mindfulness exercise. She chose a *Describe* mindfulness exercise. As she had only been doing DBT for 5 months, it was very short, lasting only two minutes, asking her to describe what she could smell, see and hear. At the end there was a brief message about being non-judgemental and self-compassionate. She was then prompted to see if she would like to do another exercise or if she would like to make that mindfulness exercise her exercise of the day. She had found it useful and set a reminder for when she was on the bus, which she knew to be a difficult time for her.
>
> She liked doing a short mindfulness exercise first thing, and managed to get dressed and put her make-up on feeling okay, but walking to the bus stop she started to have negative thoughts. Her thoughts ran on about how she looked stupid, her clothes were old and ugly she was ugly, she was wearing too much make-up, her hair was a mess, everyone was thinking how awful she looked. She decided to try a walking mindfulness exercise

that she had seen on the app, using her headphones. She picked another *Describe* mindfulness to describe her surroundings on the way to the bus-stop. Her judgmental thoughts continued a little, but she noticed the negative self-talk and wondered what other skills she should be using to bring them down, but it was hard and she gave up. However, she was pleased she had noticed herself noticing. The mindfulness app seemed to be helping a little. When she felt a bit calmer, she tried to describe how she was feeling as she waited for the bus.

On the bus, she didn't have the right change and the driver snapped at her, making her feel worse. In tears she went to find a seat to hide in. Her thoughts raced: Why did everyone hate her? Why was she so soft? She was useless. She would be better off dead. This was a terrible idea, she should never have left her room to go into college. She would leave, because she couldn't keep doing this. Her thoughts turned to self-harming and pulling out her hair.

Once seated she glanced at her phone and saw the reminder to do the exercise of the day. This reminded her to open the app. She chose to do a mindfulness exercise from the app that she'd done a few times before whilst calm, to check her feelings and thoughts. On doing the exercise, she realised she was feeling upset with the driver's reaction. She also looked at her notes on useful skills in the Crisis Plan and saw she had noted the half-smile skill as being useful when she was feeling bad, remembering that facial expressions can affect mood. She realised that she was still having some other negative thoughts, and noticed the thought patterns that were her 'go to' when she was feeling depressed or anxious; self-criticism, about her looks and abilities, about past wrongs and future failings. As her judgmental thoughts continued, she tried to challenge them, and she remembered another mindfulness exercise on the app which had her naming thoughts and letting them go. After a minute or so though it became too hard, so she stopped.

As the bus drove slowly through the morning traffic, she vaguely knew she should be using her DBT skills and using the app. Her negative emotions started to became stronger. She tried to stop the thoughts, but she couldn't clear her mind, it was too busy. A child was crying and screaming. Some older kids were laughing. They were probably laughing at her. She decided to get out the app and see if there were any mindful journey exercises. She also made a note to remind herself to be mindful on the bus rather than on the walk to the bus-stop. She found a *Describe* exercise for travelling and another for anchoring in a busy place or situation. She chose to try the latter in *Describe* mode. The app prompted her to try an *Observe* exercise; however, she decided *Describe* was easier for her when there were so many people on this bus and so much noise. The exercise was another short one which prompted her to be aware of the sounds around her and describe them, rather than trying to block them out.

The short 2-minute exercise helped her to be more focused on what was happening around her and her thoughts about that. She also noted a particularly persistent negative thought and made a note in the app Notes section to discuss it with her therapist in the next one-to-one session. By the time the bus arrived at college, India was still feeling apprehensive, but was also looking forward to seeing her friends and doing some college work.

Scenario 1 – Claims analysis for activity scenario

Starting the day with a short mindfulness exercise

+ Negative thoughts are challenged at the start of the day.
+ India is able to chose the exercise she likes.
+ India can set an alarm to help her practice mindfulness.
+ Doing mindfulness first thing may give India a chance to practice *relaxed mindfulness*.
- India has to be willing to do the exercise.

Time alone whilst walking allows thinking space

- India's thoughts are increasingly negative when she is alone with time to think.
+ India is able to use the time to practise mindfulness.
+ India is able to notice negative self-talk, even if she does not yet have other skills to deal with this.
+ Rumination leading to deepening negative affect is prevented, although some negative thoughts are still present.

External factors and reactions can have a powerful effect

+ Sometimes people's reactions are based on an action that should be reflected on.
- Negative reactions can trigger strong negative affect.
+ India is able to use the app to help understand and challenge her thoughts and reactions.
+ India is able to look at her Crisis Plan easily using the app.

Mindfulness lowers thoughts of self-harm and suicide

- Unchecked rumination is dangerous for India's health and well-being.
+ The app can be used in a crisis to help suggest skills.
+ Different mindfulness skills and modes can be used to help negative thoughts.
+ The app can be used to note down negative thoughts for later discussion.

Reminders and easy access to mindfulness help daily activities and goals to be met

+ India is able to go to college and will not fall behind with her work.
- India is seeing some of the positive results from mindfulness which will prompt her to keep practising the skill.
- There may still be some negative affect, but it has lessened considerable.

Scenario 1 – Further explanation of the activity scenario

Supporting negative mood

This scenario shows how the app could be used to help India to support her negative mood and notice and challenge her thought processes. This means that instead of not wanting to be in contact with people, and wanting to self-harm, she would have more confidence to go to college, interact with friends and catch up on her work.

Types of mindfulness exercise

The scenario starts with a short mindfulness exercise at the start of the day. The non-clinical mindfulness practitioners found a formal early morning practice very helpful. As India is an Entrant level client, she cannot access long mindfulness sessions, but even a short mindfulness exercise first thing might help to set the tone for the day and help to build up her practice. The app encourages India to use the mindfulness skill in particular, but also to build on mindfulness by using other skills which might help in certain situations, once she can become aware of her thoughts and emotions.

Implications for app design

The app might have an area where clients can note the skills that they find useful or that they forget to use, as clients mentioned they thought this would be useful in the interviews.

5.4.2 Russell Jones

Scenario 2 – Different modes of DBT mindfulness

The starting point for this scenario was the quote:

> I just don't have time to sit down and dwell for 2 minutes, 3 minutes, 4 minutes, because I have a busy lifestyle. [Suzy]

This scenario illustrates that Russell Jones is really struggling with the mindfulness skill and does not understand what to do. He also wants to be more mindful of his emotions, especially when he starts getting angry.

Scenario 2 – Problem scenario

Scenario 2 – Problem scenario goals

1. To be able to understand mindfulness.

2. To use mindfulness to help with noticing anger.
3. To stop angry outbursts with no control.
4. To stop feeling in a fog with the skills.

Scenario 2 – Problem Scenario

Russell was finding learning the skills quite difficult and struggling with mindfulness in particular. His girlfriend had bought him a book on mindfulness and he had downloaded an app onto his phone, but he found using both difficult. The breathing exercises triggered unhappy memories. In DBT skills group he did not really understand what was meant by the *Observe* skill. He blamed himself for being too stupid to understand, and mindfulness for being too weird. Why were they teaching them mindfulness anyway?

Russell's hobby was playing football, he liked to go to practise twice a week and sometimes played on a Sunday. He had heard in skills group about using mindfulness when participating and wondered if he could practise playing football mindfully. He tried, but found it a struggle to know if he was doing mindfulness the correct way.

After football he met his girlfriend for a drink, he really wanted to see her, but was feeling annoyed about being taken off the pitch early, because there had been a lot of players at practice. He discussed it at length with her until she tried to change the subject. They then got into an argument because he thought she wasn't taking him seriously, which ended with her going home. He knows he was in the wrong and that he should try to practice mindfulness and other skills more, but finds it very difficult to know where to start.

Scenario 2 – Claims analysis for problem scenario

Practising different mindfulness *What* modes is encouraged
+ Russell is trying to practice different modes of mindfulness. - Russell blames himself for failure to understand mindfulness when he fails. - Russell does not know how to begin doing the participate skill.

Standard commercial apps and books may not be suitable for DBT mindfulness
+ There are many different commercially available mindfulness apps and books. - The apps are not directed at DBT clients and may contain exercises which are too difficult or unpleasant in the early stages of DBT. - Being unable to use the app leads to Russell having negative thoughts about himself and mindfulness.

Mindfulness helps awareness of affect and cognitive processes

+ Mindfulness can be used to help in relationships by bringing awareness of mental states.
- Russell is unable to access and observe his emotions and thoughts, leading to an argument.
- Russell is engaging in black-and-white thinking, without using mindfulness to challenge his thought processes.

Scenario 2 – Further explanation of the problem scenario

DBT modes of mindfulness

This scenario shows Russell Jones, a Beginner client who is finding mindfulness challenging. He has been unable to use a conventional mindfulness app, as in the early part of the therapy they are often not suitable. Like many clients, he finds one of the modes of mindfulness more difficult (Observe), but would like to try using Participate more. Playing football is something that Russell enjoys and this would be a good chance to try relaxed mindfulness, without pressure. However, not having practised other participate exercises he finds it difficult.

Emotional dysfunction

This scenario also shows that Russell is not good at judging his emotional state. He is displaying emotional dysfunction, reacting very negatively to a small but annoying incident, which he blows up into a big deal. He is also displaying black and white thinking, when his girlfriend seems slightly unsympathetic, he starts an argument, even though she has listened to him discuss it.

S2 – Activity Scenario – Different modes of DBT mindfulness

S2 – Activity Scenario – Helping Russell with different modes of DBT mindfulness

Russell was finding learning the skills quite difficult and struggling with mindfulness in particular. He tried the DBT mindfulness skills app. It offered him options to try different modes of mindfulness, which he found helpful. One exercise talked him through making a hot drink using mindful participation, which he found beneficial in understanding what was required. The app also had some *Observe* mindfulness exercises. However, he decided to leave those until he felt more comfortable with participate. He was also happy to read and understand a short paragraph about how DBT skills used mindfulness as the core skill.

Russell's hobby was playing football, he liked to go to practise twice a week and sometimes played on a Sunday. He had heard in skills group about using mindfulness when participating and wondered if he could play football mindfully. He had been practising mindful participation all week doing short exercises at home and using the app. He tried playing mindfully, and found it a bit difficult, but it helped him to focus on the game and his thoughts around what was happening. He felt pleased with his efforts, and thought he would continue trying, although he also knew he needed to practise at home more.

After football he met his girlfriend for a drink, he really wanted to see her, but was aware that he was annoyed about being taken off the pitch early, because there had been a lot of players at practice. On the way to the pub he noted the incident in the diary on the app. He discussed it for a while with her, and realised his emotions were running very high, after mindfully *checking in* with himself, which he had also been practising using the app. He did not want to get annoyed with his girlfriend, so he asked her if she would mind if he had an early night. Whilst walking home he listened to another mindfulness exercise and tried to bring down the heightened affect and notice his angry thoughts.

Scenario 2 – Claims analysis for activity scenario

Practising different mindfulness *What* modes is encouraged

+ Russell is trying to practice different modes of mindfulness.
+ The app gives him step by step instructions as he is doing the actions.
+ Russell can practise the participate skill whenever he wants to, with guided exercises.
+ Russell is not ready to try the Describe skill yet, but the app can remind him from time to time.

Standard commercial apps and books may not be suitable for DBT mindfulness

+ There are many different commercially available mindfulness apps and books
- The apps are not directed at DBT clients and may contain exercises which are too difficult or unpleasant in the early stages of DBT.
- Being unable to use the app leads to Russell having negative thoughts about himself and mindfulness.

Mindfulness helps awareness of affect and cognitive processes

+ Mindfulness can be used to help in relationships by bringing awareness of mental states.
- Russell is unable to access and observe his emotions and thoughts, leading to an argument.
- Russell is engaging in black-and-white thinking, without using mindfulness to challenge his thought processes.

Scenario 2 – Further explanation of the activity scenario

In the activity scenario, possible uses of the app to explore different modes of mindfulness, known as the *What* skills are shown.

In addition, as seen in the previous chapter, different stakeholders may have conflicting ideas about the context, the content, the system and the goals, and therefore conflicting requirements may emerge. Requirements analysis is a skill of judging, interpreting and balancing. In practise, generating requirements would most likely be done iteratively with design, development and evaluation. However, focusing on the requirements generation process, allows a discussion about how this can help Health research to better engage users at the design stage.

The requirements are not a collection of inflexible directions, but rather guidelines which keep the DMHI remains consistent (Rogers et al., 2012). In a mental health setting, it is important to have requirements which can be used to state the desired therapeutic outcomes of the system (Doherty et al., 2010), as well as the users' goals for and experience with the therapy. Having therapeutic outcomes as a requirement also helps in setting some of the metrics against which the system will be tested. Chapter 4 highlighted how the clients and clinicians experiences DBT skills training and made some suggestions about how this might translate into a DMHI.

The process detailed in this chapter is based on existing UCD methods of creating personas, scenarios and experience maps. However, as the users have a mental health disorder, in this research the "standard" methods are extended and used slightly differently, incorporating high-level details of the challenges brought by the disorder. In addition, the personas use the first-person voice to reflect the seriousness of their illness and make them more empathetic and are more detailed than usual. This also allows a reflection of the early stage clients inability to construct a narrative about their agency to bring about a deep understanding and control of the skills (Section **??**, which becomes resolved in the later stage clients. Experience maps are used as part of the requirements document, because, whilst the four personas give good snapshots of clients at different stages in the process, the journey is not as straightforward as that of the non-clinical population in acquiring and embedding mindfulness. This needs to be reflected in a DMHI which is appropriate for clients at all stages of the DBT therapeutic process.

5.5 Discussion

This chapter describes Study 3, documenting the *Define* step in the UCD process (Section 2.2). It details creating a URD for a DMHI to help clients acquire DBT Mindfulness skills. A URD was necessary, because for complex users and therapies, such as those involved in this research, listing the requirements in Section 5.3.4, without a context, would be too abstract. Designers would not have an insight into any potential constraints or taboos which could adversely affect the DMHI and its effect on the users. For example, people with BPD have very sensitive affective reactions (Linehan, 1993). If they are distressed, their reactions can result in self-harming and suicidality, so it is very important that requirements are correctly understood, so that nothing in the DMHI will unintentionally cause harm to the end-users.

5.5.1 Contributions

The work in this chapter makes the following contributions, adding to other work on doing design in challenging contexts (Wärnestål et al., 2017; Doherty et al., 2010; Thieme et al., 2016):

1. It provides design insights into how, in the *Define* step of a UCD process, requirements can be defined, making explicit the necessary steps, the flexibility and the extensive time required, which other researchers may find of benefit when working in similar areas. The requirements consisted of personas at different stages in the DBT journey, a UX map showing the journey through acquiring DBT and scenarios. This was a time-consuming process and the requirements went through many iterations, as it was not clear from the previous literature how such designs should be done in the BPD/DBT context. Though I discussed my work with supervisors and clinicians, I was working alone, and once the data was collected I had no access to the stakeholders. One suggestion from having undertaken this process, is that it would have been better accomplished by a team, with at least two people to share the workload and the problems.
2. It shows that UCD can be done in this context, but it needs to be adapted for people living with BPD. This is also very useful for researchers working in this area, as it details where adaptations were necessary. In this way the work also makes contributions to design knowledge. For example, the models need to be more explicit in detailing aspects of the disorder and its causes, and they should include a lot more detail than a standard persona would (cf Figure 2.2). In Section 5.5.3, below, I reflect on where the adaptations were made.
3. In developing the requirements, I also had to manage certain design differences between the views of end-user clients and stakeholder DBT clinicians towards some of the skills. In this, empathic UCD gave me a deep understanding of the users' lived experience of acquiring DBT, emotional experiences of having BPD and their personal contexts, as well as insights about the clinicians' feelings and motivations towards the clients. The dialogical approach helped me to make design decisions about what to include and not include, after listening to differing stakeholder views. This helped to define areas to ask about in Study 4. It also helped in how to approach the URD, which other researchers may find useful when working in a similar context. There was also a dichotomy which arose between the individualistic view of the DBT clinicians towards the clients in therapy seen in Study 2, and the aggregated approach to design, in UCD, for example using archetypes of end-users in personas. These are addressed in the requirements, but would need prototyping in the *Design* and *Evaluate* steps in future work to fully resolve.
4. I produce a URD, which can be used by a design team to develop the DMHI. The full URD, with detailed requirements, can be found in Appendix I.

5.5.2 URD design process overview

All three of the tools developed here look a very long time to develop and get right so that they reflected the clients properly. As a design team would not have access to recordings, modelling users and their requirements accurately is very important as the URD becomes the source of truth for the design.

Personas

I tried a number of ways to synthesis my data (see Chapter 5). The assumption personas were found to be useful for setting down my ideas and revealing any biases. They also made good focuses for helpful discussions with clinicians. Ultimately, I had to define the personas using other criteria; however, I retained some content from the assumption persona and used it in the details of the final personas.

Compared to a non-clinical more traditional persona (see Figure 2.2 in Chapter 2 for an example), the personas presented in this chapter have a lot more detail, including details of abuse, self-harming and other presentations of the disorder. As well as making the personas more empathetic, as people with BPD are often classified as difficult or manipulative, it also ensures that constraints and taboos, for example on breathing-type mindfulness practices or bodyscans, are well-motivated for a design team. They also need to take seriously the self-harming aspect of these users, but also to understand that at the beginning, DBT seeks to reduce self-harm and other self-defeating behaviours, rather than stopping them, as that is not possible. Validating any reductions made is the most important thing in the early stages of DBT. Personas have been used previously in healthcare, Turner et al. (2013) used personas and scenarios to model communicable diseases. They have also been used with vulnerable populations, for example, in elderly people (Nunes et al., 2010; LeRouge et al., 2013), in representing children who had survived cancer (Wärnestål et al., 2017) and in a tool to support clinicians (Rodrigues et al., 2015). Similar to my study, Nunes et al. (2010) tested diabetic elderly person personas with clinicians. They acknowledge that this is not a replacement for end-user validation, but assert that it gave them confidence in their persona creation process. By contrast, a persona-based method of design was seen as the best way to access and work with children surviving cancer (Wärnestål et al., 2017) in a sensitive design context. This may be a solution to working with clients with a mental health disorder.

In addition, the personas use the first-person voice to reflect the seriousness of their illness and make them more empathetic. This is appropriate for clients at all stages of the DBT therapeutic process, incorporating high-level details of the challenges brought by the disorder.

UX maps and scenarios

Experience maps are used as part of the requirements document, because, whilst the four personas give good snapshots of clients at different stages in the process, the journey is not as straightforward as that of the non-clinical population in acquiring and embedding mindfulness. This needs to be reflected in a DMHI, with the experience maps giving an overview of the whole user journey and the requirements at each stage. The 24-hour map shows that BPD affects the whole life of people with this diagnosis and the DMHI should be able to offer support at any time of the day. The scenarios are used as examples, to show what can be done with this method.

Requirements list

Requirements analysis is a skill of judging, interpreting and balancing. In practise, generating requirements would most likely be done iteratively with design, development and evaluation. However, focusing on the requirements generation process, allows a discussion about how this can help researchers to better engage users at the Define stage.

The requirements list was seen as a successful addition to the URD. It reflects some of the data from Study 1, which was confirmed in the interviews in Study 2. The full list can be found in Section 5.1.1.

5.5.3 Adaptions to standard UCD methods

The process detailed in this chapter is based on standard UCD methods of creating personas, scenarios and user experience maps, which document and contextualise the user requirements. However, as the users are living with a mental health disorder, in this research, I adapted these standard methods, extending them to cover users with a mental health disorder. I did this by:

1. Incorporating high-level details of the causes, manifestations and challenges in acquiring the skills for this user group due to BPD.
2. Giving personas a first-person narrative rather than the usual third-person narrative to add weight to the seriousness of their illness and make them more empathetic.
3. Using the first person to allow personas to reflect that early stage clients are unable to construct a narrative about their ability or agency to bring about a deep understanding and control of the skills (Section **??**), which becomes resolved in the later stage clients.
4. Using user experience maps as part of the requirements document to reflect that the clients' journey in acquiring and embedding DBT skills, in particular mindfulness, is not as straightforward as that of the non-clinical population acquiring mindfulness skills. The four personas give a good snapshot of clients at different stages in the process, but the user experience map shows that the progression from stage to stage is complex with different needs at each stage. This needs to be reflected in a DMHI which is appropriate for clients at all stages of the DBT therapeutic process.
5. Making the scenarios reflect internal monologues and thought processes which the client users may be experiencing. These can be difficult to read, but are symptomatic of the disorder and one of the issues that DBT seeks to address.

5.5.4 Answering research sub-question 2

The knowledge gained from this study helps to answer sub-question 2:

What are client requirements for a DMHI supporting mindfulness skills acquisition as part of DBT?

The URD produced in this study, including the listed requirements, would give a DMHI designer team a detailed picture of the requirements for end-users of a DMHI for DBT Mindfulness from which a design could be created and tested. This is further discussed in Section 7.3.2.

Improvements in design from the URD

Based on the interview data, it is necessary to help new and established clients to understand what Mindfulness is and to remind the clients why Mindfulness skills are important in DBT. I hypothesise that by using my URD in the UCD *Design* step for a DMHI, it will add a number of features that are not found in existing DBT apps.

Firstly, I give explicit guidance on exactly what to include and what not to include, based on the clients' data. In addition, compared to the design of the DBT apps Medtep (Suñol et al., 2017) and the DBT Coach (Schroeder et al., 2018), my requirements allow for a lot more flexibility, tailoring and personalisation of the DMHI. For example, my requirements allow clients to pick which Mindfulness skills exercise they prefer, while also gently encouraging them to use the others. Moreover, certain colours and images may be triggering and so my design allows clients to change an aesthetic to suit their needs.

On a deeper level, the app addresses the different stages that clients go through when undertaking DBT and adapts to the different stages with different types of exercises, lengths of exercises and messages according to which stage the client is at. Thus, the app grows with them, rather than being something that they use for a few months and then grow out of, or that they find too difficult to use as a beginner. Whilst the journey was a clear discourse, with the stages emerging from the data, the stages should be an underlying concept, because clients may go up and down the stages and they may also feel stigmatised by being labelled if they needed to go back to a previous stage.

As seen throughout the interview data, validation is very important. Even when clients do not practice, using the dialectic of *acceptance and change*, clients can be validated and encouraged, with an emphasis on very short, calm practices whenever possible, using *relaxed* mindfulness to build up the practice. Validation when the app was not used or a session was missed was not seen in any of the previous apps.

I hypothesise that by using these requirements to design a DMHI for DBT Mindfulness skills, the app will be used more and have less usage attrition and more retention leading to better efficacy and clinical results (Torous et al., 2018).

5.5.5 What was successful or not in this process

Design artefacts

The persona creation process was somewhat successful. It took a long time to create the full personas. The A and P method was useful as a framework, but was designed to be used by a team in industry so as a person working on their own, I cut it down in places to suit the smaller reduced setting I was working in. It was useful having steps to follow which made me think about assumption personas. Although a lot of the work I did on the assumption personas was rejected in the end, because the categories were not helpful once I had the interview data, they were very useful to see where my assumptions were not accurate. They were was also very good for discussions with the Tuke DBT team and my supervisor, to see where I had understood DBT and the clients as a non-clinical person. Finally, some of the data from the assumption personas, for example backgrounds on abuse from discussions with clinicians, was usefully retained as part of the final personas. If I were to use this method again, I would recommend using it as a team, or as a solo researcher, following the cut down method details in this Chapter.

The scenarios were successful in showing the use of the app, and also in explaining to a development team the seriousness of the disorder, especially when the self-harming thoughts were added. I think the UX map was really useful, it took a very long time to get it right and I realise that it should have incorporated a way of showing clients going both backwards and forwards in the process as well as stopping and re-starting not as linear as shown in the UX map. Having better tools to do this would have helped. Over all doing participatory persona and scenario desing may have been better.

Are the stages reflective of the DBT experience?

Following a UCD method for turning the interview data into documents which reflect the clients, their requirements and their path through DBT enabled a deep processing of the data and familiarity with the DBT journey. The stages of DBT that were revealed are discrete stages, but clients may go up and down the stages during the learning process. As a result of learning the skills being interconnected with gaining a new mental model of the world and self-image, if this is challenged, the client may do backwards in the stages or stay at the same learning stage for a long time.

Clients with a mental health disorder

The URD was based on a small number of clients and clinicians. In addition, the clients seen in the DBT group at the Tuke Centre tended to be those with the most life-threatening presentations of the mental health disorder, meaning that the URD reflects this, and may be geared to patients with the most severe symptoms and presentations. However, as discussed, this is not seen as problematic, as those with less severe symptoms would still be able to use a DMHI designed using this URD, they would almost certainly progress faster through the stages though.

5.5.6 Reflexivity

In developing the URD, I had to balance my empathic stance towards the clients with wanting to portray the hardships of their lives and their struggles in a way that would be useful to a design team.

I also needed to balance my constructivist view of the world, in which we create the world through our experiences, rather than there being one absolute truth, with my role as a user researcher. Therefore, I had to consider how to approach and balance the differing views of the clients and the clinicians, for example on which skills were more important, or on the use of aggregated UCD methods over individually focused clinical therapeutic methods. In this, the dialogical approach, in which users and stakeholders are active participants in shaping a design, as part of an ongoing, meaningful dialogue (Wright & McCarthy, 2022), and experience-centred empathic UCD (Wright & McCarthy, 2008) in which the user's emotional experiences and personal contexts play a key role, were useful in helping me to both listen and treat the interview data and viewpoints expressed respectfully. I tried to learn from them, whilst also being able to synthesise the viewpoints and make design decisions as a user researcher. Using these approaches taught me how to be a more empathic and more confident user researcher, listening to my participants, but making my own design decisions.

Overall, reflecting on the process, I would have liked to work more with the clients in this phase of the UCD process, and involved them in more discussions, further using an iterative dialogical approach to develop the URD; however, this was not possible within the ethical and time constraints that I faced. Given the constraints, I was very happy with the tools that I developed and the overall URD.

5.6 Conclusion

This chapter detailed the *Define* step of a UCD process in transforming the data collected from interviews with clients and clinicians into a URD for a DMHI to help deliver DBT mindfulness skills. A URD specifies the requirements that users expect from the DMHI. This chapter discusses the process of developing documents and presents the completed documents, so that researchers can understand how the processes are used with a real data example, and see the advantages and disadvantages of UCD methods. The URD contains examples of personas, UX maps and scenarios which could aid a design team.

Study 3 details how data from Study 2 supplemented with some details from Study 1 was analysed to produce a User Requirements Document (URD) for a DMHI for DBT mindfulness. UCD techniques were used and adjusted for the particular context of users with a mental health condition. The document contains innovative UCD documents: a User Experience (UX) map of the DBT learning process with five stages and a 24-hour UX map of a DBT early stage user.

A number of documents are shown and discussed in this chapter and a full URD, which contains all of the documents produced, and a full list of requirements can be seen in Appendix I. However, not all of the documents generated in this chapter made it into the final URD which was produced for validation. Time constraints on participants validating the document dictated the size of the document and led to some of the documents not using used in the final validation.

5.6.1 Looking ahead to the next chapter

Having generated a URD, the next step in the UCD process is to validate the requirements. Therefore, the next chapter looks at validating some of the documents produced in this chapter. Due to time restrictions in running the study, not all of the produced documents were included. The process in choosing a representative extract of documents to include and who was chosen to validate are detailed.

Chapter 6

Validating requirements for a DBT Mindfulness app

6.1 Background

In the previous chapter, the results from Study 2 were used to produce a User Requirements Document (URD) for a DMHI to help deliver DBT Mindfulness skills (Study 3). In the URD, UCD techniques, extended for a clinical population with a mental health disorder are used to portray user requirements in a way that might be used by an app design/development team. This chapter examines the validation of the requirements to ensure completeness, accuracy and appropriateness for both the clients and the therapy (Rubin & Chisnell, 2008), and for the personas it is the final part of the persona development process which I followed (Adlin & Pruitt, 2010).

In addition to validating the requirements, this study allowed me to gain insights into how the DBT clients' lived experience, gathered in the Study 2 interviews, was viewed by clinicians. The clinicians' reactions to the information presented in the URD has wider implications for a DMHI development due to the tension in the divergence of views between the clients undertaking the treatment (the end-users) and the clinicians.

The approach taken in this thesis was empathic UCD (Section 1.1.3) within a constructivist paradigm (Section 1.5.2). As part of this, I wanted to follow a dialogical approach (Wright & McCarthy, 2008) (Section 1.1.3), in which differing views can be discussed and different stakeholders can learn from each other. Due to constraints of ethics and time, interviews about the URD were not possible. However, the method I used to validate tried to stay true to the spirit of the dialogical approach. I asked the expert participants their opinions - after each closed question there was an open question for them to add comments. I responded to these iteratively, by listening to their responses, making the changes they suggested and re-presenting the amended artefacts for further comment in the next round.

Validation of the requirements using the end-users of the intervention (the clients) (Doherty et al., 2010), as well as stakeholders, like the clinicians, would have been the most desirable outcome at this stage of the UCD process. Unfortunately, I was not able to do this for a number of reasons, illustrating some of the challenges when doing research with vulnerable groups with a mental illness, such as BPD. However, for ethical reasons, validating the URD with clinicians, as done in this study, and then using the dialogical approach to test prototype designs in future work, in the next phase of the UCD process (the Design phase), with client end-users may be more suitable, for reasons further explored in the Discussion (see p.290).

As discussed in Chapter 4, the DBT client population is difficult to access and gaining NHS ethical permission is lengthy and stringent. This notwithstanding, I was planning to use DBT clients to validate the requirements. However, at this point in my research timetable, *The Retreat* underwent a major restructuring programme. As part of the changes, the DBT Group at the Tuke Centre lost its funding and was terminated, leaving no direct access to DBT clients or to most DBT clinicians. I looked at recruiting clients in DBT groups elsewhere, and clients who had left, but the logistics of this proved difficult mainly due to Data Protection. In addition, by the time the situation became clear, even if clients could have been found, time constraints meant that another lengthy NHS ethics process would not have been possible. The DBT clinicians had either been made redundant or redeployed into other areas and all DBT treatment of clients stopped. Therefore, given the situation at the Tuke Centre and the time constraints of the research project, I concluded that although it was not the best solution, for pragmatic reasons, the URD should be reviewed using DBT clinicians, who as stakeholders would serve as proxy end-users to validate the URD. While this is far from the traditional UCD ideal of validating with end users (Doherty et al., 2010; Rubin & Chisnell, 2008), the requirements themselves were derived from client accounts. One of the lessons I learnt from doing this research was about the challenges of accessing end users. As discussed in Chapter 7, if I were doing a similar study again, I would think much longer term about recruiting hard to access participants.

I decided that using experienced DBT clinicians to validate the requirements and URD was acceptable, as clinicians would almost certainly comprise part of a DBT app development team. However, I recognise that not using the end-users is more problematic and this is discussed in more depth in Section 6.6.1 and Chapter 7. Although the validation technique was not ideal, nonetheless, using the clinicians did give further insight into the diverging narratives between clients and clinicians. In addition, validating with clinicians allowed me to study to what extent UCD-derived requirements and their representations are perceived as useful and insightful by clinical practitioners. This helps to answer the wider question about whether detailing the use of UCD processes in designing a DMHI for people with BPD holds untapped potential for current standard DMHI design and development.

The study also encountered other issues; the initial study design, which involved testing all the documents produced in Study 3 (Chapter 5) revealed the study length was extremely long – over three hours. Therefore, in an attempt to ensure full participant engagement and retention, a reduced number of the documents created in Study 3 made it into the URD used for validation. Three documents were included in the final URD. The first comprised two personas. The second contained the DBT user experience (UX) journey map and the third contained one persona and one scenario. The study design process is discussed below.

The overall findings from this study were:

- Generally, the requirements as listed were seen as accurate and appropriate for the client group. There were some suggestions for things which could be added for completeness, for example allowing for non-linear DBT journeys. The UX Map and the scenarios were seen as complete, accurate and appropriate by the clinicians, and the final version of these were highly praised by many of the experts.
- The personas caused more controversy due to some of the clinicians not agreeing with the personas' struggle with Mindfulness skills. There was tension between

experts who found the personas to be representative of clients with BPD, and experts who considered the personas' engagement with Mindfulness was not representative of the DBT clients they were used to working with.

- An app for a mental health disorder like BPD may need to have requirements beyond the app itself, so that clients do not see the app as another thing that they need to do or are failing to do, causing more distress. This is an area where stakeholder engagement with the DMHI is important, to give support to early stage clients.

6.2 Methodology

6.2.1 Aims

The study aimed to validate the requirements in the URD generated in Study 3, from user data generated in Study 2 and supported by data from Study 1. In particular, I wanted to discover:

- whether the representations in the URD contain a ground truth about DBT and DBT clients. That is, is the information seen as real or true, as if provided by direct observation and measurement?
- whether DBT clinicians considered the documents in the URD to be insightful.
- whether the classifications used in the documents were recognised as good representations in terms of:
    - Establishing the validity of the personas – were they realistic representations of DBT clients?
    - Establishing the validity of the user journeys - were they realistic representations of the clients' journey through learning DBT skills
    - Establishing the validity of the scenarios – were they recognisable as times/ events which were representative of when using a DBT Mindfulness app would be helpful?
- the clinicians' opinions on doing requirements validation in this way.

In discovering answers to these points, the information allowed me to answer thesis sub-question 3 - How are client-derived UCD requirements viewed by expert clinicians? and contributed to answering sub-question 4 - What are the emergent issues and potential amendments for UCD user requirements gathering methods when working on DMHIs for end-user groups with challenging mental health disorders like BPD?

6.2.2 Study design

Initial design

The initial study design, had two focus groups, one consisting of clients and the other of clinicians. The plan was to explain UCD methods and the documents in the URD, show group members the URD, and follow this by a group discussion. However, the demise of the DBT Group at the Tuke Centre meant that I had to consider other study design options.

Design changes - motivation

As explained above, after the DBT group was disbanded, I had no access to former patients and no time to find new patient participants and undergo another lengthy NREC ethics process. I also no longer had access to many DBT clinicians, as most former staff contact details were not available to me. Taking a pragmatic approach in a challenging situation, I decided to recruit DBT clinicians from across the UK.

DBT is a specialist therapy, and the number of trained therapists is thus not large. In order to accommodate busy DBT clinician participants, most of whom were not based in York, the initial study design using focus groups was rejected as the cost and logistics of gathering clinicians together was prohibitive;[1] Therefore, I decided to ask the same questions in an online survey, allowing participants from diverse geographical locations to take part, giving flexibility over when the participants completed the study and hopefully allowing me to recruit a lot of participants.

In the course of the study, I had read about a number of Delphi-studies, which are used frequently in Health. The iterative nature of improving through reaching consensus over different rounds reminded me of iterative UCD processes to improve a design. Therefore, in the spirit of wanting to do iterative UCD-type work, and also with a spirit of curiosity to use a method method well-known in Health I decided rather than just doing a survey, I would use a Delphi-inspired questionnaire design. This allowed me to improve the URD over two rounds, feeding back the question scores and participant comments to gain consensus about the user requirements designs from the group.

New study design

This study collected information about DBT experts' opinions on the documents within the URD over two rounds:

- In the first round, experts scored clinical aspects of the URD documents, and gave a reason for the score, so that both quantitative and qualitative data was collected.
- Round 2 was based on an interpretation of the Delphi study method. The documents were improved based on the scores and comments in Round 1, and shown to participants, who were asked to comment on the changes. Participants were also shown comments made by participants in Round 1 and asked to re-answer some of the question giving further comment. In addition some UCD questions were asked.

Delphi studies and Delphi-inspired studies

A Delphi Study is a systematic method which uses a panel of experts to reach a reliable consensus (Okoli & Pawlowski, 2004). To achieve this, expert opinions on an issue are sought anonymously over a number of rounds. The individual and group responses

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[1] This was pre-COVID and before the widespread use of online meetings.

elicited in one round are presented as controlled feedback to the panel in the next round, allowing them to reflect on the data, modify their position and hopefully draw closer to consensus (Linstone et al., 1975).

Whilst this study took inspiration from the Delphi philosophy of seeking consensus through participants seeing each others' ratings or comments on an issue or document, my study's methodology differed from a Delphi study in a number of ways (Heiko, 2012; Okoli & Pawlowski, 2004; Linstone et al., 1975):

1. Delphi studies typically present a document for comment, and this is then re-presented in further rounds with some changes being made. For example, in a study to find agreement on using big data in obesity-related health research (Vogel et al., 2019), in Round 1, participants agreed or disagreed with 77 statements about using big data in obesity research. They could also contribute new statements. The statements were incorporated and the document re-rated in Rounds 2 and 3. Whereas, in my study, whilst documents were amended based on ratings/comments and represented, only one question (out of 4 or 5) was re-asked in each section, due to time constraints.
2. In a Delphi study, the document(s) are presented in a consistent way. Due to time issues in my study, in Round 1, three separate documents were presented online, but in Round 2 one document was emailed to participants, followed by an online questionnaire. Changes are explained in depth in Section 6.2.5.
3. A Delphi study can continue with rounds until consensus is reached, but in my study, consensus was not reached in all the re-asked questions in two Rounds and further rounds were not possible.
4. Delphi studies do not usually use Likert-scale questionnaires.
5. Delphi studies give controlled feedback (i.e. feedback is determined by the researcher), which I did in my study; however, although the data was statistically analysed, the stats were not fed back to participants.
6. In a Delphi study, all participants can see all comments, which they could not do in my study; the comments which were presented in Round 2 were selected by me to represent answers to the questions being re-asked, because participant study completion time did not allow all questions to be re-asked and all responses given in the first round to be shown.
7. In my study, when recruiting participants, I asked if they would take part in 2 rounds or just the first round. This was done to encourage busy clinicians to sign up. In a Delphi study, the experts are expected to take part in all rounds.

Therefore, this is presented as a Delphi-inspired or Delphi-influenced study. There were a number of advantages to using this type of study, as opposed to a focus group: it reduces the influence of higher status group members on the opinion of lower status members; it reduces the ability of the group to put pressure on members to reach agreement; and, it reduces the ability of a dominant personality to have a disproportionate influence on group opinions (Van Zolingen & Klaassen, 2003). The disadvantages were the time required and whether gaining consensus was appropriate for validating requirements. This is further discussed in Section 6.6.1.

The Round 1 study design started as one long questionnaire, which became 3 shorter questionnaire sections after piloting (see Section 6.2.4). In addition, following the piloting process, I thought the original study design, where I considered having 3+ rounds would be too arduous for busy clinicians, I decided therefore to only have two rounds, with the complete study not taking participants more than three hours in total. Participants were made aware of the time each section should take to complete before agreeing to participate. The changes made to the study design for Round 2 are discussed in Section 6.4.

6.2.3 Participants

Recruitment

Recruitment proved difficult because DBT is not widely used and the study was perceived as potentially demanding and time-consuming. Participants were recruited using purposive sampling through a number of avenues: contacting former DBT staff from the Tuke Centre; contacting DBT therapists using online counselling lists like the BACP (Footnote2), using online lists of clinicians using the websites of reputable professional bodies, like the British Association for Counselling and Psychotherapy (BACP)[2] filtered for DBT and BPD; snowballing to participants' colleagues; and, social media. Although accessing this group was more straightforward than accessing clients would have been, thanks to online lists and clinician participants not requiring NHS ethical permission, due to the limited number of DBT therapists and the time required for the study, recruitment was not fast or easy.

Fifteen participants took part in Round 1, from over 100 DBT therapists who were contacted. Of these, some did not respond and others were not willing to commit the time my study required. In a full Delphi study, there is no clear recommended panel size. However, results may be biased if representation of the groups being studied is not achieved (Hardy, 2004). Twelve of the 15 participants took part in Round 2. Whilst some attrition of participants between rounds is to be expected (Van Zolingen & Klaassen, 2003), the remaining participants were considered representative of the spectrum of views.

Having a majority of participants who were unfamiliar with my research reduced the selection bias of using experts who might be more sympathetic to the URD and the methodology employed. Such bias might come from clinicians who had either worked with the original client participants, or who had discussed Study 2 with me whilst I was on placement with the DBT Group at the Tuke Centre.

Demographics

Participants were all DBT experts with a wide experience of using DBT in different settings, as potential participants expressing an interest were screened with a short questionnaire asking about their DBT qualifications and experience (Appendix G), to ensure they had received DBT training and delivered DBT skills in a therapeutic context. In total fifteen participants were recruited, five identifying as male, eight identifying as female and two non-binary. The age range is shown in Table 6.1. Fourteen

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[2] https://www.bacp.co.uk

participants were located in the UK and one participant was located in the United States. Individual time delivering DBT and type of DBT practice is not given to preserve anonymity; the range of time in practice for participants was 19 months to 13 years, with 5 years 3 months as the mean.

Age-range	Number
18 - 25	1
26 - 35	7
36 - 45	6
65+	1

Table 6.1: Study participant age-range

6.2.4 Piloting

In this study, the time required of the experts was quite lengthy, as it involved reading a number of documents, understanding the purpose of the documents and then answering questions, over two Rounds. Due to its complexity, with a lot of links that had to work, the study was piloted a number of times. The two pilots were students in the Computer Science department at the University of York. They were not familiar with UCD processes or DBT. As I was testing that the study flow made sense, that all the moving parts worked correctly, that there were no spelling etc errors, and not collecting information about the documents, the pilots did not need to be domain experts.

Pilot Study 1

Pilot Study 1 looked at the original study document, which had been cut down from the Chapter 5 URD containing everything produced in Study 3, called at this stage *the online questionnaire*. One concern of the potential participants I approached was the time the study would take. My Tuke Centre supervisor was also keen that the study not be too lengthy. Therefore, I was very aware of this becoming a factor when I started recruiting participants, and thus as part of piloting.

The pilot participant was unfamiliar with HCI methods, including UCD, as I wanted to see if enough information was given for participants to make sense of the different sections in the study. *The online questionnaire* consisted of all of the documents from the URD and all questions in a single document. *The online questionnaire* was piloted at around 2 hours and was reported to be a little confusing in places. I realised it was too long and therefore split the questionnaire into three documents: Part 1 containing the personas; Part 2 containing the UX Map; and, Part 3 containing the scenarios. This allowed the study to be administered more easily, made the documents less confusing as only one ‘tool’ was contained in each one and ensured that participants did not have to spend more than 40 minutes on any one part.

Pilot Study 2

In Pilot Study 2, a second pilot participant was used. Pilot Study 2 started with the new Part 1, the personas document, which originally contained three personas, India Birch, Russell Jones and Catriona Desouza. After the pilot reported back, several of the questions were changed slightly for clarification. The pilot participant reported that the study had taken 45 minutes to complete. I considered this was still too long for participants, as there were two other Parts in the study to complete in addition. This required asking participants to spend over two hours on Round 1 of the study. As recruitment was potentially going to be problematic, I considered that making the study less onerous at this stage was the best thing to do. Therefore, I cut the final number of personas in Part 1 from three to two and changed the questions slightly. Ideally I would have shown all of the personas, as all are important. The India Birch persona was moved to Part 3, as the scenario used this persona, so it was necessary for background information. Part 1 was thus reduced so that it would take around 30 minutes to complete.

Part 2 (the UX Map) was piloted at around 40 minutes and Part 3 (Scenarios) at around 30 minutes, some minor spelling and grammar mistakes were reported. Part 2 was considered lengthy, but it was difficult to reduce the time needed for this Part. Therefore, to reduce the overall time needed for the study, Part 3 was cut from three scenarios to one, taking it to around 15 minutes to complete.

Pilot study 3

The original pilot participant piloted the 3 Parts with the changes incorporated. He reported no problems with Parts 1-3 and time taken as 30 minutes, 40 minutes and 15 minutes respectively. This brought the total time of the study to under 1.5 hours. Whilst this meant that the participants did not see the complete URD, I pragmatically considered that the sections shown were representative of DBT clients, as they showed an early stage client and a later stage client and UCD methodology (personas, scenarios and the user journey were shown), whilst improving the chance that busy clinicians would be willing to sign up as participants. Reflections on the study process and how it could be improved are given in Section 6.6.1 and Chapter 7.

6.2.5 Materials

In this study, the time required of the experts was quite lengthy, as it involved reading a number of documents, understanding the purpose of the documents and then answering questions, over two Rounds. As shown in the Piloting section above, the study was kept as short as possible, whilst covering the necessary points. As the study was considered arduous for busy clinicians, it was decided to only have two Rounds and that the complete study should not take participants more than three hours in total. Participants were made aware of the time each section should take to complete before agreeing to participate. Following piloting, the materials used in the final study were as follows.

Round 1 Materials

In Round 1, all materials were presented online. The three online questionnaires (Parts 1-3) were constructed using Google Forms. This meant that all data collected was placed into a spreadsheet with access times and dates. Participants were requested to complete each individual Part in one sitting, as at that time, Google Forms could not save data if closed and re-opened. However, they could complete the three Parts over several days if they wished.

Part 1 – Personas

The Personas survey (see Appendix C)[3] started with a short explanation of personas and their purpose in the UCD process. Two personas were then presented, Russell Jones, a *Beginner* level client and Catriona Desouza, a *Gaining Confidence* client (see also Figures 5.5 and 5.6). These personas were chosen from the original four that were developed in Study 3 (Chapter 5). They were chosen as interesting in terms of using the app, because they were at different stages, which meant that different levels of support and different exercises would be presented to them by the app.

Although ideally, in a full URD verification, all four personas would be included, so that designers and developers understood there were different requirements at each learning stage. The final two presented personas were chosen for a number of reasons: firstly, the differences between the two presented personas was very obvious. They both had some experience of DBT, but were at different stages. Catriona had more understanding of the skills and was seeing more of the benefits from DBT skills use. This was more obvious than the differences between India Birch, the *Entrant* persona (Figure 5.4) and Russell, which were more subtle. Secondly, Russell and Catriona were both still struggling to learn and apply Mindfulness and other skills, but were not completely lost in the way that the *Entrant* level persona was. The *scenarios* were written to reflect this aspect of India Birch, so she appears in Part 3 (Scenarios) of Round 1 of the study, as background information, where the persona is not directly assessed by participants, but they were able to comment on her. In an ideal world, with many willing participants, I would also have shown India in Part 1, to illustrate a client having the most issues in acquiring Mindfulness and needing a lot of support, but pragmatically that was not possible. Therefore, in Part 1, Russell was chosen over India, with India shown in Part 3, because in this way 3 of the 4 developed personas were exposed to the participants.

After each persona, four questions were asked, developed to meet the study aims. The overall aim was for participants to reach consensus in their opinion that the personas represented a ground truth about DBT clients and DBT skills acquisition. The questions were asked about the aspects of the personas wanted to find out whether the personas were realistic representations of a typical client at that stage. Therefore, they asked how far different aspects of the persona were representative. The questions asked about aspects seen as important in the interview data. The aim of the study was to gain an understanding of the aspects of the personas which were seen as the most important. Therefore within the 8 questions, I asked opinions on different aspects of the persona questions which were likely to produce the required answers.

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[3] All Study 4 appendices include a link to the online questionnaires for ease of reading.

Questions rated the aspects on a 5-point Likert scale, with 1 being *Not at all like a [stage] DBT client / skills user* and 5 *Very much like a [stage] DBT client / skills user*. A Likert scale was used, so that a numerical value was given to the attitudes of each participant for each question, with the participants understanding what the numbers on the Likert scale meant. The scores could be easily analysed and each question had an overall ‘attitude score’. All structured questions were followed by an open question asking participants to elaborate on their answer. Finally, there were two open questions which asked whether the persona revealed anything surprising or insightful to the clinicians, to discover any information I might have missed. The Part 1 questionnaire ended with three general questions about the method, asking whether participants were familiar with the persona design method. In answering this I was able to see how far they had understood what I was trying to achieve and whether they understood the UCD method. Also, whether they found one of other of the personas more representative and realistic, to understand if there was an aspect of one or other of the personas which seemed more representative and why.

Part 2 – UX Map

In Part 2, the five-year UX Journey Map for DBT (Figure 5.9) and a document giving a detailed justification for the final requirements listed in the Map were presented (see Appendix D). Participants were asked eight questions about different aspects of the map, the final requirements and the UX Map method. Questions rated aspects on a 5-point Likert scale, with the labels varying depending on what was being asked. Five was consistently a high score and one a low score. All structured questions were followed by an open question asking participants to elaborate on their answer. The questionnaire ended with three general questions about familiarity with the method and how useful the map would be in explaining the DBT mindfulness learning process to a software designer.

Part 3 – Scenarios

Part 3 presented problem and activity scenarios involving India Birch (see 5.4 and Appendix (E) attempting to use the Mindfulness skills, with and without using the DMHI (called an app in the study). India Birch is an *Entrant* level persona. Including India Birch here allows three of the four learning stages of persona developed in Study 3 to be exposed to the clinicians; although the India Birch persona is not appraised here, her actions in the scenarios are. The persona was presented first, so that participants assessing the scenario showing India using the app were aware of which learning stage India was at and the challenges she faced in using Mindfulness. However, participants were not directly asked about the India Birch persona.

Three questions were asked about the representation of the issues and app use in the scenarios. Questions rated aspects on a 5-point Likert scale, with the labels varying depending on what was being asked. Five was consistently a high score and one a low score. All structured questions were followed by a further open question asking participants to elaborate on their answer. The questionnaire ended with three general questions about the method.

Round 2 Materials

At the end of Round 1, based on the question scores and comments of the expert participants, the original models of DBT clients and DBT acquisition, the personas, UX Map and scenarios, were amended to try to obtain closer agreement about the contents of the models from all participants. The amendments are detailed in Section 6.4, following the Round 1 results.

Once the amendments had been made, in Round 2 the documents were re-presented to the participants for further comment.

Motivating changes to documents

Statistical analysis was carried out on the Likert scores and used to determine which changes were made. However, the stats were not fed back to the participants in Round 2, although the comments were, as I thought that they may not be understood.

After reviewing the changes, the relevant section questions, where the changes were focused, were then re-asked. For example, changes to the Russell persona led to me re-asking: *How far is Russell's attitude to Mindfulness representative of a typical early stage DBT client?* It should be noted that Delphi studies usually feed back the complete document in all Rounds, asking the same questions (e.g. Vogel et al., 2019). However, as this was a Delphi-inspired study, whilst the participants saw the amended documents, only the questions which caused most conflict and divergence were fed back. The reason for this was because it was clear that participants had found completing the three Parts of Round 1 arduous, owing to time constraints. Therefore, not everything that was the focus of a question in Round 1 was amended, particularly when participants had few objections or consensus was high. In future studies, I will give time and the amount of content careful consideration. This is discussed further in Section 6.6.1.

Changes to presentation method

The way the documents were presented to the participants also changed in Round 2. Rather than having 3 Parts presented online, a single User Requirements Document (URD) was emailed to the participants. The URD contained a longer explanation about each of the three Parts (personas, UX Maps and scenarios). The additional information was included due to comments in Round 1 which showed that some of the clinicians had misapprehensions about the document's uses, due to an unfamiliarity with UCD techniques. The amended documents were also contained in the URD, with an explanation of all the changes which I had made. This is discussed further in Section 6.4.1.

Online questionnaire

Once participants had read the document, they were sent a link to an online questionnaire to complete (see Appendix F). This re-asked questions from Round 1 Parts 1-3. It also contained a new section, General Questions.

General Questions section

Like other Delphi and Delphi-inspired studies (Löfmark & Thorell-Ekstrand, 2004; Lilja & Jaakkola, 2010; Francis et al., 2018; Adams et al., 2022, *inter alia*), my study introduced new questions in Round 2, based on what was found in Round 1. These questions built on the Delphi philosophy in that they reflected back participant information from the questionnaires in Round 1 (although not with direct quotes) and I was looking to: 1. get further information from participants; and, 2. see if consensus was possible on these points. These were also the sort of questions that might have been asked in the focus group in the original study design, as part of the conversation process. Therefore, I considered them to be important questions to include. These questions reflect that the opinions of the experts in Round 1 were listened to.

The general questions were about the design of the models used in the study (personas, UX Map and scenarios), for example about the formality of the personas' language and gender, and the usefulness of the UX Map and scenarios (see Appendix F for the full questions asked).

Amendments

The amendments are detailed in Section 6.4, following the Round 1 results.

6.2.6 Procedure

The study procedure was different in Round 1 and Round 2.

Round 1

1. Potential participants were asked to complete a sign-up form containing an Information Sheet about the study and asking about their DBT training and experience using DBT with clients.
2. Participants were then emailed the link to the online Consent Form. This document contained:
    - A link to the Information Sheet in case participants had forgotten anything.
    - Consent to take part in Part 1
    - Consent to take part in Part 2
    - Consent for data from Part 1 to be used in Part 2
    - Demographics questions
3. Participants were emailed a unique randomly generated identifier to use when completing all forms. All Parts of the study were completed with participants using this to preserve participant anonymity. Sequential numbers were not used to prevent this affecting performance, if participants thought they were first or last, for example.

4. Participants completed Part 1 - Personas, comprising 10 questions. Once Part 1 had been completed, participants were sent the link to Part 2 - the UX Map and once this was completed, the same for Part 3 - Scenarios.
5. Participants were asked to complete the three Round 1 Parts within a week of being sent the first link. However, reminders to complete all three Parts were sent to some participants.
6. Once participants had completed Round 1, they were thanked for their time and expertise and sent a £15 Amazon voucher for being willing to take part.
7. The analysis was done and new documents were generated. A complete URD was generated, as detailed above.

Round 2

1. Two weeks later, participants were contacted to check that they were still happy to take part in Round 2. Two participants declined, citing time constraints, but confirmed they were happy for their data to be included in Part 2 and the study write-up. One participant did not reply, despite several contact attempts, which was considered unfortunate as they were one of the most critical voices in Round 1 and their opinion on the amended document and the comments would have been interesting and informative.
2. The remaining participants were emailed the PDF of the amended URD and asked to read it. After five days they were sent the link to the final questionnaire.
3. Participants were given a week to complete the Round 2 questionnaire. They were prompted to do this after 5 days.
4. Once participants had completed the Round 2 questionnaire, they were thanked for their time and expertise and sent a £10 Amazon voucher for being willing to take part.
5. The final analysis was done.

6.2.7 Analysis methods

In both Round 1 and Round 2, the analysis was split into the quantitative analysis of the Likert scores and the qualitative analysis of the free text answer data. Following the analysis of the question scores and the comments in Round 1 which gave some helpful and constructive feedback, I amended parts of the original models of DBT clients and DBT acquisition to try to accommodate the comments.

Quantitative analysis

The quantitative analysis followed this procedure:

1. I began by determining whether the score data was normally distributed using a histogram of the scores for each question. All data was determined to be non-parametric.

2. As the data was non-parametric, I then found the medians and interquartile ranges (IQR) for each question. The IQR determines the spread of the data, with the median showing the central tendency of the data.
3. Finally, I ran a Wilcoxon Signed-Rank test on each question[4] using 3, the middle of the Likert scale, as the standard value. This determined the significance of the question scores.
4. Questions which showed $p \leq .05$ were seen as reaching a significant consensus.

Qualitative analysis

Participant comments and reasons for scoring the questions were analysed using a general qualitative method to determine where the participants thought the documents were successful and where they were seen as unrepresentative or incorrect in some way. Thematic Analysis was not done due to time constraints at this point in the research.

Codes were not predetermined, but based on two pre-determined themes, as this study had very specific aims:

Theme 1 - Were the classifications used in the documents good representations in terms of establishing the validity of the personas, the UX Map and the scenarios?

Theme 2 - Was the URD insightful about DBT and/or the clients?,

These are discussed in Section 6.5.2.

The next section details the quantitative and qualitative results for Round 1.

6.3 Results - Round 1

The questions were asked to try to find a high degree of consensus between the participants. The results from Round 1 were used to amend the URD. It was then re-presented to Experts in Round 2. A considerable amount of consensus about the URD was found in Round 1, although, some participants had a preoccupation with one issue and this was seen throughout their answers. Other participants seemed to have misunderstood the exact purpose of the documents. This section presents examples of answers to each of the three Parts and then a general overview of the results for Round 1 is given, highlighting and justifying the amendments made to the URD.

6.3.1 Part 1 Personas – Quantitative evaluation

Table 6.2 shows the questions used in Part 1 with the results of the range, median scores with ≥ 3 being significant, as positive ratings are meaningful, and 1st and 3rd quartiles. The IQR, which is the 3rd quartile minus the 1st quartile, and shows how the data clustered without outliers which might skew the data with 5-4 showing a strong positive agreement between participants on the question being asked. In most questions, my data clustered around scores of 4 and 5 so the IQR was very small, as the data were

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[4] This test determines whether the median of the sample is equal to a known standard value.

Question	Range	Median score	IQR	Z	p
1.1 How far is Russell Jones' Background representative of a typical early stage DBT client?	3-5	4	1 (5-4)	-3.06	.002
1.2 How far is Russell's attitude to DBT representative of a typical early stage DBT client?	1-5	5	1 (5-4)	-2.59	.009
1.3 How far is Russell's attitude to Mindfulness representative of a typical early stage DBT client?	1-5	5	1 (5-4)	-2.70	.007
1.4 How far are Russell's Goals, Fears and Aspirations representative of a typical early stage DBT client?	1-5	4	1 (5-4)	-2.45	.014
1.7 How far is Catriona's Background representative of a typical longer-term user of DBT skills?	3-5	4	2 (5-3)	-2.93	.009
1.8 How far is Catriona's attitude to DBT representative of a typical longer-term user of DBT skills?	2-5	4	1 (5-4)	-2.73	.006
1.9 How far is Catriona's attitude to Mindfulness representative of a typical longer-term user of DBT skills?	1-5	4	1 (5-4)	-1.87	.062
1.10 How far are Catriona's Goals, Fears and Aspirations representative of a typical longer-term user of DBT skills?	2-5	4	2 (5-3)	-2.31	.021

Table 6.2: Analysis of Part 1 showing the range, median, IQR (3rd-1st quartiles), and Wilcoxon Signed-Rank Test Z and p (n=15 participants)

very tightly clustered. The results from the Wilcoxon Signed-Rank Test Z^5 and p are also given in Table 6.2. All questions had a median score ≥ 4. All medians except question 1.9 showed significance at $p \leq .05$ between the Likert score median (3) and the actual median, showing there was positive consensus in the personas questions, except for question 1.9 where consensus was not reached.

In order to try to improve the document and gain full consensus with all participants giving a score ≥ 4, the range of scores for each question was examined more closely. The answers participants gave to the open-ended follow up questions, asking them to elaborate on the reason for the score they had given, were closely examined, particularly where participants had given a score of 1 or 2, in order to see where the personas might need to be changed for re-presentation in Round 2.

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[5] Z gives the test statistic value. Z must be < -1.96 or > 1.96 to show significance.

6.3.2 Part 1 Personas – Qualitative evaluation

This section examines the answers participants gave to elaborate on the score they had given a question. Answers to questions 1.1 - 1.4, on the Russell Jones persona, revealed that the majority of experts were positive about the persona method and the individual Russell persona. However, a couple of the participants were quite negative overall about the way that clients, the DBT experience and the Mindfulness skill was portrayed. Whilst many participants found the portrayals in the personas representative, praising the portrayal of the clients and DBT, some of the experts found the portrayal of DBT to be inaccurate, making the therapy seem too challenging. Comments were normative, for example, saying the client *shouldn't be like this*. The persona portrayals were seen as inaccurate and their therapists were blamed for the clients' lack of progress, inability to learn and difficulty with mindfulness.

> Q 1.2 How far is Russell Jones' attitude to DBT representative of a typical early stage DBT client?
>
> [Expert KDC2 - score 5] It is common for individuals to feel overwhelmed at first and find it difficult to implement the skills when overcome with intense emotions.
>
> [Expert L6DT - score 4] This seems like someone who is finding DBT helpful when they take part in the sessions, but hasn't yet got to the point where they can use the techniques when they need them the most i.e. when they are most under stress and vulnerable.

Both of the above answers give positive comments on the Russell Jones persona, reflecting the high scores of 5 - (very much so) and 4 respectively, confirming that the portrayal of Russell's struggles with DBT are seen as realistic and usual by participant KDC2. The stage that Russell is at in the DBT journey is also recognisable to L6DT. By contrast, participant 7CO9 did not find the Russell persona convincing scoring the question 1 - (not at all), as seen below.

> Q 1.2 How far is Russell's attitude to DBT representative of a typical early stage DBT client?
>
> [Participant 7CO9 - score 1] This client has only been in therapy 6 months, so we wouldn't expect them to be the expert and know all the skills and concepts - this for me would represent a therapy interfering behaviour i.e. the therapist is failing the client and not identifying these difficulties with the client - and the client's therapy interfering behaviour which should have been identified and pre-empted at the beginning would be feeling that he is stupid and might not do well, so this should have been problem solved at the beginning to enable concepts and skills to be clear and helping him to learn them. The client would also be practicing these skills every week and things that got in the way would be problem-solved so it shouldn't ever get to that stage[...] If I heard a client say this I would be highly concerned about the therapy being non-adherent and the therapist seriously failing this client - this has never been my experience to date. I think this extract paints DBT as failing and a hopeless therapy which I don't endorse - and which could remove someone's hope that it can work and they can do it. I

> don't support that.

Participant 7CO9 sees the Russell persona as inaccurate, because for her, as a client, he should not have been allowed to get to this stage. The emphasis on the therapist wanting to use her skills to help the client is very strong here. She is reacting to the Russell persona like a real client. Participant 7CO9 sees the portrayal of DBT and Mindfulness skills at the start of the therapy in this persona, not as representing challenges for the client, but as portraying DBT or the therapist as deficient. The final sentence leads me to believe that this participant had not really understood the use of personas as archetypal specifications of client types, which represent the most important requirements of a class of end-users for use by a design team, but was reacting to the persona as if they were an actual portrayal of a client.

Question 1.9, which did not reach consensus, also elicited a range of comments:

> Q 1.9 How far is Catriona's attitude to mindfulness representative of a typical longer-term user of DBT skills?
>
> [Expert UT8G - score 5] Catriona seems to understand the concept and uses it in the correct way, to bring herself back into the moment and connect with the emotion she is experiencing in the present to manage in the best way.
>
> [Expert 1QLV - score 4] Longer term clients realise the usefulness of Wise Mind and being in the moment because it can help them monitor themselves and live their lives. For many people mindfulness does seem like a really strange idea at first, but with practice I have seen that many clients recognise its use. Belief in its effectiveness is doubtful at the start, it's not a quick solution, remembering to be mindful is a large part.
>
> [Expert 7CO9 - score 2] again, more so than the first case, but i still find it hard to endorse that it's really difficult to grasp e.g. mindfulness. the skills and therapy were developed by someone with bpd afterall, and so are purposefully simplified. the client should be practising them with the support of the therapist. it makes me think that she was too rushed through therapy and not supported well to understand them. i always use personal examples to help people grasp the concepts, and practice new ways of doing the skills to help learning. i agree that some people have judgements about [Mindfulness] at first and it can seem abstract until they're supported to understand the many different ways it can be done[. . .]
>
> [Expert NK2F - score 1] Clients don't take this long to understand mindfulness, it's not that difficult to grasp.
>
> [Expert K9ZT - score 1] She is an artist...

The comments following the higher scores (4 and 5) reflect the aspect of DBT Mindfulness the persona is trying to convey, reflecting data from clients at this level of learning. UT8G interprets Catriona's actions in terms of DBT skills, finding the persona is representative of a longer-term DBT client. Participant 1QLV also sees Catriona's continuing struggles as representative of this type of client. This answer embodies a dialectic of understanding why mindfulness is difficult, but also encouraging the client to use the skills. However, participant 7CO9's answer does not recognise any dialectic, rather it questions the portrayal of the therapy as challenging and the clients as having difficulty. There is a lack of acceptance that this is where the client is and compassion for the client's struggle. Participant 7CO9 sees the client's issues in black and white terms, as down to her therapist failing her. The comments from 7CO9 about clients at the beginning appear to contradict the comments they made about the Russell persona earlier.

One of the issues with using this method was the lack of dialogue with the participants and not having the ability to ask follow up questions. This is further discussed in Section 6.6.1. In addition, participant K9ZT's comment and score were rather puzzling. They were contacted to ask for clarification on the comment, but unfortunately did not respond and did not take part in Round 2. It is taken to mean that Catriona's profession means her attitude is inappropriate or unrealistic. However, as no other comments were made about Catriona's profession, no changes were made to it.

6.3.3 Part 2 UX Map – Quantitative evaluation

Table 6.3 shows the questions used in Part 2 with the range, median scores and 1st and 3rd quartiles. As in the Part 1 data, the IQR was very small in all cases, as the data points were very tightly clustered. The results from the Wilcoxon Signed-Rank Test Z and p are also given in Table 6.3. All questions had a median score ≥ 4. All medians were significant at $p \leq .05$, between the Likert score median (3) and the actual median, showing there was general consensus on questions about the validity of the UX Map.

6.3.4 Part 2 UX Map – Qualitative evaluation

As in Part 1, the results show questions with a majority of scores of 4 and 5, but with a couple of very low scores (1 or 2) given. In order to examine why this was happening the comments which accompanied the questions were examined. It was gratifying to see that the requirements which came from the UX Map (Questions 2.5-2.8) had a strong consensus amongst the experts, because of the time it had taken to complete. The extracts below from Question 2.2 show a range of answers given to elaborate on the scores given.

> Q 2.2 How far do the progression stages represent the clients' progress in acquiring DBT Mindfulness skills?
>
> [Expert 8TSF - score 5] The progression stages correspond largely with the experience of my clients, though again I would note that the progression is not always linear, and the journey above does not account for lapses in the client's practices.
>
> [Expert S3JH - score 4] I think the stages are a good reflection and the descriptors match well but I'm not sure how helpful it is to include timeframes. I think it is quite an individual process and clients progress along very differently.

Question	Range	Median score	IQR	Z	p
2.1 How far does the UX Map match your experience of clients' typical progress in acquiring DBT mindfulness skills?	1-5	4	0 (4-4)	-2.48	.013
2.2 How far do the progression stages represent the clients' progress in acquiring DBT mindfulness skills	1-5	4	2 (5-3)	-2.10	.036
2.3 Looking at the Experience level, how well do the quotes, graphical representations and short explanations represent the experience of acquiring DBT mindfulness skills?	2-5	4	2 (5-3)	-2.62	.009
2.4 Looking at the Individual Level, how well does it represent clients' needs, issues and experiences around acquiring DBT mindfulness skills?	1-5	4	1 (5-4)	-2.52	.012
2.5 After reading the Expanded General Requirements, how appropriate do you think the General Requirements are for clients acquiring DBT Mindfulness skills? Looking at the Individual Level: how well does it represent clients' needs, issues and experiences around acquiring DBT mindfulness skills?	3-5	5	1 (5-4)	-3.30	.001
2.6 How complete are the General Requirements for clients acquiring DBT Mindfulness skills? Do you think any important Requirements have been overlooked?	3-5	4	0 (4-4)	-3.30	.001
2.7 How far do the Stage Requirements seem appropriate for clients acquiring DBT Mindfulness skills at each stage?	4-5	5	1 (5-4)	-3.41	.001
2.8 How complete are the Stage/Individual Requirements for clients acquiring DBT Mindfulness skills at each stage? Have any important Stage level Requirements have been overlooked?	3-5	4	1 (5-4)	-3.18	.002
2.10 Imagine you had to explain to a software developer the typical path of a client learning DBT Mindfulness skills. How useful would you find the present UX Map for that explanation?	2-5	5	1 (5-4)	-3.24	.001

Table 6.3: Analysis of Part 2 showing the values of the medians, IQR (3rd-1st quartiles), and Wilcoxon Signed-Rank Test Z and p (n=15 participants)

> [Expert 1QLV - score 3] I think the proficiency, stage names, and categories are representative. What is less representative is the timeline. I think the timeline is roughly correct but it's just so variable for each client it doesn't strike me as particularly useful. There will be clients who will go through a DBT cycle and just not understand mindfulness at all. There will be others who understand it after 2 or 3 months. So I'd urge caution with trying to represent client progress through time.

One of the comments that many participants made about the UX Map was that the inclusion of a timeline was not particularly helpful, as clients all proceed at their own pace. Another comment, is that of participant 8TSF, who mentions that the map does not show a non-linear progress or cases where participants have set-backs. This is discussed further in Section 6.6.1.

> Q 2.2 How far do the progression stages represent the clients' progress in acquiring DBT Mindfulness skills?
>
> [Expert NK2F - score 2] I don't think it takes this long. After running a group for 4 years, two hours per week I seen changes a lot sooner[. . .] However, from discussions in weekly consult our clients would not take this long. They first were allowed 6 months in the program, then they were provided with another 6 following this. Rarely did clients go other a year. All clients who were willing to use skills no longer met the diagnosis of BPD following a reassessment with a consultant.
>
> [Expert 7CO9 - score 1] As noted above, this should be addressed within a few weeks to help clients get to grips. if a client came to me after 6 months and was in a fog still i would be very concerned. but I think its true of labels such as entrant, beginner etc.

The participants who gave the lowest scores are in disagreement with the other experts that for some clients the process can take longer. At the Tuke Centre, clients were in DBT from 1 year to 4+ years. Again further discussion with these participants would have been useful at this stage.

The experts were also asked to comment on the use of the UX Map for its intended purpose, to help explain DBT to a software developer. Some of the comments are shown below:

> Q 2.10 Imagine you had to explain to a software designer/developer the typical path of a client learning DBT Mindfulness skills and what an application would need to do to support them. How useful would you find the present User Experience Map for that explanation?
>
> [Participant 8TSF - score 5] The UEM is accessible to those without a clinical background. I would feel comfortable explaining a client's DBT/MF journey using the UEM.
>
> [Participant XV1Z - score 5] The map breaks down and simplifies what can feel like (and often is) a complicated, confusing and overwhelming journey (for client and therapist!).

> [Participant LA4C - score 5] It is a very useful map of the experience and has a lot of good detail in it that I would want including

These three comments were very positive about the UX Map and its use in explaining the process to a non-clinician. However, other comments pointed out where the UX Map could be improved:

> [Participant LQLV - score 4] I think it's a really good representation of what clients go through. I feel that there are a few nuanced aspects missing, such as the fact that clients can go in both directions (in my experience), and that this client group can particularly struggle with negative triggers (which was covered in the accompanying document, to be fair). I think if I looked at the document on its own I'd be able to roughly get the idea, but it would probably require some conversations too. Obviously these clients are complicated and I think there are a lot of subtle issues such as the variability of the timing of each stage, for example, that can be tricky to understand. But as it stands the document is very thorough and I would find it useful.

This participant points out something which is missing in the UX Map, that clients may not follow a linear straightforward path through DBT. Again, a conversation with this participant about how the UX Map would be used in a consultation with a designer/developer may have cleared up any uncertainties about the design process.

Finally a negative comment which covers the time taken to learn mindfulness. Her comments are coloured by the rest of the URD so may not reflect a true score of the map here. In addition she gave a low score to everything, because the data I found in the interviews did not reflect her experience of DBT clients.

> [Participant 7CO9 - score 2] i'd introduce some of the things i've previously mentioned, and i query the things raised already re how long it should take to skill up a client with mindfulness

6.3.5 Part 3 Scenarios – Quantitative evaluation

The questions, range, median and IQR of the scores and the Z and p values, show that the median scores of the questions were statistically significant with a score of 4 or 5 (Table 6.4). As in Parts 1 and 2 most questions scored over 4 and had $> 80\%$ approval. Therefore, the ranges of scores and the comments were examined more closely. As the range shows, all but one question on the scenarios had a majority of high (> 3) scores. In order to examine the range of scores further, the comments which accompanied the questions are looked at in more detail in the next section.

6.3.6 Part 3 Scenarios – Qualitative evaluation

Extracts from the answers to Question 3.2 are shown below, representing typical answers in Part 3.

> [Participant MY94 - score 5] Internal interruptions are almost indiscriminate, the client could need help at any time.

Question	Range	Median score	IQR	Z	p
3.1 How well does the Problem Scenario represent the sorts of issues an Entrant/ Beginner level client might have?	1-5	4	1 (5-4)	-2.61	.009
3.2 How far does the Activity Scenario show realistic possible uses for Mindfulness skills?	2-5	4	1 (5-4)	-2.90	.004
3.3 How far does the Activity Scenario show realistic possible uses for a Mindfulness skills app?	3-5	4	1 (5-4)	-3.18	.002
3.5 Imagine you had to explain to a developer the possible everyday uses of Mindfulness skills that could be technically supported in a DBT Mindfulness app. How useful would you find the Scenario in doing so?	3-5	5	1 (5-4)	-3.06	.002

Table 6.4: Analysis of Part 3 showing the values of the medians, IQR (3rd-1st quartiles), and Wilcoxon Signed-Rank Test Z and p (n=15 participants)

> [Participant 7FYL - score 5] It reflects that DBT/therapy can HELP, it doesn't magic anything away. I also liked that it was realistic that a number of difficulties arose for the client in a short space of time - this is life. The scenario helps to reflect that we can ride those waves (of thoughts, feelings, emotions) and still do things that matter to us.

The positive comments, and high scores, above see the scenario as representative of a client's experience of life and how DBT may help. The less positive scores and comments, seen below could be more detailed. It is difficult to know how they connect to the scenarios. Participant G39T's comment I found a little strange coming from a DBT expert and Mindfulness teacher. The comment from Participant NK2F and the score given reflects the rest of the URD, rather than the scenario, as there is nothing in the scenario that would cause this comment. India Birch is a beginner client who has only been undertaking DBT for a short time.

> [Participant 7CO9 - score 3] helping to ground certainly and shift attention to present moment experiences.
>
> [Participant G39T - score 3] I don't know how to cope with mindfulness when traveling by bus and having 50 people around you...
>
> [Participant NK2F - score 2] Clients should be actively encouraged to participate in bringing skills to life[. . .] Mindfulness can be life changing, it doesn't and shouldn't take this long for anyone to learn.

Table 6.5: Amendments to the personas

Changes to the Russell Jones persona	**Changes to the Catriona Desouza persona**
Demographics changed slightly. He has now been in DBT for 4 months as opposed to 6 months. He is also less competent at work, no longer completing an apprenticeship.	**Demographics** CBT was removed in favour of continuing with DBT
Goals Complete the DBT course -- **removed**. Dampen suicide/other behaviour urges **Replaced with.** Have better relationships with people. **Fears** I'll never get better. I'm too stupid to do DBT. **replaced with** I worry that DBT won't work for me. **Aspirations** To have a life without self-harm urges. And To be able to live with BPD. **Replaced with** To have a better life and be able to live with BPD.	Nothing changed in Catriona's **Goals** or **Aspirations**. **Fears** If I'm more assertive people won't like me My personality is set in stone and I can't change **Replaced with** I'd like to meet a partner but worry a little about being in a relationship That me and my work are not `good enough'
Background I've seen a few therapists over the last few years' was **removed** as it may cause confusion. My girlfriend, Maddie broke up with me after a row. I threatened to kill myself if she left and she said if I didn't get help she would. Maddie is my main reason for doing DBT. **was changed to make the point clearer**: I was rowing a lot with my girlfriend, Maddie and she said she would break up with me if I didn't get help. My main reason for doing DBT is to have a good life with her.	**Background**, CBT was **removed** in favour of continuing with DBT to do the trauma processing. This is to make it less confusing for the software development team by adding another therapy. Reference to a previous marriage was removed.
DBT time in DBT was changed from 6 months to 4 months, making him a client who is earlier in the DBT process. `I know I need to be better for Maddie' was **removed**. Whilst this is realistic, it will not help the designers and may confuse them.	**DBT** - DBT is really difficult to grasp at first, especially mindfulness. It's taken a long time to get it, over 3 years, but once you do, it helps a lot. **Replaced with** DBT was really difficult to grasp at first, especially mindfulness. It's taken me a long time to completely embed the DBT skills, over two years, but now I have, it helps a lot.
Mindfulness sentence order was rearranged and some were slightly rewritten. Nothing was added or removed.	**Mindfulness** was reordered. I still have really bad times. So, I don't think I'll ever stop having issues, but after a crisis, at least I now know what to do to get better in terms of using the skills **Replaced with** I still have bad times, I don't think I'll ever stop having issues, but after a crisis, at least I now know how to get better by using the DBT skills.

6.4 Amendments to Round 1 documents

As explained in Section 6.2.5, due to participants' time constraints, it was not possible to re-ask all the questions from Round 1 in Round 2, and as most questions reached a statistically significant consensus[6] in Round 1, changes were made where there was least consensus and based on the participants' comments, in all three documents. Specific questions based around the changes were then re-asked.

6.4.1 URD

Section 6.2.5 describes the changes in how Round 2 was presented to the participants. The URD that was sent to the participants started by explaining the purpose of the URD, the scope of the app, and then giving a detailed overview of the individual models, with the sections in each one explained. For example, it stated that the quotations at the top of each persona are real quotes from clients. It also contains General Requirements for a software development team.

6.4.2 Personas

In amending the personas, some of the comments about negativity were taken into account, along with other more positive comments about the *Goals*, *Fears* and *Aspirations*. The amendments made to the personas can be seen in Table 6.5.

6.4.3 Changes to the UX Map

In the UX Map a number of small changes were made, following the experts' comments.

Stages

In *Stages*, the timeline was removed, as the most controversial part of the UX Map.

Experiences

The *Intermediate* quote was changed because it included a reference to time.

Thoughts

Proficient stage thoughts were slightly changed and rearranged to read better.

Individual stage requirements

Add diary was moved from *Competent* to *Beginner* level.

Beginner level: '2' was added to – Add Mindfulness to more daily activities (2-3+).

Competent level: Changed to – Reminders can become less frequent if client is happy (eg daily). This would give control over this to the client/user.

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[6] Delphi studies have considered various ways to define a consensus. I used 80% or more of the participants agreeing (Berk et al., 2011).

General Requirements

An additional paragraph of requirements was added and included in the Expanded General Requirements following experts' suggestions:

- Show progress in engagement with Mindfulness – helps to encourage/maintain engagement.
- Give feedback on enjoyment of Mindfulness – shows clients they are enjoying it more.
- Encourage use of less liked Mindfulness exercises – this can be helpful in moving towards acceptance.

The final UX Map can be seen in Appendix D.

6.4.4 Scenarios

A few changes were made to the scenarios. The main change was adding self-harming thoughts to the scenario, as one of the participants suggested this as typical of a client at this stage. The final scenarios can be seen in Appendix E.

6.5 Results - Round 2

In Round 2, the full URD with the amended documents and details of changes was sent to the participants. This can be found in Appendix **??**. As detailed in Section 6.4.1, participants then completed an online questionnaire, consisting of four sections, General Questions, Personas, UX Map and Scenarios. The quantitative and qualitative results of this are given below.

6.5.1 General questions

G1. Persona language

The first question asked specifically about the language used by the personas, as they spoke in the first person, because this was commented on in Round 1.

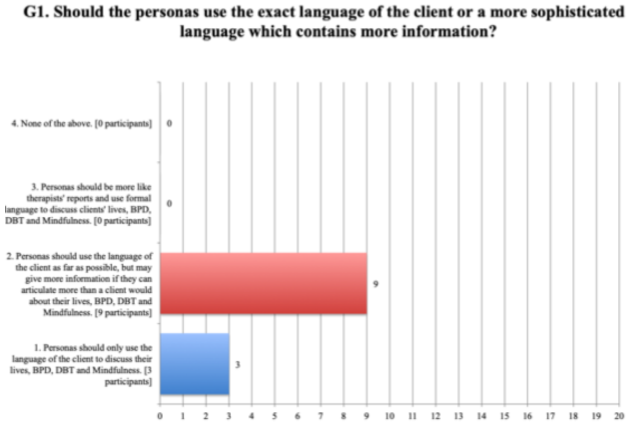


Figure 6.1: Persona language question

Figure 6.1 shows that from the four possible answers to this question, 3 participants chose 1 and 9 chose answer 2. No participants chose answer 3 or 4. Participants also justified their answers to this question. Extracts from the answers to Question G1 are shown below, representing typical participant answers to this question:

> [Participant MY94 - answer 1] I prefer to read the actual language of the client in the persona so I can feel involved and engaged
>
> [Participant S3JHI - answer 2] I think it is important to maintain the voice of the service user but appreciate that more information may be required to ensure a full understanding of user requirements.
>
> [Participant XV1Z - answer 2] Assuming personas are there as an aid/to provide info: it makes sense that they should come across both as knowledgeable, but also accessible.

It was not clear to me whether Participant MY94 had understood the purpose or reason for having a persona. Their answer is based on a personal reaction, rather than thinking about how a persona could help in the design process. The other two participants have understood the purpose and why it may be necessary to supplement the persona's language when necessary.

G2. Persona voice

Personas are traditionally written in the third person, but because these personas have a diagnosis of BPD, I wanted to make the experience more empathetic, so I wrote them in the first person. I was interested to know whether the clinicians thought this made a difference.

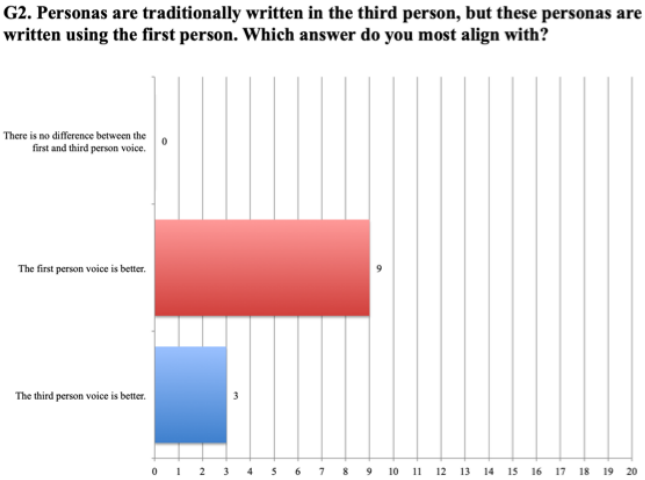


Figure 6.2: Persona voice question

Figure 6.2 shows the spread of answers. The extracts below throw light on why the participants answered G2 like this.

Some participants preferred first person voice.

> [Participant XV1Z] I can better internalise a first person narrative

> [Participant UT8G] First person makes it sound more like it has come from a client

Others saw the third person voice was better.

> [Participant NK2F] The traditional method of personas being written in third person is fine, although we can lose sight of the person within this method I feel. There seems to be a better connection to a persons story when written in first person. As though we can imagine ourselves in that positions more easily.

> [Participant S3JH] I think either would be effective in conveying user needs, for me it is the content that is important. A third person narrative may resolve some of the issues raised by participants in relation to how articulate the service user would be at each stage in the therapeutic process?

The participant comments reflect that all the participants had a preference. However, the point raised by Participant S3JH is a fair comment in relation to resolving issues raised by the previous question. The clinicians' response to the voice of the persona is discussed in Section6.5.2.

G3. Number of personas

Question G3 asked two questions in one. In Study 3, I designed 4 personas, but due to keeping time commitments down, I only presented 2 for comment in Round 1. I wanted to know if this was enough, or whether the clinicians thought more were needed. There was also disagreement about how BPD clients were represented in the personas; some participants found it unacceptable to abstract and mix information from different individual client interviews. Others thought personas were a good idea, but the number thought necessary was questioned. Therefore, G3 asks about the number and diversity of personas.

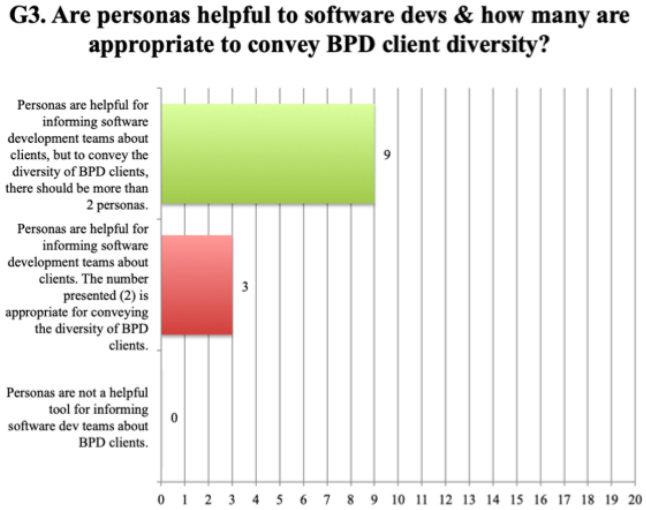


Figure 6.3: Persona number question

Figure 6.3 shows the response to G3. Extracts from the answers to Question G3 giving reasons are shown below, representing typical participant answers to this question:

> [Participant 2TCM] BPD is a very predictable mental health disorder, and there are many different variants of the that we have yet to understand, therefore the greater selection of input from these individuals would be the better. However, I would severely caution the utilisation of such an mix match of therapeutic experiences as it may cause confusion and be detrimental if the material has not been suitably vetted by both the contributor and the therapeutic participant.

The quote from Participant 2TCM is a good illustration of the tension I found in the research between the clinicians seeing themselves as the experts on DBT and having an individualistic approach to clients, as opposed to the UCD approach which looks for a synthesis of a group of users. Resolving these tensions between the clinicians' approach and a UCD approach is discussed further in Section 6.5.2 and Chapter 7.

> [Participant FGW3] I agree that the population is extremely diverse and it would be difficult to capture all in such a small number of personas; on the other hand, having many more might complicate the process.

This shows the opposite view, where more personas are considered desirable. There is also an understanding of the balance between the URD providing enough information and too much information.

G4. Gender of personas

A question about persona gender was included because it came up in the comments from Round 1. In UCD, personas should represent the end users including any gender splits. Studies show that most BPD diagnosed clients in clinical settings are female; however, some surveys suggest an equal prevalence of BPD in males and females in the community, but males are not so frequently given this diagnosis.

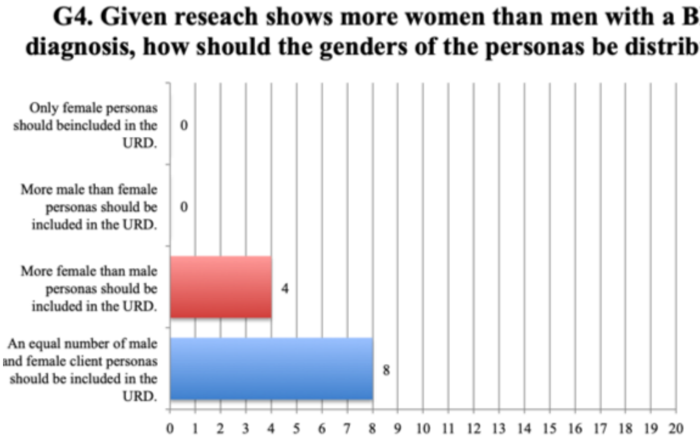


Figure 6.4: Persona gender question

The results from G4 can be seen in Figure 6.4, showing something of a split in opinion in the clinicians on this subject. Extracts justifying the answers to Question G4 are shown below:

> [Participant VAf5] I think it is important to have an equal gender representation in the app development phase so that the finished product is accessible to all who may wish to use it.

VAF5 makes a fair comment on thinking about the end-users. This is expanded by XV1Z, who makes extends the point about not including men as potentially being harmful to men, leading to more shame and feeling stigmatised...

> [Participant XV1Z] I'm unsure about this. My experience (which is inpatient) is that there are more women diagnosed as having BPD; however, my preference would be not to gender the diagnosis or therefore the personas, as this would invalidate the experience of men, and potentially perpetuate stigma around men having this diagnosis as well as the idea that men are dangerous and should be avoided (men often being equated with abusers for those women with the diagnosis).

> [Participant 1QLV] I'm honestly not sure about the gender divide in BPD prevalence. The NICE guidelines indicate that women present to services with BPD more often than men, and I have been told that it can be a gendered disorder due to how some of the diagnostic criteria are phrased (i.e. emotional instability is more likely to be recognised in women than men, for sociological reasons). I certainly know that in the service I work for, we've only had a handful of clients that were men in over 5 years of it running, whilst we've had tens of women. However, I can't offer a firmly

> informed opinion. With the limited evidence I have, I would lean towards more female than male personas.

The clinician's answers to this question are interesting as some seem to be giving a socially acceptable answer that does not reflect the reality of the current situation where a lot more women than men are diagnosed with BPD. This raises an interesting point, should the app design think about a future where potentially more men are diagnosed, or should the design only reflect the current situation? As we are designing for end-users now, the latter would be preferable.

6.5.2 Personas

For the personas, only one question was asked in order to discover whether the amended Mindfulness sections could create more consensus from the experts. The participants were asked to look at the personas and at the scores and comments given by participants in Round 1. See Figure 6.7 for an example from Part 1 Question 3 and Appendix F for the rest.

Please note that for the rest of the questions, one participant scored everything as 3 and did not engage with the open discussion questions. It is suggested that picking the neutral response option (3) allows participants who do not know about or are indifferent to the content to choose no opinion or neutral opinion instead of having to choose a response that does not reflect what they believe (Edwards & Smith, 2014; Krosnick et al., 2002). This participant stated that they could not open the links; however, the information was also available in the URD they were emailed and all the other participants were able to open the documents.

Russell James

Question	Range	Median	IQR	Z	p
P1.3 How far is Russell's attitude to Mindfulness representative of a typical early stage DBT client?	2-5	4.5	1 (5-4)	-2.67	.008

Table 6.6: Analysis of amended Mindfulness in Russell Jones showing the range, median, IQR (3rd-1st quartiles), and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

The result is significant at p $\leq .01$. The results show that within the participants there was consensus of $> 80\%$, with only one participant who was still not happy about the depiction of Russell's struggles with Mindfulness skills. The comment below reveals why this belief continued.

Table 6.7: Comments and score for Round 1 Part 1 Question 3

ID:	**1.3 How far is Russell's attitude to Mindfulness representative of a typical early stage client?**	
	Score (1-5)	Reason for score given
7fyl	5	Mindfulness is a complex concept that we as a society often don't practice so it can feel "odd/weird" to start thinking about our worlds in this way when we start therapy.
la4c	5	He answers like a typical person (DBT or not) trying to learn mindfulness for the first time! Sounds easy but hard to do in practice.
kdc2	5	Many people find mindfulness a difficult concept to grasp, particularly when feeling strong emotions and having difficult thoughts.
p7se	5	He is confused and doesn't get it. This commonly happens at early stages
ut8g	5	Some client's find this difficult/uncomfortable/pointless initially, until it is explained clearly to them, giving them different, more proactive ways of doing mindfulness.
s3jh	5	I think this representation is very accurate based on difficulties voiced by clients I have worked with. Mindfulness is a difficult skill to learn and can seem quite abstract initially.
xv1z	5	"Just looking at a leaf". His judgements and thoughts get in the way of actually practising it, and the fact that he struggles to complete homework/remember to use mindfulness when his emotions aren't already overwhelming reinforces them. It feels pointless.
l6dt	5	People often don't understand mindfulness and can be dismissive of it, or think it doesn't/can't work for them. It takes time for an understanding to develop and for it to become meaningful to the person.
k9zt	5	He is really representative of a lot of clients I have seen, who are only a few months into their DBT journey
fgw3	4	I think his difficulties understanding it and 'getting' how to do it are perfectly normal for this stage in DBT.
2tcm	4	It is a new concept that has been re branded from Buddhist teachings; people here the name, read the literature but do not know how to apply it to themselves either through lack of education or understanding but a good therapist / teacher / practitioner can rectify that.
1qlv	4	I have encountered many clients who find mindfulness hard at beginning, particularly due to a lack of understanding.
my94	4	Mindfulness, whether part of DBT or not, is often a challenge to appreciate and practice
7co9	3	Maybe the judgement about the leaf exercise, or finding it hard when they're experiencing emotional distress, but again this would be a failing of the therapist in not supporting this client better and teaching them this. I have often had clients come with judgements and who have struggled with it initially, but then you have to be creative and use lots of different types of mindfulness, e.g. of taste, sound, fun exercises with bubbles, etc. etc. it's not all about a leaf. Also, the point of mindfulness is to use it in moments when they're not distressed so they learn the skill, in order to practice applying it more in emotionally distressing moments. Again I'm not too keen on the quote about mindfulness being really hard - it's painting it as hopeless and goes against mindfulness completely i.e. that is a judgement, and the therapist should be teaching the client to notice these judgements which in itself would be mindful!
nk2f	1	When I teach mindfulness the first task is to ensure all clients understand the aims and purpose of what being mindful is all about. If it’s about wilfulness (an aspect of DBT) then this is addressed with kindness.

Average score: 4.3/5

> [Participant NK2F - score 2] I'm still a little confused as to why clients are 'overthinking' mindfulness and stuck in a top down approach to the process. Perhaps our team may have done more to assist people's confusion from the outset. This may have had something to do with the DBT training we received? During this process we were strongly encouraged to challenge our own views of what it meant to be mindful and we were taught many techniques. But, I'm guessing that some clients could feel like this early on?

Again, it would have been interesting to follow up this comment and understand what exactly is meant by *challenge our own views of what it meant to be mindful*. The rejection of a client's lived experience as valid and the creation of an explanation as their therapists failing them is discussed in Section .

There were also a number of positive comments, which not only accepted the lived experience of this persona, but also recognised the attitudes from their own clinical practices:

> [Participant UT8G - score 5] This is something I hear from clients in practice in the initial stages of mindfulness
>
> [Participant XV1Z - score 5] The lack of understanding the point of the exercises, combined with the judgements (that it must be his fault for not getting it), feel familiar.

There was also agreement and constructive feedback in the form of one participant's experience of how a *beginner* male client might react to learning Mindfulness skills:

> [Participant KDC2 - score 4] A real sense of 'what's the point?' is something that I experience with my male service-users. I often see a more externalising response, however - 'I think it's me, I'm not good at learning new things' could be replaced by 'They're making me learn something that is pointless and doesn't work' in some cases.

This is something that could have been explored if further rounds had been used in this study.

Catriona Desouza

Mindfulness was also the focus of the question for the Catriona persona. The questions scores are significant at $p \leq .05$, as shown in Table 6.8. The results revealed that within the participants there was consensus of $> 80\%$, with only two participants who were still not happy about the depiction of Mindfulness skills in Catriona.

The qualitative analysis again revealed a mixture of participants finding the persona representative of their clients, participants worrying about the client represented and participants doubting the lived experience portrayed in the Catriona persona, even though it came from the data I collected. The first answer is hard to follow in places, but I included it for several reasons.

> [Particpant 2TCM - score 4] I think that this is a more attuned version to a long-term DBT and mindfulness client. However there are a few things

Question	Range	Median	IQR	Z	p
P1.9 How far is Catriona's attitude to Mindfulness representative of a typical later stage DBT client?	1-5	5	1 (5-4)	-2.31	.02

Table 6.8: Analysis of amended Mindfulness in Catriona Desouza showing range, median, IQR, and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

> that I would still alter a further. The fact that she is an artist and also the sentiment in the statement which you said that mindfulness 'does not take long to understand, as it is not take long to grasp'. Again, you're having to deal with certain types of personality, and also if you were to present an individual with the concept which in your mind is quite basic, and iif these persons were unable to grasp the basic concept, it might alienate further. You may get away with it being in a persona, but again just been mindful of certain comments as they merely any individuals. The rest, however, looks good.

Difficult to follow answers, which nevertheless look like they may be interesting, could not be followed up in this study. However, the participant points out, like a participant in Round 1 that an artist is an unlikely occupation for her. Something that a further round might address. The rest is a little hard to follow, but they seem to be saying that the persona should be more positive. It is unclear who the participant thinks may be affected by reading this, whether a client validating the persona, or if they have misunderstood where it will be used.

The next quote is again normative, using the word "should". The therapist is putting their standards of behaviour on to Catriona. It's not clear why he quotes Linehan (the founder of DBT) here. Is he saying that she looks like she is failing?

> [Participant NK2F - score 1]I still don't think it should take a year to understand mindfulness, I really don't. However, this could be typical of clients from different groups and teams. If this was a problem that it would be raised in DBT consult. "The client isn't the problem, only the therapy team can fail" is one quote I remember from Marsha Linehan.

Finally two participants who see the Catriona persona as very representative.

> [Participant KDC2 - score 5] Very appropriate - still needs prompting and support but appreciates the purpose and benefit.

> [Participant LA4C - score 5] I like the way in which she still struggles with it but tries to use it. She has learnt what mindfulness skills work for her. Others may still struggle more even at this stage

6.5.3 UX Map

Round 2 re-asked 2 questions about the UX Map. When answering the questions, participants were shown the scores and comments given to those questions in Round 1.

Question P2.1 asked participants about the changed Map as a whole. The result in Table 6.9 is significant at $p \leq .01$, showing consensus among participants about the UX Map. The scores also show stability of scoring within participants across the 2 rounds, adding to my confidence in the final scores.

The qualitative data showed why the scores were high, and the particular features that the participants liked or thought were still missing.

> [Participant 2TCM - score 4] I can see with a thorough research and feedback that you've gained, the answers have been developed and I would say that is fairly typical of an individual utilising both DBT and mindfulness skills.
>
> [Participant NK2F - score 4] The map is very well designed and put together, it is easy to follow and understand. I feel is does match up to those acquiring DBT mindfulness skills. I really like the quote about it being difficult, however, that the client still practices. It is very well put together and really concise.

It is interesting that although the UX Map is praised, the participants do not score it 5, but do not explain why not. One issues with using a Likert scale is that some participants may be reluctant to select the extreme options. Other participants scored the Map 5, mentioning that it is improved by the changes I made, even though they would like to add more functionality:

> [Participant KDC2 - score 5] Better without timeline - timescales are different for everyone and often non-linear.

Adding the non-linear nature of the clients' progress to the Map was also noted by other participants

> [Participant XV1Z - score 4] I prefer the lack of time attached to this. I almost feel like some acknowledgement of the process not necessarily being linear might also help; but overall it feels like the lack of "deadlines" re: being an "entrant" etc is helpful.
>
> [Participant LA4C - score 4] Much better without the time line. I like the visual representations of the way in which skills emerge (experience). Only thing difficult to represent is the potential for moving backwards as well as forwards through the process.

The non-linearity of the journey for some clients is something that could be added to

Question	Range	Median	IQR	Z	p
P2.1 How far does the UX Map match your experience of typical progress in acquiring DBT Mindfulness skills?	3-5	4.5	0.5 (5-4.5)	-2.93	.003

Table 6.9: Analysis of amended UX Map showing the values of the range, the median, the IQR and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

the map and tested in further rounds. In terms of a DMHI for DBT Mindfulness, it could be added as a requirement that clients should be able to access content at all stages.

> [Participant 1QLV - score 4] I think that the description is really good. In particular it captures the changes that occur over time from not understanding mindfulness at first, to then understanding it a bit more but struggling to put it into practice etc...

Question	Range	Median	IQR	Z	p
P2.2 Looking specifically at the Stages level: How far do the progression stages (in green), the proficiency and high-level categories represent the clients' progress in acquiring DBT Mindfulness skills?	3-5	5	1 (5-4)	-2.93	.003

Table 6.10: Analysis of amended UX Map showing the values of the range, the median, the IQR and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

Question p2.2 focused on the Stages. The results for the second question, P2.2 are shown in Table 6.10. It is significant at $p \leq .01$. Again all scores except the one mentioned above (3) were 4 or 5.

The follow up answers explain why this score was given, as well as adding suggestions. As in the previous question these are mainly about the journey being non-linear. Although other suggestions are also made, for example about the meaning of being proficient at the Mindfulness skill:

> [Participant XV1Z - score 4] Again, I like this - the only reason I'm scoring 4 is because it's occurred to me that it could be helpful to acknowledge that it may not be 100% linear (feeling proficient in some skills, doubting proficiency in others, losing confidence due to using a behaviour etc etc).
>
> [Participant KL5R - score 5] Reflects what I see in my practice. Clients can go up and down the scale though
>
> [Participant 2TCM - score 4] I think the stages in green are quite good, however, I would also add the further suggestion the to be proficient in mindfulness does not necessarily mean using everyday, however that you can use it effectively In whatever situation you need to.

Participant NK2F compares the UX Map to other guidelines for teaching mindfulness. It is interesting that the same stages are seen in non-clinical practitioners.

> [Participant NK2F - score 5] Not only in DBT put in traditional mindfulness this represents a good insight into the process a client will make. Well designed and real easy to follow too. It is similar to the Good Practice Guidelines I use as a mindfulness teacher.

Finally a couple of comments about the stages not being in synch for all skills, and the way that even though a skill is understood, the client still may not be able to use it until a later stage:

> [Participant LA4C - score 4] As above, sometimes life events can affect people's skill use and we might aquire different skills in different ways i.e. mindfulness might be at intermediate and distress tolerance might be beginner.
>
> [Participant 1QLV - score 4] I recognise these stages from the clients I see. Usually understanding comes first, then usage is improved, and finally the client starts to see regular benefits.

6.5.4 Scenarios

Question	Range	Median	IQR	Z	p
P3.2 How far does the Activity Scenario show realistic possible uses for mindfulness skills?	3-5	5	0.5 (5-4.5)	-2.93	.003

Table 6.11: Analysis of amended activity scenario showing median, range, IQR, and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

The results in Table 6.11 show the stats from question 3.2, with the score for this answer being significant at $p \leq .01$. Again all scores except the one mentioned above (3) were 4 or 5, with the majority being 5. As the scores show and as reflected in the comments, the scenario was the model that the expert participants liked the most.

> [Participant 2TCM - score 5] I think that this particular [scenario] has been very concise, and is highlighted key points regarding mindfulness, including the fact that yes it is something that can be quite easily to teach, and therefore something which you can pass on easily. I also firmly agree with the point that it is not a magical device which can cure all mental illness, and there must be something in place to ensure that any client who is undergoing this process is made aware of that fact, if nothing else in the ethical considerations that are implied by that statement.
>
> [Participant NK2F - score 5] Superb! Really concise, each scenario is well thought out. Noticing her self talk in scenario one is very helpful. In 3, I like how she reminds herself to use the app. It provides a great deal of hope that things can improve. It also shows the absolute struggle clients with BPD face on a day to day basis.

Some participants also suggested how other DBT skill sets and specific skills could be brought in and used in the scenario:

> [Participant S3JH - score 5] I think these are realistic, just a minor note that the person would potentially need to be aware of the skills taught in the interpersonal effectiveness module and an early user might not be able to rely on these skills.

> [Participant XV1Z - score 5] I reiterate my previous comments re: all of these opportunities being perfect for mindfulness. I think this demonstrates the usefulness of a mindfulness-based app, and I can see how the other skills might fit in around this (e.g. distress tolerance, if the present moment is too hard to tolerate).
>
> [Participant 1QLV - score 5] I think it shows very realistic uses. Mindfulness can help to stop rumination and allow someone to engage with their thoughts and feelings in the present... However, occasionally in DBT we do recommend distraction,[7] if mindfulness isn't proving effective.

Other comments focused on the app, thinking about how/where it might be used and the type of client who might be able to use it, and possibly that more encouragement might be needed:

> [Participant KDC2 - score 5] I agree that it does depend on where the service-user is in the process of learning, but I can definitely see how mindfulness would be helpful in this scenario, both before and during the bus journey. I think that thought should be given to exercises that can be completed on a busy bus with headphones in.
>
> [Participant LA4C - score 4] The client is working very hard to manage her emotions and reactions. It reflects really well an ideal of trying something, it not working, then trying something else. How this reflects real practice might be difficult - she is only five months in. I would say it is good for a very proactive motivated client. Others might give up quicker!

Many of the points about the models seen above could be introduced in a further round, or they could be incorporated into an app which was then tested on clients.

Question	Range	Median score	IQR	Z	p
P3.5 Imagine you had to explain to a developer the possible everyday uses of mindfulness skills that could be technically supported in a DBT Mindfulness app. How useful would you find the Scenario in doing so?	3-5	5	0.5 (5-4.5)	-2.93	.003

Table 6.12: Analysis of P3.5 showing median, range, IQR , and Wilcoxon Signed-Rank Test Z and p (n=12 participants)

The results in Table 6.12 show the score is significant at $p \leq .01$. The results revealed that 9 participants scored this question 5, two 4 and one 3 (as discussed above).

In addition to the quantitative results, the comments reflect that the experts see the scenarios as being very helpful in showing where the app could be helpful and situations it could be used in:

---

[7] Distract is a Distress Tolerance skill. It is used to distract from a problem in a crisis situation and is a short-term solution for when the client are not able to use other skills like Mindfulness.

> [Participant S3JH - score 5] I think this accurately captures potential uses of Mindfulness.
>
> [Participant KDC2 - score 5] A minute-by-minute account looks like it would be very helpful.
>
> [Participant XV1Z - score 5] I would feel like I was selling mindfulness well! It demonstrates just how useful and integral it is to staying safe and tolerating difficult emotions/situations.
>
> [Participant 1QLV - score 4] The scenario demonstrates a wide range of app functions - from reminders to notes, to examples of activities. It seems really helpful, and the nice thing about the scenario is that it provides a demonstration of how it could work.

Other participants focused on the client experience:

> [Participant NK2F - score 5] It's excellent. I think they would get a true sense of what the client will be experiencing having BPD. I think they would find great use in reading through the scenarios in turn as they are well throughout.
>
> [Participant 7SHP - score 5] It may be hard to understand this client group, so would he helpful
>
> [Participant KL5R - score 5] It shows the sorts of things this client would experience.

The final comment in this questions shows the assertion of the therapist as expert on the treatment, rather than letting the clients use the app as they choose, it is seen as something that would sit within the therapeutic context, being guided by the therapist:

> [Participant 2TCM - score 4]I think that I would find the information provided very good, and using the application in conjunction with therapy would be a great starting point, I will be quite honest with you that I will add my own spin and personal take on it as I'm sure every other therapist would, however as a base resource I think it is very good.

6.5.5 Part 5 - Final Comments section

In this section, participants were asked for any final comments on the URD. A selection of the answers is given below

> [Participant 2TCM] I think you've done an excellent job in your amending of the process so far, however, I would like to reiterate the fact that it is extremely difficult in creating personas to hit hundred percent of the people hundred percent of the time. You are going to find out that individuality will cause difficulty and that the implications of a magical cure will not necessarily guarantee a success rate of 100%. If you manage to ascertain between 85 and 90%, I think you're doing extremely well and I think the application has the benefit to ensure that it can be used as a support tool. I would firmly suggest that this is only used as a support tool, and not implies in any way to be used as a form of self-help on its own, as BPD

> being a type B personality disorder needs to have some influence from a therapist.
>
> [Participant NK2F] I think it's excellent. I guess my only concern is how long it's taking for some clients to understand mindfulness. However, this is nothing to do with the URD.
>
> [Participant KDC2] I think that it would be difficult to capture every client's needs and experience, but I think that the URD is generic enough to apply to most DBT clients.
>
> [Participant VMQ4] Overall the improvements made are really good and reflects some of the thoughts I had with the first version.
>
> [Participant 1QLV] No more comments; I think it's really good! You've taken on some of the feedback I had from last time about removing the time-frames from the UX Map, and I think that's the only significant hesitation I had.

In terms of taking on board the changes suggested by the participants and establishing the validity of the URD, the results show that the study successfully did this.

6.6 Discussion

In using a Delphi-influenced study, I was attempting to add some of the iterative dialogical approach (Wright & McCarthy, 2022) into the process. Although I was unable to have direct conversations with the participants, I was mindful of how the dialogical approach sees design as a co-production and part of this is looking at the world from a stakeholders' point of view. Therefore, I was very interested to hear what the clinicians, as experts in DBT, thought of the artefacts I had spent so long producing. As well as asking closed questions, the three questionnaires allowed participants to add comments on the artefacts I presented. The answers were often quite detailed, giving me a good understanding of why participants had given a certain score, and where they saw positives and negatives in the URD. Some of the clinicians who participated were unwilling to accept the requirements as detailed in the documents, even though they were grounded in the interview data, because it was not how they as clinicians had experienced DBT. This study also highlighted the hostility expressed by some clinicians when presented with clients' views which did not reflect their own discourse of DBT as a treatment for BPD, and their rejection of my findings from the client interviews, used as input data to the URD developed in Study 3.

In undertaking this study, other researchers in this area can see how the methodology works and the amount of effort running a study like this takes. They can also use my experience as a map to run a similar type of study. This Delphi-inspired study was complex and challenging to run, with the data helping to answer sub-question 3. I learnt a lot about validating requirements, working with experts and running studies of this type. This section begins with a discussion of the methodology, and then examines the themes. Theme 1: were the classifications used in the documents good representations in terms of establishing the validity of the personas, the UX map and the scenarios? Theme 2: was the URD insightful about DBT and/or the clients? Together these themes help to answer research sub-question 3, which is discussed in the final section.

6.6.1 Method Discussion

Problems of validating with clinicians

UCD recommends validating requirements with end-users (Lazar et al., 2017). Whilst personas can be beneficial in effectively conveying design requirements to stakeholders (Cooper, 2004), validating with the clinicians was problematic, because the client end-users of the DMHI were not able to say whether the requirements in the URD were accurate or not. In creating a suitable DBT DMHI, the end users need to have input into the requirements to check that the things that help and hinder them, and what they actually want in terms of content has been understood (Lazar et al., 2017). However, for pragmatic reasons, I chose to validate with clinicians. As the final comments show, clinicians see themselves as working closely with clients using the app, due to the nature of the disorder, rather than it being a stand-alone DMHI. Therefore as stakeholders, validating with them was seen as one step in the validation process. In addition, when creating a clinically valid DMHI, expert input can be important to ensure the content is correct (Lazar et al., 2017). Doherty et al. (2010) recommends using a group of end-users and stakeholders to validate.

Clinicians would certainly be part of a stakeholder group, so their inclusion is not unwarranted. The requirements themselves were derived from client accounts; thus, validating them with clinicians, as well as giving feedback on the URD, also provided crucial insight into how client and clinician views on DBT for BDP relate. Validating with clinicians also allowed me to study to what extent UCD-derived requirements and their representations were perceived as useful and insightful by clinical practitioners, answering the research question of whether UCD can be used in this context. The pragmatic approach that I took in validating the requirements with DBT clinicians can be defended by the following points. The clinicians were experts in DBT and all had first hand experience of working with clients with BPD, therefore the DBT information presented was very familiar to them.

Benefits of validating with clinicians

However, although it is not the traditional standard view of validating in UCD, in dealing with end-users with a mental health disorder, there may be benefits to validating with clinicians first. Some of the clinicians thought the personas were too negative about DBT being effective. If this was true, then using personas that show people struggling in acquiring DBT skills could potentially have a negative affect on the clients, especially the beginners. Therefore, validating first with clinicians and then with clients, or with a mixed group may be better. The personas and the scenario were made necessarily detailed. The personas include information about self-harming, self-harming urges and abuse. The scenario depicts a very difficult morning commute with a lot of negative self talk and mentions thoughts of self-harming. I did this in order to show a development team who might not be aware, the seriousness of the disorder, and to gain empathy for the users when designing the DMHI (Norman & Draper, 1986). However, such documents might be very difficult for clients to read, triggering self-defeating behaviours. Another situation where proxy users might be appropriate is when a specific application or tool is being developed and it is undergoing multiple iterations before a proof-of-concept is complete. If users with the specific disability would not be available to take part in all stages and all iterations of design, then proxy users might be suitable in limited stages and limited circumstances, for preliminary evaluation (Lazar et al., 2017).

Leading on from this, if I were to validate with clients, special measures, similar to those employed in running the interview study (Study 2), would need to be in place after a validation session. Study 2 involved giving the clients a list at the start of the interview reminding them who they could contact if they were triggered by anything in the interview (DBT therapist, GP, etc) and having GPs and DBT staff aware of the interview and that they might need to be available immediately after the interview, if clients needed to discuss anything. This would mean that these sessions would therefore need to be in person and possibly at a therapy centre. However, because the clinicians did not need such back up, this study could be run online. Whilst ease of running a study should not be the main or the only criterion when deciding on participants, it is one of a number of factors which needs to be balanced when carrying out UCD.

It is clear that validating these types of requirements need to carefully thought about and may be a balancing act. It is not desirable to create something no one wants, but clients maybe be better validating at the prototype stage, or being shown the list of requirements without the detailed personas and scenarios.

In UCD, requirements should be validated with end users (Lazar et al., 2017). However, recruiting end-users who are difficult to access needs careful consideration, right from the start of a project. Accessing vulnerable people's data is not easy. For this study, finding DBT client participants, after the Tuke Centre DBT group was disbanded was extremely hard. I was told that neither I nor any of the Tuke staff was allowed to contact any of the former DBT clients, as they had not given permission for that. I contacted other DBT groups, but other clinical centres were not keen to take part in the research. In addition, lengthy ethical processes, such as the NHS REC, necessary when working with vulnerable groups, needed to be considered and applied for in plenty of time. This meant that the time involved prohibited me running the study with clients, as the position of the the DBT group at the Tuke Centre took a couple of months to clarify and due to all the changes, the study design was not clear until late in the day. Whilst coping with changes and unexpected occurrences is part of research, if I were running this study now, I would do it differently, with much more planning of the whole project and including more contingency plans from the start.

Using a Delphi-inspired method

Having reflected on the use of a Delphi-inspired method using an online survey in this study, I can see that while the data produced was sufficient to validate the URD and answer sub-question 3, the method had a number of flaws. If I were to carry out this study again, I would chose another method, for a number of reasons.

Validation through seeking consensus

Seeking consensus may not be the right approach or a good way to make changes to personas, because personas should represent archetypes of different user groups (Cooper et al., 2014), if this case clients at different stages. However, trying to get consensus about a persona may lead to generic representations, which is the opposite of the underlying philosophy behind using personas which represent individual users. The personas were made using a rigorous and thorough UCD method, and were based on data obtained in interviews with clients and observations of clients whilst on placement at the Tuke Centre.

Round 2 - problems with presenting the materials

Whilst the questions were asked online, as discussed in Section 6.4, the participants had been sent a PDF of the URD, explaining the UCD background to the models used and the functions of the different sections. However, it was clear to me from some of the comments that some participants had not read or only skim read the URD, revealing a flaw in the methodology I used, because it relied on participants doing things that I had no control over. The answers some participants gave were based on a personal reaction rather than how the documents might be helpful in the development of a Mindfulness app. This could also be a function of their world view as primarily mental health clinicians. Again, without talking to them it was impossible to know. Nonetheless, the information was still interesting and helpful to me in understanding the requirements gathering process.

Time required

Setting up the study took a very long time due to the amount of material involved and the number of times it had to be piloted. Recruiting participants took a long time due to DBT being an empirically tested but not widely used therapy, therefore accessing therapists proved difficult. In addition, the study required a considerable time commitment from the participants as it was run over two rounds.

Most importantly, the 3 documents used in the final study had to be brief, as the whole study had to be under 3 hours, (1.5 hours over the first Round). This meant that a lot of the original documents that I produced could not be included. One way to overcome this issue this would be to use different groups. However, following the corona virus lock-downs, many people are more used to working online and in online meetings. Therefore, online focus groups might be a possibility for a better way to run validations. Alternatively, talking to people individually with the documents presented to them beforehand might also achieve better results.

Overcoming misunderstandings

Using participants who were understandably not knowledgeable about UCD led to some misunderstandings, particularly about the personas. Face-to-face contact / involvement from the beginning, perhaps over a number of sessions, might have been able to help clear this up. The experts' unfamiliarity with the models and the language lead to some misunderstandings, which could have been resolved doing a formal interview type study with emailed documents and online interviews if necessary. Thus any misunderstandings and questions could have been cleared up more easily.

6.6.2 Theme 1: were the classifications used in the documents good representations in terms of establishing the validity of the personas, the UX map and the scenarios?

Personas

In establishing whether the classifications in the personas were good representations, the attitude to Mindfulness and statements about Mindfulness were the biggest bones of contention. Whilst the majority of therapists recognised clients' attitudes as accurately portraying clients, and even reflected that they had heard similar statements from their clients, a minority did not identify with the portrayal of acquiring Mindfulness in the personas, seeing them as taking much to long to acquire mindfulness.

Some parts of the personas were not questioned, for example, the stage the client was at, their backgrounds, and their reason for undertaking DBT. Client language was an issue for some. The personas were more contentious and as mentioned above, this is where actual end-users may have been helpful. However, as also mentioned above, using the clients to validate these personas may have been triggering, therefore using the personas as input to wire-frames or some other initial design might have been better.

UX map and scenarios

Overall the scenarios and the UX map achieved consensus scores and particularly at the end of Round 2, all participants were happy with these documents and they were see as representing DBT and useful. They were much less contentious than the personas.

Overall

The document overall was seen as helpful and representative of the end users.

6.6.3 Theme 2: was the URD insightful about DBT and/or the clients?

Whilst the participants approved of an app to help deliver DBT, it was seen by several as needing support from therapists rather than being used as a stand-alone tool, (which it was, I should have made this clearer in the Introduction). In terms of the URD showing an accurate and deep understanding of DBT clients, a number of the clinicians stated that they had seen this behaviour or the behaviour was typical of clients they had dealt with.

Whilst the clinicians acknowledged the clients understood their condition, some saw the problems faced by the personas as coming from a lack of expertise in those delivering therapy. The personas were not just seen as snapshots of where the client was at that time. Rather, some of the participants reacted to them as if they were real and wanted to "fix" them or at least account for why they were having problems. One point here is that the fundamental dialectic in DBT is acceptance and change (Linehan, 1993) (see Section 2.4.4. **Acceptance** that given the client's life situation, they are where they are in terms of struggling, and at the same time they have to **change**, by learning the skills, to make their life better. However, the acceptance in these clinicians is missing. This almost feels like the persona is a professional criticism for them. Perhaps we cannot expect experts to be dispassionate about documents in their field, especially when they perceive the documents as making their field look incompetent or showing colleagues as not doing a good job

6.6.4 Answering sub-question 3

Study design critique

Sub-question 3 asks: *To what extent are UCD-derived requirements and their representation perceived as useful and insightful by clinicians?* In Study 4, the personas were contentious, and as mentioned above in Section 6.6.1, this is where using end-users may have been helpful. However, as also discussed above, using the clients to validate these personas may have been triggering; therefore using the personas as input to wire-frames or some other initial design might be a better decision.

In designing for the clients with the most challenging presentations as the key or primary personas Cooper et al. (2014) suggests that even if they are not the largest segment of the client user group, other clients with less constraints in the user group will still be greatly satisfied. Although this is explained in the URD, it is not clear that clinician participants had the time to read this or understood it. Using a method like interviews or a focus group to validate may have led to more consensus and learning on both sides and should be borne in mind by future researchers. In addition, many of the points about the models seen above could be introduced in a further round with more explanation, or they could be incorporated into a DMHI low-fi prototype in the next phase of the design process, which could then be tested on clients.

Typically Delphi methods are not used in UCD. As discussed above, I would have liked to use the dialogical approach (Wright & McCarthy, 2022) here, and think it would have helped the more critical clinicians to better understand the UCD process and the purpose of the URD. In discussing the dialogical approach, McCarthy and Wright (2022, p.55) assert that "[n]ew understanding is created in the respectful, responsive engagement with dissimilarity." This research tries to engage both clients and clinicians in the research process, as the views of both are important. Engaging stakeholders is key in the development, implementation and evaluation of DMHIs and an important part of socially desirable and acceptable digital innovations (Jirotka et al., 2017). Using a focus group or other face-to-face discussion method, I also think both myself and the clinicians may have been able to learn from this process. However, by using a Delphi-type study over two rounds, with experts given space to comment after each question, I tried to replicate the spirit of the dialogical approach, to listen to and understand differing stakeholder viewpoints, make design decisions based on this and represent them for further comment.

It would have been interesting to address the different attitudes I found to the design artefacts I produced, but time and logistical constraints did not allow this. It may be that the dialogical approach, whilst worthy in helping the design, is quite time-consuming. This is a key point for other researchers and is addressed in Section 7.5.

Simons (2010) interviewed clients and clinicians, reporting that clinicians constructed themselves as healers and saw clients with BPD undergoing DBT as difficult to deal with due to the clients' slow progress and disruption of their own treatment, which frustrated the clinicians' role as a healer. Like the studies discussed above, the clients saw DBT as positive, even life-changing, as a new identity arose from acquiring the skills, similar to Cunningham et al. (2004), but as in other studies, it was also constructed as difficult, and struggles with mindfulness were ongoing. Support of the group and their therapist was seen as key, as also noted in McSherry et al. (2012). However, the number of interviewees was small, leading to possible limits in the discourses found.

This study shows that the requirements were seen as very useful, particularly the UX Map and the scenarios. The scenario in the URD portrays a client as successfully using DBT Mindfulness to alleviate a very stressful morning commute. However, the personas portrayed Mindfulness acquisition and use as extremely difficult, based on the client interviews and my observations of client struggling with Mindfulness skills at the Tuke Centre. One of the emerging issues was therefore that some clinicians, especially if they are not used to working with more extreme clients, find it difficult to deal with clients' struggles and want to find solutions for them. Seen in terms of clinicians constructing themselves as healers (Simons, 2010), it is possible that if their colleagues in the models are implicitly portrayed as not healing, this is very difficult for some participants and triggers a need to heal or fix the personas.

This is backed up by the scenarios where the client is shown as doing well and using Mindfulness to help herself, being praised, even though some participants acknowledged that this was a portrayal of a very motivated client (implying most would not be able to achieve this). Many of the points about the models seen above could be introduced in a further round, or they could be incorporated into an app which was then tested on clients in the Design phase. This works towards showing that UCD can be used as a methodology with people with BPD, although adaptions must be made to allow for the context.

6.6.5 Reflexivity

At the end of this study, I was puzzled and curious. I knew that my models were grounded in my data and my experience of observing clients and chatting to clinicians at the Tuke Centre. I wanted to understand more about why the client experiences had been rejected by some participants and why the personas' experiences were seen as a fault in their therapists not questioning them. I would have loved to engage more here using the dialogical approach (Wright & McCarthy, 2022), because it seemed like a good opportunity for myself and the clinicians to learn from each other, in the same way the nuns and the designers widened their views on the overall process of the prayer companion (Gaver et al., 2010). However, that was not possible, within my chosen methodology.

6.7 Conclusion

The final User Requirements Document reflects the majority views of a group of DBT clinicians on suitable requirements for a digital intervention for DBT Mindfulness for people with a diagnosis of BPD who are undertaking DBT skills training. This suggests that a UCD process can be used to gather suitable requirements for a DMHI for DBT Mindfulness which takes into account the unique needs of people living with BPD. The requirements allow for extra support for learning Mindfulness, so that clients feel validated and encouraged throughout the learning stages.

The next chapter summarises the research, and answers the sub-questions and the overall research question.

Chapter 7

Discussion and conclusion

7.1 Introduction

This thesis documents a rigorous, empathic (Wright & McCarthy, 2008) UCD (Norman & Draper, 1986; Gulliksen et al., 2003) research-based process to ascertain how UCD methods can be used to gather and present user requirements for a DMHI for patients with Borderline Personality Disorder (BPD). I critically reflect on the adequacy and implications of using UCD techniques to gather, analyse and validate requirements for the design of a DMHI for DBT presented for validation in a user requirements document (URD), discussing the methodological work which is necessary in gathering requirements for a DMHI for a vulnerable clinical population diagnosed with BPD.

BPD is a pervasive disorder with high affective disregulation, leading to unstable self-image, cognitive processes and personal relationships (Linehan et al., 1993; Leichsenring et al., 2011). Treating BPD patients is complicated by therapy-interfering behaviours (Swales & Heard, 2016), and the disorder is associated with significant stigma (Masland et al., 2023). DBT is a long-term, specialised, gold standard treatment for BPD (Stoffers-Winterling et al., 2012; Choi-Kain et al., 2017) (detailed in Section 2.4). DBT is a long, highly manualised treatment, with Mindfulness at its core (Linehan, 1993; Linehan et al., 1993).

The requirements were developed through collaborative engagement with clients and clinicians at *The Retreat York*, a private, charitable, psychiatric hospital. This institution sponsored this research and was key in shaping the research scope and objectives. Therefore, specifically, I set out user requirements for an adjunctive treatment app to sit alongside a DBT programme to assist patients in acquiring and practising the *skills* in the Mindfulness module. This was reified using design artefacts in the UCD process which model DBT users and their journey. These can be found in the User Requirements Document (URD; Appendix I).

This research shows the extensive methodological work which is needed in the context of vulnerable, hard-to-reach user groups with complex mental health challenges to sufficiently understand and communicate user requirements, pain points, and contexts of use of a DMHI, so that other user researchers looking to work with BPD and other vulnerable people can learn from this experience (Contributions 1 and 2). Conducting such extensive work was justified by the deep understanding of the end users and their journey through DBT which I gained. This provided value through giving the ability to fully represent the requirements of people living with a life-threatening mental illness (detailed in Contribution 3), including several that contradicted the design of other recent DBT DMHIs .

As part of the substantial methodological work required in this challenging setting, the approach taken in the research was empathic UCD (Mattelmäki et al., 2014). Empathy in design is a skillset rather than a psychological construct (Drouet et al., 2024). Empathic UCD allows the researcher to gain a deep understanding of the users and their lived experience, particularly the user's emotional experiences and personal contexts, which are very important for end-users with a diagnosis of BPD. I looked in depth at the experience of long-term mindfulness practitioners, and the experience of delivering and learning DBT skills in clients and clinicians, constructing a user requirements document (URD) and validating the requirements I had generated. In using empathic UCD, I gathered a comprehensive understanding of users, tasks and their context, their goals, needs and requirements. This chapter details how that approach can be used by other researchers and the work involved to do so.

7.2 Research motivation

There were three motivations for undertaking this research.

1. DBT is a difficult and long-term therapy, with the Mindfulness skills module being both the foundation and the hardest to learn and practice. There is a gap in the literature on designing retention-sustaining and engaging Mindfulness-based DMHIs for people undertaking DBT.
2. There is a methodological gap in whether and how well UCD methods and tools can be used with this vulnerable and hard-to-access group and where it might need to be adjusted.
3. In the Health literature, when designing DMHIs for people living with a mental illness, the initial design work was often not well described, or focused on the clinical input, leading to the conclusion that there was a user-centric design description gap.

The research questions were formed from these motivations. These are detailed and answered in the next section.

7.2.1 Studies

To carry out the research, a series of studies were conducted, with the results of one study informing the work in the next, to differing degrees, with each giving a view of the issues highlighted in the literature (Coyle & Doherty, 2009; Doherty et al., 2010; Waycott et al., 2015) around problems with designing DMHIs for challenging mental health contexts. Study 1 examined how long-term mindfulness practitioners had gained and maintained the practice of mindfulness in their lives. Study 2 examined how target stakeholders perceived DBT skills training. From this study, the DBT skill of *Mindfulness* was selected as the skill to focus on in the requirements development, as it was seen as key by clients and clinicians. From the Study 2 data, a User Requirements Document (URD; see Appendix H) was developed in Study 3. Parts of this were validated in Study 4 with DBT clinicians.

7.3 Research questions

Following from the motivations, the research question this work sought to answer was:

> How can using user-centred design methods support gathering user requirements for an adjunctive app to support people with Borderline Personality Disorder undertaking the Dialectical Behaviour Therapy Mindfulness module?

In answering this question I fill some of the gaps in the research seen in the motivations. The headline answer to the research question is that UCD can work to support the initial stages of a design process in this context, as the URD shows, but in addition to the considerable work needed in a UCD process, a lot more methodological work and adaption of UCD is required due to the context. UCD in any context is a time-consuming process, and this is doubly so undertaking empathic UCD in a challenging context, where considerable planning, flexibility and emotional labour was necessary (see Section 7.4). However, in undertaking this research, I found results that made the considerable work in the process worthwhile, which would not have emerged if I had not used this in-depth method, and which are not only *not* present in the other DBT apps in the literature (Section 2.3), but some of which contradict the app contents. Examples of findings were: the five stages of DBT that clients undertaking DBT pass through, with differing needs at different stages; and, the shift in beliefs about themselves and the world that was necessary before they could acquire the skills fully and progress in the therapy, The benefits of using UCD in this challenging context are detailed in Contribution 3 (p.321).

In addition, in developing the requirements, I had to manage some small design differences between the views of end-user clients and stakeholder DBT clinicians, towards some of the DBT skills. In this, empathic UCD and a dialogical approach helped me as a designer to make good design decisions (discussed in Section 7.3.2). There was also a dichotomy which arose around the individualistic view of the DBT clinicians about the clients in therapy seen in Studies 2 and 4, and the aggregated approach to designing for archetypes of end-users, used in UCD, which are addressed in the requirements, but would need prototyping in future work to fully resolve. As discussed in Section 6.6.1, an overt dialogue was not possible in Study 4, due to time and ethical constraints (see Section 6.6.1). This difference in viewpoints would not have been found without using UCD, and is of particular interest given the lack of overt detail about the design process in the DBT apps literature (see Sections 2.3.3 - 2.3.6).

Despite the amount of work involved, I consider UCD to have been worth the considerable time and effort and a good choice in gathering requirements for vulnerable, hard-to-reach groups. Through the use of empathic UCD, it allowed depth of understanding of the users, their emotional responses and their personal contexts, but also flexibility through the use of proxies where necessary. The significant labour the work involved was also valuable and beneficial because I believe that as designers and responsible members of society, we have a duty to involve all members of society in the design process, particularly those whose voices are often not heard, even if it requires extensive methodological work to gain the trust of the users, understand their context and struggles and then illustrate this in a way that is approved of by end-users and stakeholders. This research will show other researchers how such work is possible in a challenging environment, give a process to follow, and suggest improvements and things to avoid in future research, exemplifying what can be gained from using this method.

In answering the question, four sub-questions were addressed. Each focuses a different lens on part of the main question:

1. How do non-clinical practitioners and DBT clients achieve and maintain mindfulness skills and practice?
2. What are the DBT client requirements for a DMHI supporting Mindfulness skills acquisition?
3. How are client-derived UCD requirements viewed by DBT clinicians?
4. What are emergent issues and potential amendments for UCD user requirements gathering methods when working on DMHIs for an end-user group with BPD?

I answer the sub-questions, then return to answer the overall question in more depth.

7.3.1 SQ1. How do non-clinical practitioners and DBT clients achieve and maintain mindfulness skills and practice?

Through answering this question, I show where the data that the requirements were based on came from. Grounding them in data acquired from end-users, and primary and secondary proxies in Studies 1 and 2. Study 1 explored how mindfulness practice is embedded into a *mindful life*, using a diary study with follow up interviews to collect data on when participants were and were not mindful. This showed the triggers, motivations, ways of engagement and practices that help experienced mindfulness practitioners remember and maintain the practice of mindfulness in daily life and the constraints on doing so. Using a non-clinical population in Study 1 gave results from participants who had embedded mindfulness into their life without also having to deal with a mental health disorder. Whilst UCD advocates using end-users in design research, it also allows a flexible pragmatic approach when end-users are not immediately accessible. The reasons for running this initial study are given in Sections 1.4.3 and 3.1.1. Briefly, it scoped the research, eventually leading to a digital game being rejected as a delivery mode, in favour of an adjunctive app (see Section 1.3) during Study 2 and COTS mindfulness apps being rejected; it gave some design ideas to feed forward into Study 2; it allowed potentially triggering questions about non-use of mindfulness to be asked, the answers to which proved useful as potential design ideas. In addition, as an inexperienced researcher, it allowed me to run an initial study, with all the steps that involves, without the extra work involved in working with people with BPD.

To allow other researchers to learn from this work, the design points arising from the following discussion are detailed as part of Contribution 1. The amendments made to UCD are discussed in Contribution 2, and the benefits from using UCD are in Contribution 3 (Contributions -Section 7.5).

Headline findings

The results from the individual studies can be seen in Chapters 3 and 4. I first look at the headline results from each study, and then compare how the results differed or agreed between the two groups of participants. For the non-clinical practitioners, four themes were seen as important in achieving their practice. The main finding was a taxonomy of how mindfulness is used in different contexts, with formal and informal *relaxed* mindfulness practice building the 'mindfulness muscles' for use in more difficult circumstances as the practice of *purposeful* mindfulness.

1. *Gaining a mindful life* – how participants moved from trying to remember to be mindful to mindfulness becoming incorporated into their life.
2. *Contexts of use* – termed in this research *relaxed mindfulness*, used in non-stressful situations, and *purposeful mindfulness* used in more difficult situations.
3. *Time and cognitive demands* – the main constraints on mindfulness use were strong demands on time and lack of cognitive capacity.
4. *Mindful social interaction* – describes participants using mindfulness skills in social interactions as teachers, parents and managers.

In Study 2, the overarching client participant discourses were:

1. DBT as a reliable help for a better life, but not a panacea.
2. The process of learning DBT skills going from being "in a fog" to gaining confidence, then becoming proficient and finally maintaining skills.
3. Mindfulness as strange, challenging and the foundation skill.

Motivation and choice

When I ran Study 1, I did not know how alike I would find the two contexts of mindfulness. After reflecting on the findings of Study 1 and understanding the clients and their struggles with BPD better in Study 2, I realised that coping with BPD and undertaking DBT Mindfulness was not the same as the non-clinical practitioners doing mindfulness.

Firstly, the non-clinical practitioners had chosen to undertake mindfulness. Although this was often in response to a physical or mental health issue, they had picked mindfulness specifically as a choice. They knew what to expect when they started the course or started their practice. However, for the clients, undertaking DBT often followed a number of hospitalisations for self-harming and suicidality. Therefore, they frequently started DBT not knowing what it entailed, with Mindfulness being an unexpected shock. In the beginning, the clients reported not understanding what was happening in the Mindfulness practice which happened at the start of every skills session, what they should be doing or why Mindfulness was being practised (e.g. *why are we sitting here looking at a leaf very intently? (Emily)*), with this confusion adding to difficulties in acquiring Mindfulness skills.

In addition, not only was the motivation to start and continue to use mindfulness different in the two groups, for the clients, maybe their life depended on them being able to access and use Mindfulness skills; at the same time, BPD affects how Mindfulness skills are used, which facets of Mindfulness practice are accessed/rejected and which are found most useful. In Study 1, the reasons given for undertaking mindfulness were physical or mental health issues (chronic pain conditions, anxiety, addictions to cigarettes and alcohol etc). Mindfulness was cited as very much helping to deal with those issues. In Study 2, client discourse 1, Mindfulness skills were seen as strongly contributing to awareness of thoughts and emotions and embedding better use of other DBT skills, leading to the social good of a better life. However, DBT and Mindfulness skills are *not* a solution to the underlying trauma which contributed to BPD (Linehan, 1993), with work on that only taking place after clients have the skills to manage the intense emotions which that work instigates.

Articulation of learning mindfulness

The non-clinical user group were able to fluently and consistently describe their pathway to embedding mindfulness in their lives, even when it had taken them a while to understand it. The more experienced clients were also able to do this, constructing acquiring the skills as a process of moving from not understanding to growing in confidence in using the skills and confidence in the skills working, to becoming a proficient user of the skills, but always having to maintain this use in the future. Being at the start of the journey, the beginner clients could articulate where they were in the process, with their hopes for a future where they were able to use the skills, but not being able to narrate how that would happen. DBT skills were seen by the clinicians as requiring an expertise that the beginner is not yet capable of bringing to them. Although the beginner client in Study 2 thought Mindfulness would be helpful, she was at the beginning of DBT and presented herself as the problem, not the complexity or difficulty of the therapy or BPD being therapy-interfering. The other clients also saw challenges in learning Mindfulness as a personal failing, rather than blaming the disorder for making the practice of DBT skills more difficult.

Mindfulness takes time

As the non-clinical practitioners were learning and embedding mindfulness into their lives without also having to deal with a mental health disorder, they developed mindfulness skills fairly quickly, as was also seen in the literature on short-term mindfulness (Allen et al., 2009; Morone et al., 2008, *inter alia*). After undertaking an initial short course, they understood what they had to do and they started to see results from practising mindfulness after a short time. By contrast, the clients reported that understanding Mindfulness took a long time and embedding it into their lives took even longer. The clinician interviews showed that the history of trauma that DBT clients frequently have makes mindfully sitting with their thoughts very difficult, as they spend a lot of time trying to block out their thoughts completely. Facing the thoughts and strong affect accompanying their past experiences can make clients feel worse in the initial stages of DBT. The reality of mindfulness bringing up unpleasant thoughts was acknowledged by the non-clinical participants, but they were able to be much more self-compassionate with themselves when such thoughts occurred, whereas the client group were more self-critical. This may also be a function of time, as the longer participants practise mindfulness, the less self-blame, and the more self-compassion they had when they were not mindful (Bishop, 2002). Self-blaming for not practising also feeds into the self-compassion discussion below.

Finally, the research showed that learning and practising the *Mindfulness* skills was very difficult for the “in a fog” DBT clients, especially in the first 3-9 months. As well as the disorder being therapy-interfering, clients did not want to experience painful thoughts due to often prolonged trauma and abuse (Linehan, 1993), which had often been distracted from with self-harming and other dysfunctional behaviours (*ibid.*)

Self-compassion

On the whole, the non-clinical practitioners were able to be compassionate and especially self-compassionate when they did not have time or found it hard to practise calmly. This is important in times when practitioners or clients find mindfulness difficult, when the inner voice is self-critical or harsh, or when mindfulness is not used or not practised. Related to the point above, it is also very important for the clients to try to access self-compassion when facing and dealing with trauma and the thoughts and feelings surrounding this. However, self-compassion was seen by clients as one of the most difficult parts of being mindful. This links back to the findings in Singer & Engert (2019) and Hildebrandt et al. (2017) that it is important to practice socio-emotional mindfulness, for example, focusing on loving kindness meditations, in order to access being non-judgemental, accepting, and having compassion and self-compassion. These were the qualities that the clients struggled with the most. In the DBT taught at the Tuke Centre, the Mindfulness module included Compassion-Focused Therapy (Gilbert, 2009). This reintroduced some of the socio-emotional practices which may have been slightly lost in the necessarily reductionist version of mindfulness used in DBT.

Contexts of relaxed and purposeful mindfulness

The experienced practitioners in Study 1 described the pathway to developing a mindful life as including having a formal morning meditation, and taking opportunities to do relaxed informal mindfulness whenever possible. They also asserted that some of the things that prevented this, such as time and cognitive capacity constraints, could be overcome. Overall one of the biggest differences was the *purposeful* use of mindfulness, as the non-clinical practitioners had the luxury of time to practice *relaxed* mindfulness in different forms, using standard ways to learn, like bodyscans and breath awareness. In contrast to this, clients learnt through a more convoluted route, with shorter practices, in which the introductory practices of breath awareness and bodyscans could not be used. Therefore, it was important to include this aspect in the requirements (Section 5.3.4).

By contrast, the clients were often trying to practise purposeful mindfulness, especially at the beginning, without having very much practise of either formal mindfulness or relaxed informal mindfulness. Thus, they were starting at the hardest level, trying to play a concerto without being able to practise scales first. Early-stage clients constructed Mindfulness as helpful, but were unable to practice Mindfulness skills at all. Clients further on in the process could construct the learning journey, detailing how difficult the acquisition process had been and how it went hand-in-hand with building confidence in their ability to use the skills and that the skills improved their lives. Recognising that there were different stages for the DBT clients, rather than it being a smoother process of learning and then practising, as seen in the non-clinical participants, is important and is reflected in the requirements.

Social interactions and learning

Finally, for some of the non-clinical practitioners, practising in a group and the support of a group was seen as extremely helpful. This was also true of the beginner DBT client. However, when asked about allowing communication with other clients, for example in a forum, as part of the DMHI, the clients were adamant they would not like such a feature. This use of a forum is seen in DBT DMHI MedTep (Suñol et al., 2017), although without a clear user requirement, and there is no specific feedback given on this feature. All features that are added to a DMHI should have their basis in user requirements to promote use and restrict attrition (Gulliksen et al., 2003).

In addition, Study 2 found that the clients did not want any representations from an avatar, even a non-human one, which suggests that using a conversational agent (*eMarsha*), as in the DBT DMHI *Pocket Skills* (Schroeder et al., 2018), again without motivation from user requirements, may have stopped or discouraged users from using the DMHI. Schroeder et al. found that some users were put off using the app by the agent, and retention was also poor, although reasons for this were not sought.

7.3.2 SQ2. What are the client requirements for a DMHI supporting mindfulness skills acquisition as part of DBT?

This section reviews the requirements. The literature on DBT apps (see Sections 2.3.3 - 2.3.6) does not detail how the apps were developed and whether users were included, or if included, what part they played, and no requirements are detailed. Therefore, it is not clear how best to design apps to support BPD clients with DBT in this context. Through answering this question, this research developed a high-quality, data-grounded User Requirements Document (URD) detailing the DMHI requirements for the context of users with BPD, with requirements that are clear, precise, and unambiguous (Rogers et al., 2012). It also starts to offer some possible design responses. This is not an attempt to solutionise; any design suggestions would need to be tested through prototypes to understand the clients' reaction. The requirements are not a collection of inflexible directions, but guidelines to ensure that the DMHI remains consistent (Rogers et al., 2012). In a challenging mental health setting, it is important to have requirements which can be used to state the desired therapeutic outcomes of the system (Doherty et al., 2010), as well as the users' goals for and experience with the therapy. Having therapeutic outcomes as a requirement also helps in setting some of the metrics against which the system will be tested. In a full requirements spec these would come from clinicians based on the therapy and the metrics they use to measure.

In Study 3, data from Study 2, supplemented by Study 1 and knowledge about BPD and DBT generated on placement at the Tuke Centre was analysed. UCD techniques were used and adjusted to produce a URD (Appendix I) for use by a design team for a DMHI to support acquiring the Mindfulness skills module. It is an advantage of empathic UCD that different stakeholder views can be acknowledged in the design process, taking a dialogical approach (Section 1.1.4) in listening to, learning from and responding to the participants' differing views from my perspective as a designer. Using empathic UCD (Section 1.1.3) to understand users' lived experiences, emotions and life situation from their perspective (Wright & McCarthy, 2008). I used empathic, narrative-based, story-telling methods (*ibid.*) to model the user requirements of people with BPD, using tailored, life-inspired experiences represented in personas, scenarios and user journey maps (Carroll & Rosson, 1990; Cooper et al., 2014; Kalbach, 2016). The documents contain details of the disorder and the clients' struggles, making them a more difficult read than typical consumer-type documents. The URD contains:

- Four personas of DBT clients at different stages in the DBT process. The personas extended a standard persona, having much more detail than a typical persona and detailed elements of their background, including the trauma they had undergone, how this affected them, their self harming behaviours, and thoughts of and attempts at death by suicide.
- Two User Experience (UX) maps were constructed. The first showing an Entrant level DBT client going through a typical day, which illustrated where her painpoints were and where DBT Mindfulness would help her. The second showed DBT as a process with 5 stages and mapped the journey of an archetypal user through the stages, examining the learning tasks and learning challenges at each stage. In this document, short versions of the requirements were listed.
- Scenarios were constructed for two of the personas at the Entrant and Beginner levels. These personas were the ones most challenged by learning Mindfulness skills.

The full requirements for each stage are listed in the UX Map. These are really important and are backed up by all the other documents. The full version of this can be seen in 5.3.4. The short form of the general requirements can be seen below:

1. Explain/remind users why Mindfulness is so important in DBT
2. Include choices of *Observe*, *Describe*, *Participate* within each Mindfulness exercise
3. Include a Crisis Plan which can be accessed easily and updated by the user
4. Include a self-soothe area which can be accessed easily and updated by the user
5. Use dialectics to help validate and encourage
6. Include as much personalisation as possible
7. Include Mindfulness exercises which can be used at all times of the day and with many common daily tasks
8. Give encouragement at all levels
9. Encourage self-compassion and being non-judgemental at all levels
10. Make reminders to use Mindfulness personalisable
11. Emphasise practising as much as possible when calm
12. Emphasise short, frequent mindfulness practice
13. Do not include human representation or communication
14. Make the levels an underlying concept

Compassion, which is added back into DBT Mindfulness at the Tuke Centre using Compassion-Focused therapy (Gilbert, 2009) is very important. This was emphasised by the clinicians as extremely important, as well as being a large part of the DBT skills classes observation. It is also seen in the literature, as shown by Singer & Engert (2019). It is one of the most important parts of any DMHI, especially for the clients who really struggle to say one nice thing about themselves, as often seen on my Tuke Centre placement. Thus, a DMHI which will help clients undertaking DBT to learn and establish Mindfulness skills practice, as well as help them to maintain such a practice will need large amounts of validation. It may need to embrace a number of the issues discussed in Chapter 4. These include pushing the *acceptance and change* dialectic to both encourage the clients when they fail to practice, return after a few days away or repeat the same exercise a number of times, showing them that this is fine and understandable, but also to gently show them it will be helpful for them to practice the skills to help them change. Because DBT can take a long time to learn, the core dialectical stance of accepting why they have behaved in this way by validating them, but also gently by pushing them to change, is important for clients struggling to use the skills and possibly repeatedly returning to self-defeating and therapy-interfering behaviours (Swales & Heard, 2016). In the case of the core skill of Mindfulness, this may be particularly important (Dimidjian & Linehan, 2003), as the hardest and most challenging skill to understand and to embed.

As a design suggestion, it *may* be helpful for the clients to be able to listen to, watch or read short stories from other clients about successful learning of Mindfulness. This would need to be prototyped. The requirements show that the app needs to have a very good explanation of what Mindfulness is and what is expected, as well as what the client may experience, whilst giving helpful feedback and gently pushing the evidence from the literature that once Mindfulness is learnt and used often, it can bring large positive changes in behaviour and emotional dysregulation, allowing users to then choose from other skills that can be used to help the situation. The app needs to use the stages fully, getting as many Mindfulness practices in each stage as possible, given the constraints of the disorder and the clients' past trauma, trying to encourage clients to spend as much time as possible practising, even for short bursts. This 'short and often' approach is what experienced clients expressed as making a big difference.

7.3.3 SQ3. How are client-derived UCD requirements viewed by DBT clinicians?

The third sub-question examines the findings from the validation study in Chapter 6. It asks how DBT clinicians viewed some of the documents which comprise the URD in Study 3. The ideal UCD process validates with end users, but is flexible in allowing proxies to be used where end-users are not accessible. Thus, validating the documents with clinicians gave crucial insight into how client and clinician views relate to one another. Answering this question informed me about whether clinicians considered the UCD-derived requirements documents in the URD representative of the clients and the DBT learning journey and whether they perceived the documents as useful and insightful.

Positive overall

The clinicians were positive about the URD and the various documents contained within it. The requirements documents were seen as very useful, with the User Journey Map and the scenarios needing some changes in Round 1, but overall causing little controversy. For example, the clinicians did not like the timeline which was part of the original Map, as they saw each client as talking a different amount of time, and this variability made the timeline seem superfluous and potentially stigmatising. The timeline was removed for Round 2 and consensus was reached on the questions asked about the Map, with it being seen as useful to explain the DBT journey and containing good detail.

Persona design causing controversy

The personas were more controversial. The personas portrayed Mindfulness acquisition and use as extremely difficult, based on the data from the client and clinician interviews, my observations of clients struggling with Mindfulness skills at the Tuke Centre and discussions with my clinical supervisor and colleagues in the DBT team at the Tuke Centre. They were viewed by most of the clinicians as appropriate and correct. However, in establishing the validity of the personas, attitude to Mindfulness and statements about Mindfulness were the biggest bones of contention; whilst the majority of therapists recognised the personas' attitudes as accurately portraying clients, and even reflected that they had heard similar statements from their clients, a minority did not identify with this portrayal of acquiring Mindfulness. Several of the clinicians had strong opinions about why the portrayal (and therefore the personas) were wrong, based on the clients they had treated. However, they reacted to the personas as if they were real clients, and they viewed the problem of the personas taking time to acquire Mindfulness skills in terms of them not getting the appropriate therapy, so their therapists were seen as the problem.

One of the emerging issues was therefore that some clinicians, especially if they were not used to working with more extreme clients, found it difficult to deal with the portrayed clients' struggles. Some said the portrayals were not correct. Others wanted to find solutions for them. They saw the problems faced by the personas as coming from a lack of expertise in those *delivering* the therapy. Simons (2010) reported that clinicians constructed themselves as healers and saw clients with BPD undertaking DBT as difficult to deal with due to the clients' slow progress and disruption of their own treatment, which frustrated the clinicians' role as a healer. Some of the clinicians in my study did not take the view that DBT should be a long-term therapy, indicating that results should be expected much more quickly. Therefore, if clinicians are implicitly portrayed as not healing their patients/clients, this is very difficult for some clinicians and triggers a need to heal or 'fix' the personas. This is backed up by attitudes to the scenarios. In the activity scenario, the early stage client is shown using the DMHI and using Mindfulness to help herself. The scenario was praised by the participants, even though some clinicians acknowledged that this was a portrayal of a very motivated client, implying most clients at this stage would not be able to achieve this.

The personas were not just seen as snapshots of where the client was at that time. Rather, some of the participants reacted to them as if they were real and wanted to 'fix' them or at least account for why they were having problems. One point here is that the fundamental dialectic in DBT is acceptance and change (Linehan, 1993) (see Section 2.4.4), that is, **Acceptance** that given the client's life situation, they are where they are in terms of struggling, and at the same time they have to **change**, by learning the skills, to progress in the therapy and make their life better. However, the acceptance in these clinicians was missing. One possibility for this reaction is that the persona feels like a professional criticism of them. It may be unrealistic to expect clinicians to be dispassionate about documents in their field, especially when they perceive the documents as making their field look bad or incompetent; therefore, they feel a need to show their own expertise by critiquing lack of it in others.

Individuals and archetypes

There was also some tension in the differences between a minority of clinicians' attitudes to the clients, treating each client as needing individual treatment suited specifically to their situations, and UCD which aggregates types of users into groups of archetypal users in personas. There was some resistance to seeing the clients in any way as a group, although DBT as a therapy is designed for all people living with BPD. Some parts of the personas were accepted without question. The stages, their backgrounds, and their reason for undertaking DBT, for example, were all accepted as realistic portrayals. However, some clinicians took issue with the language used in the personas. Some were of the opinion that only the clients' actual language should be used in the persona, as opposed to a compromise between the clients' language and supplementing the language to aid a non-clinical design team by using more sophisticated language and giving more explanations than the client could produce. To address the clinicians' concerns about not addressing individual clients, both in Study 4 and in Study 2, it is important for the DMHI to incorporate a lot of tailoring, as reflected in the requirements in Section 7.5.

Study 4 – design critique

The personas were contentious and as mentioned above, this is where using end-users may have been helpful. However, as also mentioned above, using the clients to validate these personas may have been triggering, and therefore using the personas as input to wire-frames or some other initial design might be more appropriate.

In designing for the clients with the most challenging presentations, as the key or primary personas (Cooper et al., 2014), Cooper suggests that even if they are not the largest segment of the client user group, other clients with fewer constraints in the user group will still be greatly satisfied. Although this is explained in the URD, it is not clear that clinician participants had the time to read this or understood it. Again, using a different method to validate may have led to more consensus and learning on both sides and should be borne in mind by future researchers. In addition, many of the points about the models seen above could be introduced in a further round with more explanation, or they could be incorporated into a DMHI low-fi prototype in the next stage of the design process, which could then be tested on clients.

Typically Delphi methods are not used in UCD. The method I used to validate tried to stay true to the spirit of the dialogical approach (Wright & McCarthy, 2022). I asked the expert participants their opinions and responded to these iteratively, by listening to their responses, making the changes they suggested and re-presenting the amended artefacts for further comment in the next round. In discussing the UCD process, Wright & McCarthy (2022, p.55) assert that "[n]ew understanding is created in the respectful, responsive engagement with dissimilarity." This research tried to engage both clients and clinicians in the research process, even when the views did not concur, as the views of both are important. Engaging stakeholders is key in the development, implementation and evaluation of DMHIs and an important part of socially desirable and acceptable digital innovation (Jirotka et al., 2017). I would have liked to speak to the participants in person, and think it would have helped the more critical clinicians to understand the UCD process. In using a focus group or other more collaborative discussion method, where I could better explain UCD methods, I also think both myself and the clinicians may have been able to learn from this process. It would have been interesting to address the different attitudes I found to the design artefacts I produced, but time and logistical constraints did not allow this. It may be that the dialogical approach, whilst worthy in helping the design, is quite time-consuming. This is an important point for other researchers to consider and is addressed in Section 7.5.

7.3.4 SQ4. What are the emergent issues and potential amendments for UCD user requirements gathering methods when working on DMHIs for an end-user group with BPD?

In answering this question, I show that I was able to use UCD in this context for requirements gathering. Other researchers undertaking such work should be aware that it is very demanding and a lot of adaptions to UCD were necessary along the way. However, the results that using amended UCD produced made the work worthwhile, both for the depth of knowledge found, and also in showing that groups whose voices are often not heard in the design process can be included. This lack of inclusion may be due to the extensive methodological work needed to gain the trust of these end-users (see Contribution 3, p. 321). Thus, HCI and Health DMHI designers need to be aware that such vulnerable user groups may present unique challenges that impact the design process (Thieme et al., 2016; Doherty et al., 2010). Therefore, in this answer, I detail the issues with and amendments to standard UCD that were needed in requirements gathering, which future researchers may find helpful.

Overview of UCD process

Section 2.2 gives an overview of an ideal UCD process. This research covers the first two stages in that process. In UCD the user is involved at all stages of the design process, which gives the user researcher and design team a rigorous and compelling approach to designing what users want. UCD allows iterative adjustments to be made to a design, so that a system meets users' expectations and requirements. In this context, I used a Delphi-inspired method to improve the URD in Study 4. However, running a full UCD process, going into designing and developing in Stages 3 and 4, would have to be very carefully planned in this context, due to issues of recruitment and access to end-users, as outlined below.

Issues around participants - proxies

Issues around the nature of BPD required a considered approach to requirements gathering, design and validation (Doherty et al., 2010; Thieme et al., 2013). The standard UCD process has the end-user as an integral part from initial requirements gathering onward (Norman & Draper, 1986; Gulliksen et al., 2003; Sellung et al., 2022). In doing research with vulnerable groups, this may not always be possible or ethically responsible. Therefore, the amendment in this research was for different stakeholders and proxy users to be involved in the design process at different points. By running a preliminary study with non-clinical mindfulness practitioners (Study 1), I was able to explore concepts and ideas about mindfulness that might trigger difficult feelings for users with BPD, using long-term, non-clinical mindfulness practitioners as secondary proxies (Gupta & Panagopoulos, 2019).

DBT therapists and clinicians were primary proxies as interview participants alongside clients in Study 2 and validating the URD in Study 4. This amendment allowed me to confirm my findings without repeatedly exposing people living with BPD to studies with potentially sensitive themes. Clinicians have extensive experience with clients and the beneficial outcomes of the therapy, but they may lack specialised knowledge about *how* end users engage with the treatment and the associated technology. Therefore, following this amendment, the next stage would be to design low-fi prototypes based on the documents and test them with the end-users.

Issues in the studies

Below I examine issues arising from the studies and how amendments were made study-by-study.

Ethnographic observation

The first issue was not being able to fully ground my requirements documents in my data, due to strict ethical processes around data gathering in this context. UCD processes require documentation of all data gathered for possible future use in a design, whilst academic research requires this for rigour. Working with the DBT team at the Tuke Centre allowed me to make initial ethnographic observations of the therapy in action, the clients and how they responded to the therapy. However, as I did not gain ethical permission to write up the observations, I was not able to detail the things that I learnt; thus, for example, where I have added details to the documents developed in Study 3 (for example knowledge about presentations of BPD in skills sessions or the clients generally being well-educated), I am not able to point to the research involved, to ground this detail in the data. The amendment I made was to state this in the thesis as personal knowledge or personal communication with my clinical supervisor.

Study 1

I ran an initial qualitative data gathering study with non-clinical participants. Using methods that are also frequently used in UCD (diary study, interview), and using the typical HCI ethical documents of Information Sheet and Consent Form. From conducting this study I am able to make comparisons with Study 2 which illustrate the adaptations that were made, in terms of seeking ethical permission, requirements, contact with participants, methods, running the interviews and follow-up actions.

Study 2

In Study 2, I faced the most issues, and this was where I made a lot of amendments to the UCD process.

Amendments to type of study

Following discussions with the DBT clinicians about Study 2, one of the issues in this research was the type of study I was able to run, as I was not able to run a diary study with the clients to compare with Study 1. Firstly, the week-long format would have been too arduous; secondly, it would have been unethical to ask BPD clients the same questions as I had asked the non-clinical participants, particularly with regard to instances when they were not mindful. They could have been perceived as intrusive and negative and therefore invalidating, potentially triggering negative thoughts leading to self-harm. The motivations for being asked to complete a questionnaire also may not have been clear, causing the clients concern, with no immediate support for behavioural repercussions in place. Therefore, I amended my plans to replicate Study 1 in conducting Study 2.

Typically in qualitative work such as that used in UCD, the instrument used for data collection comes from the type of data that is required. However, the context of a mental illness with challenging presentations may require compromises to be made, to the extent that the research concerns are not the only factor that the researcher has to take into account. Thus, following discussions with clinicians, questionnaires were also rejected as a study instrument, because not having a context, they could be misinterpreted by the clients, again leading to triggering thoughts of self-harm. Interviews were seen as the best option to collect the data I wanted, as I would be able to clarify anything that was unclear directly with the clients. However, even with an interview study, fairly substantial amendments to the questions had to be made during the ethical clearance process, as discussed below.

Ethical issues

Ethical considerations are very important when working with a vulnerable group with very high rates of self-harm and suicide. These ethical considerations caused some issues because my study was strongly affected by two ethics committees stipulating how it should be conducted.

As detailed in 4.3, ethical clearance for this study took around 6 months. Filling in the NHS IRAS (Integrated Research Application System) form, which was over 80 pages, took a long time, with several re-submissions to the NHS IRAS Exeter Research Ethics Committee (NREC) before approval was granted. *The Retreat* Ethics committee also requested amendments, some of which contradicted the NREC's requests, which had to be negotiated. I also had to obtain an enhanced DBS. Finally, University of York ethical permission also had to be sought. Typically, whilst ethical processes need to be followed, three lots of ethical clearance, especially when one included the extensive NHS REC process, would be seen as a large, time-consuming amendment and one which future researchers need to be very aware of. The repercussions of these requirements are detailed below.

Participant recruitment

The recruitment process was removed from my direct control by the NREC, who would not allow me to approach the clients directly, as they were worried clients who knew me might feel pressured into being interviewed. Therefore, everything had to be done through the clinicians at the Tuke Centre. All emails were sent via a third party, which was usually the individual therapist. In addition, clients could not be offered financial incentives *a priori*, though *post hoc* was allowed. Clients that showed an interest were emailed by the clinicians with the Information Sheet and Consent Form. The clinicians then arranged for the meeting to take place before the client's one-to-one therapy session, as part of the support mechanism for anything triggering coming up in the interview.

Throughout the process I had no contact with the clients. Thus, a standard way of recruiting participants directly (for example, Lazar et al., 2017) could not be used and had to be adapted to comply with ethical concerns. I therefore had no chance to answer any questions about my research or the study. This limited the number of participants I was able to recruit, as the clinicians were very busy and this was not their top priority. Also, some clinicians were more invested in my research than others. Ideally, I would have recruited more participants, but the amendment of allowing more time for recruitment was not available due to the time constraints of the research programme. The overall effect of this on the research was probably not substantial, but it is an issue that other researchers need to be aware of.

Former service users

Another amendment to the research came in the form of possibly recruiting former service users in addition to current service users. However, the Retreat Research Governance Committee raised an issue with this not being ethical unless the former service users had given *The Retreat* permission to contact them. Finding the paperwork to establish whether permission had been given or not was considered too time-consuming by the Tuke Centre administration team; therefore, this research idea had to be abandoned, again leading to reduced participation.

Piloting

Due to the restrictions on who could be recruited and how, an issue arose with piloting the study. The interview questions were not piloted with a participant. As there were only five client participants, I did not want to use one as a pilot. Thus, the amendment was to use my clinical supervisor as a pilot, as she was in the best position to identify any question which might trigger distress in the clients. The questionnaire was not changed after piloting.

Participant documents

Amendments were requested to the participant sheets by the NREC.

Both the Information Sheet and the Consent Forms were amended to contain additional information to that in Study 1. As well as providing information about the study, these documents informed the clients that if they took part, their therapist and GP would be informed. This was a safety net for the clients, so that they were aware that they had places to turn to if anything in the interview triggered negative thoughts. This saftey net was requested by the NREC. The participants also needed to be reassured that not taking part or leaving part way through an interview would not have an adverse effect on their therapy or other healthcare, and that they would not be stigmatised in any other way by not taking part in the research (Waycott et al., 2015). Therefore, the Information Sheet and Consent Form were amended.

Interview schedule

My initial interview questions were drawn up around the experience of learning DBT. I was careful to not ask questions around why clients were undertaking DBT or anything about their history, in order not to trigger any negative responses.

The NREC and then the Retreat Ethics Committee had concerns about how much time the interviews would take, and both requested cuts to the question schedules. Thus, a number of amendments through several iterations were made in order to reduce the length of the interviews. Questions about the therapeutic relationship and dialectics of treatment were removed. Some of the questions on Mindfulness were also removed. Questions asking about client wellness were also added at the end, to check for any distress in the participant.

Recruiting

Clinical participants need more time than non-clinical participants to consider whether to take part in the interview study (Johansson et al., 2015). They may want to discuss the implications with their therapist in their one-to-one session, for example. Therefore, amendments to the length of the overall study were made.

Running the client interviews

A population with a mental health condition may be hypersensitive to how a study is run (Waycott et al., 2015). For this reason, I amended my own behaviour to be hypervigilant about this. I made sure that there were no last-minute changes, that I was especially polite to the clients, and ensured there were no hitches which might make participants reluctant to be involved. As people living with BPD, clients can have strong affective reactions to small things. As such, it was crucial to protect participants from any potential upset that may have arisen from poor study implementation.

The interview was at the more structured end of the semi-structured spectrum, with carefully constructed questions following the schedule quite tightly, although some probing was also done to expand answers where necessary. This was an amendment to my natural style of interaction with participants, which as in Study 1, is less structured and more conversation-like. Whilst the former is easier to keep track of, the latter can reveal richer data.

The fact that I could not interact with the clients prior to the interview made building a rapport before the interview impossible. Ideally, I would speak to a person on the phone or at least in an email before an interview, which starts to build a connection and helps in the interview scenario (Dexter, 1970; Dumas & Loring, 2008). However, in Study 2, the relationship had to be built in the interview itself. Building a rapport with an interviewee is very important for good interview data (Dexter, 1970; Dumas & Loring, 2008). When working with with people with a mental health disorder, who may have complex emotional issues (Waycott et al., 2015), this becomes more important and more difficult. To build a rapport I was friendly and relaxed in the interview with open body language. I greeted clients in the waiting room and asked if they wanted a drink, I then showed them to the interview room and made general chitchat whilst setting up equipment. Whilst this is fairly standard interview practice, here it became of great importance and again I was hyper-vigilant and aware of my behaviour during this time.

Finally, it was very important to have an empathic listening approach (Wright & McCarthy, 2008), so the clients could see that I saw them as people with a story to tell, not just as sources of data for my research. The ethical constraints amending the questions and formal structure of the interview made this slightly difficult; however, I tried to do this and the data-collection process was ultimately successful.

Issues may also be caused by the mental illness or medication in the interview itself, leading to cognitive difficulties, in focusing, sustaining attention, dealing with stress, and problems with short-term memory. An amendment here was to be patient and leave plenty of time for the client to answer a question, while also checking that they had understood the question or prompting them if they paused for a considerable length of time. Another amendment to a standard interview was that due to the nature of the disorder, deep probing and sensitive subjects were avoided.

The last amendment to a standard interview was my final question which checked on participants' well-being and reminded them that they could talk to their therapist or GP if they needed to. Protocols had been put in place in case any participants were disturbed by any of the questions.

Data Analysis

The standard process of data handling and analysis was also subject to amendments. The interviews were transferred to an external hard drive for secure storage and the transcriptions were made as soon as possible. The recordings were then destroyed as stipulated by the NREC, who did not want the recordings to be stored on a laptop. This had a number of implications for the research:

- The recordings are not available for other members of a design team to listen to, as is often done in design teams. Therefore, transcriptions had to be complete and models had to be detailed and faithful representations of the clients, as they were the source of truth for the project. This type of constraint needs to be borne in mind by other researchers.
- The number of researchers allowed in the interview may be limited by the ethics process. If a future team were doing similar research, there may be restrictions on the number of researchers permitted in the interviews. (In design teams I have worked in, having two user researchers and one or two people observing an online interview is standard.)

A further amendment to make sure I got the most out of the data was to use Discourse Analysis to ensure nothing subtle was missed in the analysis.

Finally, giving feedback to participants from vulnerable groups is seen as particularly important (Johansson et al., 2015) so that participants can see their impact. Unfortunately, before I was able to give feedback, the DBT group at the Tuke was disbanded and I was not allowed to contact the clients to give them overall comments from the study.

Study 3

Study 3 details the construction and development of the models which form the URD (Appendix I). In amending standard UCD, I made these models more explicit and more 'extreme' in their representation of the disorder compared to previous models. Through interviews and ethnographic observation, this research sought to give representation to user requirements for BPD to help DMHI developers to empathise with the users of that DMHI. This involves understanding users' lived experiences, emotions and life situation from their perspective (Wright & McCarthy, 2008). I use empathic narrative-based, story-telling methods (*ibid.*) to model the user requirements of people with BPD, a challenging mental illness, using tailored, life-inspired experiences represented in personas, scenarios and user journey maps (Carroll & Rosson, 1990; Cooper et al., 2014; Kalbach, 2016). The documents contain details of the disorder and the clients' struggles, making them a more difficult read than typical consumer-type documents. They took a very long time to construct and went through many iterations and discussions with the DBT team. They include the following amendments to standard UCD documents:

1. Incorporating high-level details of the causes, manifestations and challenges in acquiring the skills for this user group due to BPD.
2. Giving personas a first-person narrative rather than the usual third-person voice to add weight to the life-threatening nature of their illness and make them more empathetic.
3. Using user experience maps as part of the requirements document to reflect that the clients' journey in acquiring and embedding DBT skills, in particular Mindfulness skills, is not as straightforward as that of the non-clinical population acquiring mindfulness skills. The four personas give an accurate snapshot of clients at different stages in the process, but the user experience map shows that the progression from stage to stage is complex with different needs at each stage. This needs to be reflected in a DMHI which is appropriate for clients at all stages of the DBT therapeutic process.
4. Making the scenarios reflect very negative internal monologues, with thoughts of self-harming and other thought processes which the client users may be experiencing. These can be difficult to read, but are symptomatic of the disorder and one of the issues that DBT seeks to address.

Study 4

In Study 4, in establishing the validity of the personas, my modelling of clients' acquisition of Mindfulness and statements about Mindfulness were the biggest points of contention. Whilst the majority of therapists recognised clients' attitudes as accurately portraying clients, and even reflected that they had heard similar statements from their own clients, a minority did not identify with the portrayal of acquiring Mindfulness in the personas. Again, not using the end users was not ideal, but perhaps given the nature of the documents and their potential to trigger client participants, their input may be more beneficial at the early development stage of a DMHI.

The main amendments here were:

1. As discussed above, using proxies to validate the URD.
2. I simulated the iterative nature of UCD with a Delphi-like study over two rounds to improve the user requirements documents.
3. I had to cut down the full URD in order to be able to validate it, which meant clinicians did not see the full range of personas. Had the more critical clinicians seen the full range of personas, they may have been more amenable to them.

Other reflections and possible amendments to this study are given above in answering research sub-question 3.

7.3.5 Answering the overall research question

Through answering the four research sub-questions, I show that UCD can be used in this context, although substantial work and considerable amendments are needed. The resulting findings, the refinement of those findings into the URD, and its validation show that end-users with BPD and their requirements can be modelled in-depth, giving design teams a deeper understanding of the end-users and their context. Thus, potentially allowing them to produce a DMHI which would hopefully better retain vulnerable users in treatment, justifying the large amount of work required.

The unique perspective gained from using UCD in this context is presented in the requirements document (Appendix I), which could now be used in the next UCD phase (*Design*) to design prototypes for a DMHI. Therefore, I consider UCD to have been a good choice in gathering requirements for vulnerable, hard-to-reach groups, as it allowed depth of understanding of the users through empathic UCD, but also flexibility through the use of proxies and other amendments, as required by the challenges I faced in carrying out this research.

7.4 Reflexivity

In learning about BPD and DBT, I attended a one-year placement in the DBT Group at the Retreat's outpatient centre, the Tuke Centre. This was an important part of learning about doing research with a vulnerable group (see Section 1.5.3), and some of my experiences informed the documents in the URD.

As part of the substantial methodological work required in this challenging setting, the approach taken in the research was empathic UCD (Mattelmäki et al., 2014). Empathy in design is a skillset, rather than a psychological construct. Empathic UCD achieves a deep understanding of the users and their lived experience. The mix of expertise and knowledge found in this research was managed through a dialogical approach to empathic UCD (Wright & McCarthy, 2022). In this view, all those engaged in the design process should do so from their own perspective, seeing the viewpoints of other members in the design process as different, but open to learning from each other (Drouet et al., 2024). Therefore, as a user researcher I did not try to become the clients or the clinicians / proxies, rather I responded to the participants' world-view from their own perspective, listening and treating their views with respect, whilst trying to understand their world-view. At the same time, as a user researcher, I used my skill to synthesise all the points of view into a URD which reflected what I was hearing.

Through the work in this thesis, I have learnt a lot about UCD: using different methods and techniques; carrying out research with different populations; working with people with a life-threatening mental health issue; and, presenting that work. It has been a long and at times very difficult journey: I started this research knowing nothing about BPD, a life-threatening mental illness which has a profound effect on those who live with it. Attending the DBT sessions at the Tuke taught me a lot about other people's lives and gave me great empathy for the clients. Sometimes the skills sessions were painful. For example, realising how difficult it was for the clients (and myself as well) to be self-compassionate. We were asked to say one nice thing about ourselves. I could say something, even if I was not 100 percent convinced, and could model self-compassion to the clients. However, many of them could not even find one nice thing to say.

Coming out of the other side of this research, I am now able to say with certainty that the research was done honestly and ethically, and to the best of my ability. Whilst I acknowledge that some of what I did was not successful, and some of what I did could have probably been done better, I am able to critically reflect on and discuss that, and move forward with greatly enhanced understanding of UCD, DBT, BPD and my place in the world as an ethical researcher.

7.5 Research contributions

This thesis makes five contributions to the research. Contribution 1 specifies the design process; Contribution 2 examines the amendments made to UCD. In Contribution 3, I detail the benefits and justifications for the necessary time and effort taken in terms of my output. Contribution 4 is a contribution to design practice when working with mental health clinicians and Contribution 5 is the URD itself.

7.5.1 Contribution 1

The thesis provides insights into how requirements for a DMHI can be designed using UCD to help users with a BPD diagnosis, to acquire Mindfulness, the core skill of DBT. It makes explicit the amount of time and planning commitment required to engage properly with stakeholders in this context. UCD is not generally a quick methodology, but extra methodological work was necessary due to undertaking UCD in a challenging context, where considerable planning, flexibility and emotional labour was necessary. This contribution adds to our understanding of designing with people living with BPD and why it is difficult. Below I detail some of the factors contributing to the extensive work, to show what can be learnt.

Overview

This contribution brings together what I learnt during the research that may be useful in guiding future user researchers and design teams in how best to use UCD and gather requirements in this context. Design teams and developers can see the issues I had to overcome, with recommendations of what might be done better or differently, and the difficulties that the users face and the amount of care that needs to be taken in a UCD process with such end-users. The following points might be usefully followed when conducting a study with end-users living with a life-threatening mental health condition.

Approach

UCD is a lengthy and complex design process, involving four different stages, each with a number of steps (see Section 2.2). As the research in this thesis shows, gathering user requirements in vulnerable populations is challenging. As well as the considerable work required to recruit and gather participants, collect and synthesise data, and document findings, working with vulnerable, hard-to-reach groups requires an empathic approach. Empathic UCD achieves a deep understanding of the users and their lived experience. It is a good approach for making strong connections with the users and translating research findings into user requirements, but it takes a lot of emotional labour. It is not always easy listening to harrowing stories, seeing people having flashbacks or recalling one's own painful memories because of something that was said in a skills session, without reacting in a negative way. In undertaking this research, a lot of personal challenges arose and reflexivity was necessary (see Section 7.4).

Planning

The planning stage for this research was very important and I would advise anyone carrying out future research in this area to allow a lot of time for planning and setting up the study. Building in extra time and having available contingency plans in case everything does not go to plan is extremely important. Challenges faced in this research included the ethics process taking a long time and requiring amendments to the study; the precarious state of health funding in the UK can mean that access to therapy groups and clinics/hospitals can be suddenly cut off, and this needs contingency plans; difficulty in recruiting participants for all three studies involving humans, but especially Study 2; the considerable time it took to develop the URD to a point where I was happy that it reflected the client requirements and their context; and the time it took to set up, recruit and run an online three-part Delphi-type study over two rounds, feeding back results between rounds.

Study 1

In undertaking research with vulnerable groups, researchers should be wary of assuming that practices undertaken by people in a non-clinical situation are the same as those undertaken in a clinical context, even though the practices may have the same name and/or be superficially similar. For example, the mindfulness undertaken by the participants in Study 1 was based on the achieving the same "mental state" through meditation-type practices as DBT Mindfulness, but the techniques used for practice were sometimes very different, and the contexts of understanding and use also differed.

As my research showed, after running Study 1, and spending some time on placement, I understood that standard mindfulness apps were not suitable in a DBT context. Therefore, it is important not to assume a standard or previous solution can be adapted by adding in some therapy. In undertaking this type of research, nothing can be assumed, which may mean running studies to define things that are outside the scope of the project.

Study 2

Due to their vulnerabilities, in doing UCD, gaining access to end-users with a mental health issue can be a challenging and complex undertaking (Matthews et al., 2014). People may be difficult to locate, reluctant to engage, or healthcare professionals may be gate-keeping them. In addition, due to challenges caused by the presentation of the mental illness, as the amendments in SRQ4 show, “standard” UCD methodologies were not suitable for effectively engaging with and understanding the needs of these individuals without amendments.

I had to make a number of amendments to Study 2, including changing the format from a diary study to an interview; adding participants by including DBT clinical staff; and shortening the question schedule. Researchers need to be aware that a great deal of flexibility and patience is required in this type of study.

Gaining ethics approval

As detailed above in SQ4, when working with vulnerable groups, researchers should be aware that ethical systems are very important and that the procedures involved can be very strict, lengthy and time-consuming. Study 2, with the clients, involved three sets of ethical clearance. Completing all the necessary forms to apply for the NREC process took weeks. I then had to wait for a qualitative committee to sit, and then the documents had to be amended to satisfy the conditions they stipulated. This was followed by *The Retreat* and the University of York ethical processes. Having other work which can be done saves having research ‘dead-time’. For example, during the waiting time, I carried out Study 1 which helped to scope the project and gave some design inputs, continued with the DBT observations and started making the assumption personas.

Recruitment

Recruitment of participants can prove very difficult. I would recommend identifying other potential sources of participants before submitting the ethical application. In addition, clinical staff were generally helpful, but were also very busy. Some staff members were a lot more invested in the UCD process than others, so some were a lot more helpful in recruiting than others. Finding a ‘research champion’ if possible, as in Thieme et al. (2016), may be helpful.

Running the study

When doing research with people with a mental health disorder, the narratives of those in the early stages of treatment may serve to hide the complexities of the recovery journey. It is important to talk to people at all stages of the treatment to get a full picture of how they are affected and how they are experiencing the treatment. The experience at the start may be very different from the experience in the middle or the experience after a number of years in treatment. In addition, clients at other clinics and places delivering DBT may not have the same experiences, as the clinicians in Study 4 reflected.

Data recording and disposal

In vulnerable groups, keeping the recordings may not be permitted. Data must therefore be transcribed quickly and comprehensively. The models need to be comprehensive records of the interviews because the design team will not have access to the original recordings. How many of the design team will be given direct access to the interviews, either as interviewers or observers, may also need to be taken into consideration.

Synthesis and model designs

Once I had collected the data, I started to formulate the requirements. For complex users and complex interventions, such as a DBT Mindfulness DMHI, listing requirements without a context would be too abstract, as the designer would not have an insight into the underlying psychological needs of users with a mental health disorder or the practical constraints which could adversely affect the DMHI and the users if not taken into account. Therefore, the requirements consisted of personas at different stages in the DBT journey, a UX map showing the journey through acquiring DBT, and scenarios. This took a very long time and went through many iterations. Whilst I discussed my work with supervisors and clinicians, I was working alone. I suggest that UCD is better done in a team or with at least two people to share the workload and work on any problems that arise together.

I tried a number of ways to synthesis my data (see Chapter 5). The assumption personas were found to be useful for setting down my ideas and revealing any biases. They also made good focuses for helpful discussions with clinicians. Ultimately, I had to define the personas using other criteria; however, some of the content was retained and was used in the details of the final personas.

A design team would not have access to recordings, as they were destroyed. Therefore, having a full transcription, and modelling users and their requirements accurately is very important.

Validation

Validation using a Delphi-inspired method was a time-consuming process. The URD had to be cut down for the study and then cut down again after piloting. Controlling all the moving parts took a lot of effort. Ideally this part would be done in the context of the clinic or hospital where the research was taking place, with a full URD given to clinicians to look at, followed some days later by a discussion, where any misapprehensions could be clarified and any criticisms discussed, following the dialogical approach. In doing this, both the researchers and the clinicians may learn something about the context.

7.5.2 Contribution 2

UCD is an effective approach to designing DMHIs that fulfil user requirements, give a good user experience, and are usable and efficacious. This combination hopefully results in apps that have a lower attrition rate and can therefore potentially be more efficacious. However, when using this method with vulnerable groups like the users in this research, caution must be taken in the ethical process of obtaining data, using data and in portraying the client group. UCD methods are flexible and can be adapted to incorporate these types of user, but care must be taken. Thus, this contribution shows that UCD can be carried out in this context, but it requires considerable adaption. This is detailed in SQ4 (Section 7.3.4).

7.5.3 Contribution 3

After discussing the extensive methodological work required to engage with stakeholders in this context in Contributions 1 and 2, this contribution details what was gained in undertaking such work and justifies why it was worthwhile and beneficial. Below I discuss some of the things I learned.

Understanding level of knowledge of mindfulness

From Study 2, I learnt that unlike the practitioners in Study 1, when starting DBT, sometimes new clients did not know anything about mindfulness as a practice, why it was used and how it helped. As evidenced in the interviews, if clients had just missed the Mindfulness skills module when starting, they were extremely puzzled by the Mindfulness exercise at the start of the group sessions. They saw it as something that involved “sitting and dwelling” or “strange and challenging”, wondering not only why they were looking intently at a leaf, but also feeling anxious about discussing their experience with the group, when they did not know what that experience was supposed to be. Therefore, one of the requirements is for the DMHI to have a very good explanation of what Mindfulness is and what is expected in terms of practice and what the client may experience.

Understanding the skills acquisition journey and importance of tailoring

I learnt that the narratives of those in the early stages of treatment, who saw themselves as the problem, rather than the difficulty of acquiring the skills, and the therapy-interfering nature of BPD, hid the complexities of the recovery journey. I gained an insight into the difficulties of changing the self-harming and other dysfunctional behaviours, that both threatened their lives, due to the danger involved, but also alleviated the psychological distress, making it bearable. By talking to people at all stages of the treatment, I found the experience at the start was different from the experience of clients in the middle, or after a number of years in treatment. For example, understanding of the skills did not mean that clients could always use them. Importantly, the stages in the process of acquiring DBT skills, with clients going from being "in a fog" to gaining confidence, then becoming proficient and finally maintaining skills needed a change in their mental model before they could acquire the skills fully. This involved a transformation in the clients' beliefs about themselves, their trauma and the world. Without this change, progress in the therapy was seen as almost impossible. This meant that the design of the app could not be one-size-fits all, like previous DBT apps. As well as being adaptable to suit the different DBT stages, the design should involve large amounts of tailoring to suit an end-user's preference for certain skills and ability to engage.

Understanding amount of support needed

From the interviews in Study 2, it became clear that the clients needed considerable, and constant support and help throughout the DBT journey. They identified that the skills took a long time to acquire, and self-harming took a long time to stop, until they had gained trust in the skills and their ability to use them. Even then, they still had urges to self-harm. UCD allows the design and development of specific interventions for specific contexts. For example, in people with BPD who can be at risk of self-harming and death by suicide, a therapeutic intervention is able to not only acknowledge that, but also build in internal support in the form of validation, and external support in terms of an individually modifiable plan for what to do in a crisis and who to contact. This can help when thinking clearly may be compromised. Thus, UCD can lead to safer interventions in mental health.

Understanding the details needed in a URD

This level of work meant that in listing the requirements I could give a detailed context. I use empathic narrative-based, story-telling methods (Wright & McCarthy, 2008) to model the user requirements using life-inspired experiences. The journeys, personas and scenarios contain details of the disorder and the clients' struggles, making them a more difficult read than typical consumer-type documents. For example, making the scenarios reflect very negative internal monologues, with thoughts of self-harming and suicide. Personas contain details of abuse, self-harm and suicidal thoughts, all of which came up in either the interviews or whilst on placement at The Tuke Centre. In seeing this, a design team would have an insight into the complex underlying psychological needs of the users and the practical constraints which could adversely affect the users if not taken into account.

This work gives the design teams empathy with the end-users, allowing designs that acknowledge and respect the presentations of mental health disorders, as well as the diverse experiences within that group of users.

Understanding what was not wanted

It allows users to reject design ideas which may seem innocuous or normal to a design team, but which are anathema to the users. Some of the things to avoid were very clear from the interviews, such as not having any representations of people in the DMHI.

The clients were very clear that they did not want any representations from an avatar, even a non-human one, rejecting a non-human cartoon animal to help with exercises. This suggests that using a conversational agent (*eMarsha*), as in the DBT DMHI *Pocket Skills* (Schroeder et al., 2018), without motivation from user requirements, may have stopped or discouraged users from engaging with the DMHI. In addition, in the client interviews, the idea of the DMHI allowing users to communicate with other clients, using a chat function, was strongly rejected. However, this was discussed as a feature in the Medtep DBT app (Suñol et al., 2017), without the justification of it being a user requirement. My research suggests this would be an unpopular feature and may discourage use of the app altogether.

Designing for vulnerable users

A further benefit of doing this work is the contribution to the literature on designing with vulnerable users. In working with a population with a mental health disorder, using UCD techniques, this work builds on and adds to research with other vulnerable groups of users who have traditionally been outside the design process due to vulnerabilities making the process challenging. Examples of this include Foley et al. (2020) working with people with dementia and Thieme et al. (2016) working with inpatients with BPD and learning disabilities. Carrying out design work in this way makes vulnerable end-users less passive in the design process, giving them agency and centring their voices and experience.

It is important that vulnerable groups, such as people with a disability, people with a mental health disorder, children and the elderly are represented as end-users of technology and that technology is designed for their particular needs. Such populations may be neglected due to researchers not understanding how to work with them "on equal terms" (Johansson et al., 2015, p.69), or perceiving them as difficult populations to work with. For this reason, it was very important for me to have an empathic listening approach (Wright & McCarthy, 2008), so that the clients understood that I saw them as people with a story to tell, not just as sources of data for my research. It was also important to present their stories well and truthfully. Thus, as well as nurturing empathy, using UCD in mental healthcare can also change the perspective of researchers and design teams on working with vulnerable people in challenging and complex situations. Therefore, this type of research helps such end-users to be seen by researchers and designers as individuals, with diverse life experiences, empowered to contribute meaningfully to the design process and able and entitled to do so (Foley et al., 2020).

This is an important contribution because it will potentially lead to better retention of clients/patients in treatment programs, which has traditionally been a problem (Bakker et al., 2016; Torous et al., 2019).

7.5.4 Contribution 4

Contribution 4 is a contribution to design practice when working with mental health clinicians. It reveals and looks to overcome the dichotomy between the individualistic approach to clients necessarily seen in clinical psychologists (in Studies 2 and 4), and the aggregated view of end-users used in UCD, which I used and detailed in carrying out this research.

This was addressed in the research using empathic UCD to understand clients' and clinicians' emotions and experiences, and a dialogical approach to make design decisions about the URD content, after listening to differing stakeholder views. Resolving the differing viewpoints was addressed in the URD through having different stages in the DBT journey, involving personas at different stages and the inclusion of suggestions for as much tailoring as possible, reflecting this back to clinicians in a Delphi-style validation study.

This approach partially responds to the issue of the stakeholder clinician's individualist attitude to the clients, but would also allow clients to adjust the amount of support needed, depending on how they were feeling. In addition, allowing users a choice of which other skills could then be used to help the situation could also be included.

This was not fully resolved, as it would require further dialogue between designers and stakeholders, once designs had been created. However, is something that could be done in future work, in the *Design* and *Evaluate* phases of the UCD process (see Section 2.2.4). Thus, empathic UCD, with a dialogical approach (Wright & McCarthy, 2022) could continue to be used to engage users and stakeholders in a reflective exchange, throughout the design process.

7.5.5 Contribution 5

As Contribution 5, I produced a full URD containing the changes suggested in Study 4 and the other documents that I was not able to show in Study 4 (see Appendix I). This could be used by a design team, in the next UCD stages, to produce a DMHI for DBT Mindfulness.

7.6 Limitations

The research has a number of limitations, which should be addressed here:

- **Change of research focus** - Whilst it is understood that research changes as new information comes along, and this is not a limitation, as adaptability is important, particularly in the area of the case study, I also feel that a more focused research question, which was consistent throughout the research, would have led to more results, for example a complete design or even a prototype DMHI.
- **Study 2** - This study has the main limitation of only having five client participants, all of whom identified as female. More clients may show that the ones I interviewed were outliers and clients do not really see DBT like this. It would be interesting in particular to do a longitudinal study with clients undertaking DBT and interview them every couple of months. I am also not sure that using Discourse Analysis in this study gave better data than Thematic Analysis would have. Discourse Analysis is a difficult analysis method when doing it for the first time, it needs to be really worth the effort to use it well, which I am not sure that the results here justify. However, I did gain some interesting results, as shown in Contribution 3.
- **Study 3** - One major limitation is the time taken to produce and validate the URD. Whilst I believe empathic UCD is a very good method to use, as it is

flexible and can be used to deeply understand the users, I think it is better done as a team effort, rather than doing everything as one person.

- **Study 4** - One limitation was being time constrained in doing the validation. Another was using the Delphi-inspired method in this way to run a complex study, which was not the ideal method in many ways, as there was some misunderstanding, especially in Round 1. An interview or focus group could have clarified this quickly. However, for eliciting consensus without anyone putting undue pressure on another member or the group, it is a good method.
- **Recruitment** - If I were doing this study now, I would think longer term, and think more about recruiting well in advance of when it was necessary, especially if it were a difficult to access group.

7.7 Future work

7.7.1 Developing the requirements

There are a number of ways that this research could be expanded. Having gathered the requirements for a DMHI for DBT and validated them, it would be interesting to carry on and design/develop the DMHI using UCD methods. Firstly, to see if the requirements were accurate, and secondly, because I believe that this DMHI would be helpful to people living with BPD. Although the originators of the research idea, The Retreat York DBT group, is no longer extant, such a tool would possibly still have a market, especially given the critiques of the available DBT apps (Section 2.3).

In the next UCD stage, the *Design* (see Section 2.2) I would initially build lo-fi prototypes. It would be valuable to test these prototypes with clients or patients undertaking DBT. I would try to approach a clinic or hospital that had a DBT group and apply for ethical clearance to do an iterative design and development study with them. I would look to involve participants at all stages of the DBT journey. I would also look to recruit participants who were former-DBT clients and patients, because they would have valuable input, especially to the later stages. Once any amendments had been made, I would iteratively design, develop and test until I had a full working app. In addition, the other DBT skills modules could be included at a later date, using sister DMHIs or an extension to the DBT mindfulness DMHI.

The dialogical approach (Section 1.1.4 was used where possible, in the research done in the *Understand* and *Define* phases, documented here, to resolve differences in requirements, through respectful listening to stakeholders and using my skills as a user researcher to create the URD. However, it is perhaps most useful for resolving issues once the *Design Phase* starts. Future work, enabling collaborative conversations, where end-users and stake-holders would be active participants in shaping the design would be a satisfying way to take the work forward. To do this with DBT client end-users would need a lot of organisation and planning, but would not be impossible, and would hopefully produce a DMHI that could help those with BPD in acquiring DBT Mindfulness skills. In furthering the research in this way, the design process can be seen as one of mutual understanding and negotiation rather than me just solving a problem. I would continue to use empathic UCD (Section 1.1.3), as I think it works well with end-users with these types of issues to ensure that I had achieved a deep understanding of the end-users and their lived experience in the context of the next two UCD stages of the DMHI.

7.7.2 Extending the use of empathic UCD and the dialogical approach to other vulnerable user groups

I have produced detailed amendments (Section 7.3.4) and guides (Section 7.5.1) for how to use UCD with a vulnerable group and where amendments might need to be made. This experience could be used to do research with other vulnerable groups, using the types of models that I produced for the research here, in which empathic UCD and a dialogical approach could be used, for example, working with other types of physical or mental illness, with end-users whose voices have not been traditionally represented in the design process.

7.7.3 Extending the use of empathic UCD and the dialogical approach to other groups

Having worked with a vulnerable group using empathic UCD, I would like to extend and use my experience to work on other types of creative projects where empathic design methods and particularly dialogical approaches could be used, perhaps in an area a little less challenging where talking to the users would not require such strict ethical clearance.

Appendices

Appendix A

Client Interview Schedule

Introduction

1. How long have you been undertaking DBT?
2. How have you found DBT? Can you tell me a little about your experience of learning DBT skills at the Tuke?
3. Do you find any of the skills easier or more difficult to learn, why?

Mindfulness

1. Thinking about the skills of observe / perceive / participate, do you find any of them easier or more difficult?
2. Do you find mindfulness is helpful or not to you in learning and using the other DBT skills?
3. Do you practice mindfulness on your own? Can you talk a bit about that?

Interpersonal Effectiveness (IE) Skills

1. Have you been through the IE skills module yet?
2. How did you find the IE module? (easy or difficult to understand, hard-work or not too bad?)
3. Do you find the IE skills easy or hard to remember? Does anything help you to remember them?

Emotion Regulation (ER) Skills

1. Have you been through the ER skills module yet?
2. How did you find the ER module? (easy or difficult to understand, hard-work or not too bad?)
3. Do you find the ER skills easy or hard to remember? Does anything help you to remember them?

Distress Tolerance (DT) Skills

1. Have you been through the DT skills module yet?

2. How did you find the DT module? (easy or difficult to understand, hard-work or not too bad?)
3. Do you find the DT skills easy or hard to remember? Does anything help you to remember them?

Digital Technologies and Games

1. Do you have any experience of using technology in your day-to-day life?
2. Do you enjoy using technology?
3. Do you play any types of games on your phone, computer or other platform?

If yes:

4. What kinds?
5. What do you enjoy about playing?

If no:

6. Do you play any other games or sports?
7. What do you like to do to relax/chill out?

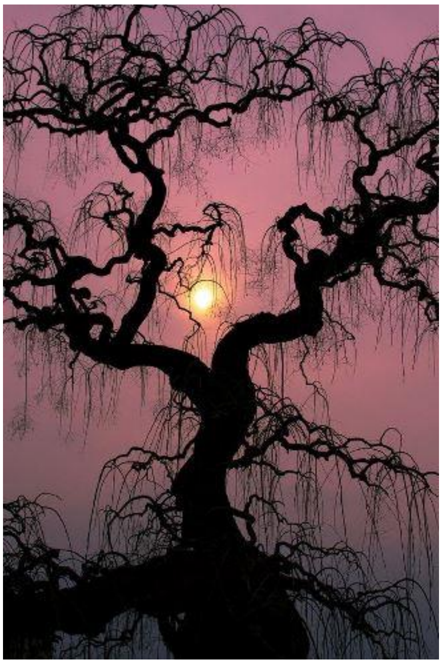
DBT Game Content

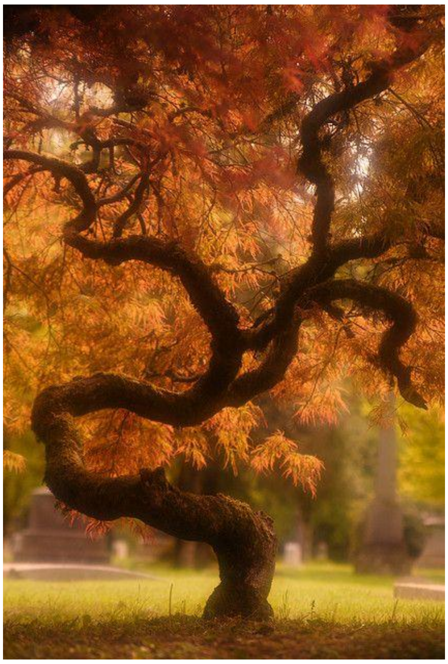
1. I'm thinking of including an area of the game where players can store distress tolerance items such as pictures, recordings short videos etc or even remind themselves of helpful things to do.

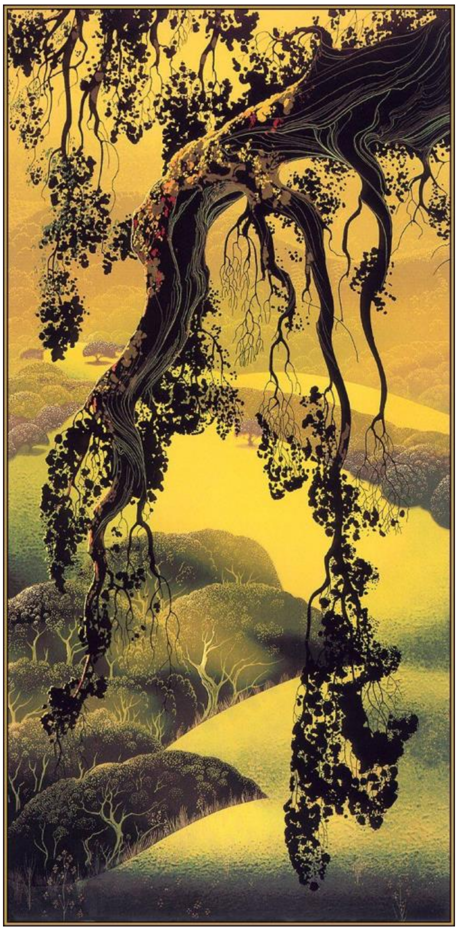
   What do you think of this? Would you use such an area?
2. What would you personally like to get out of a digital game for DBT?
3. If the game could only have one skill in the initial development, which would you pick?

Study to gather information for use in DBT game design v.1 Client Interview Schedule – Backgrounds Look and Feel

Please have a look at the following. At this stage, these are possible designs which give you an idea of the look of the game. Please note, these will not be the final backgrounds.







Appendix B

Clinician Interview Schedule

Health-care professional interview schedule

General

1. How long have you been working with DBT?
2. Which of the four skills do you find easiest / most difficult to deliver or talk to clients about, why?
3. Which of the four skills do clients find easiest / most difficult to pick up?
4. Can you talk a little about the dialectic element of DBT? Is this aspect of DBT very important? Should a game try to replicate this or ignore it?

Mindfulness

1. Can you talk a little about how clients find learning mindfulness skills?
2. Have you noticed a difference in learning the mindfulness skills of observe / perceive / participate? (In style or ease of learning) in the clients?
3. Does anything help / hinder clients in being mindful?

Interpersonal Effectiveness Skills

1. Can you talk a little about how you find teaching IE skills in terms of the clients?
2. How do clients find this skills module?
3. Do any aspects in particular stand out for you, for example as helpful or easy / difficult for clients to understand and take on board?

Emotion Regulation

1. Can you talk a little about how you find teaching ER skills in terms of the clients?
2. How do clients find this skills module?
3. Do any aspects in particular stand out for you, for example as helpful or easy / difficult for clients to understand and take on board?

Distress Tolerance

1. Can you talk a little about how you find teaching DT skills in terms of the clients?
2. How do clients tend to react to this skills module?
3. It has been stated that clients can overuse the DT skills. Have you found this?
4. Do any aspects in particular stand out for you, for example as more/less helpful or more easy/difficult for clients to understand and take on board?

Games and Digital Technologies

1. Do you use any types of games with the clients? What kinds? Are they useful/helpful? How do they respond?
2. Do you have any experience of using digital technology with the clients? (recordings, webpages, apps, etc). If yes, in which areas of DBT?
3. If the game could only have two skills in the initial development, which two would you pick?

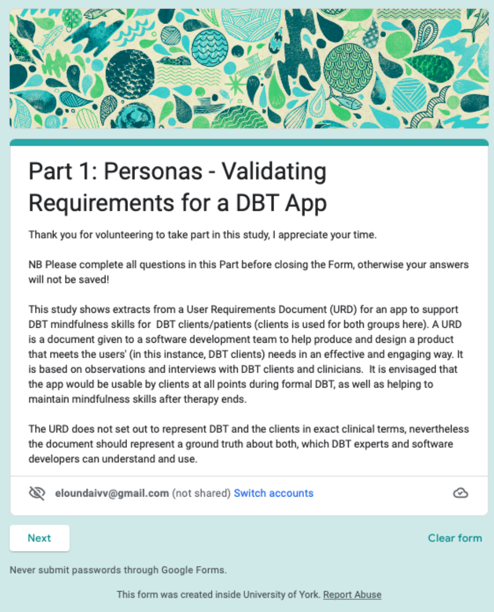
Closing

1. Is there anything else you would like to add to anything we've talked about?
2. Is there anything you think I should have asked about and didn't?
3. Are there any questions you'd like to ask me about the study?

Appendix C

Study 4 Round 1 - Part 1 Personas

Putting a Google Form into a suitable format for presentation in the Appendices was difficult. Figures C.1 and C.2 show screenshots of the first two pages. The rest of the Round 1 Part 1 - Personas questionnaire follows. The Part 1 questionnaire is also available online: https://bit.ly/S4R1Persona



Part 1: Personas - Validating Requirements for a DBT App

Thank you for volunteering to take part in this study, I appreciate your time.

NB Please complete all questions in this Part before closing the Form, otherwise your answers will not be saved!

This study shows extracts from a User Requirements Document (URD) for an app to support DBT mindfulness skills for DBT clients/patients (clients is used for both groups here). A URD is a document given to a software development team to help produce and design a product that meets the users' (in this instance, DBT clients) needs in an effective and engaging way. It is based on observations and interviews with DBT clients and clinicians. It is envisaged that the app would be usable by clients at all points during formal DBT, as well as helping to maintain mindfulness skills after therapy ends.

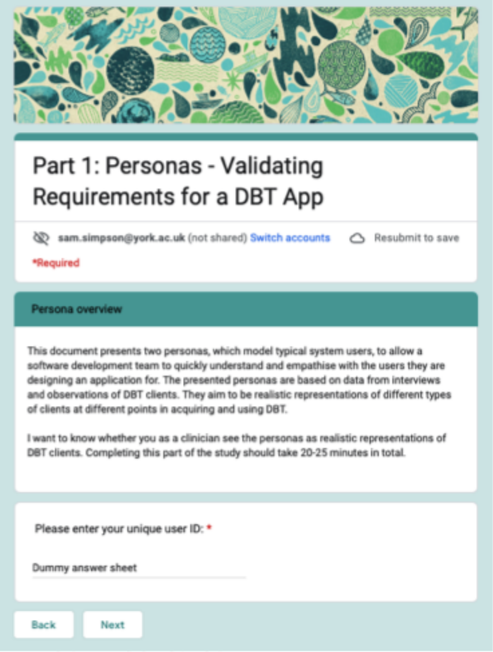
The URD does not set out to represent DBT and the clients in exact clinical terms, nevertheless the document should represent a ground truth about both, which DBT experts and software developers can understand and use.

eloundaivv@gmail.com (not shared) Switch accounts

Never submit passwords through Google Forms.

This form was created inside University of York. Report Abuse

Figure C.1: Page 1



Part 1: Personas - Validating Requirements for a DBT App

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Persona overview

This document presents two personas, which model typical system users, to allow a software development team to quickly understand and empathise with the users they are designing an application for. The presented personas are based on data from interviews and observations of DBT clients. They aim to be realistic representations of different types of clients at different points in acquiring and using DBT.

I want to know whether you as a clinician see the personas as realistic representations of DBT clients. Completing this part of the study should take 20-25 minutes in total.

Please enter your unique user ID: *

Dummy answer sheet

Figure C.2: Page 2

Part 1: Personas - Validating Requirements for a DBT App

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Persona 1 - Russell Jones

Russell Jones is a persona (a typical representation) of a DBT client who has been undertaking DBT and learning DBT mindfulness skills for a few months.

Please read the persona and answer the following questions. If the persona display is too small you can open the pdf using this link:

https://drive.google.com/file/d/1Kwr_zHAQp1wfKGjI10yLutRI5sKmpM1k/view?usp=sharing (opens in new tab)

Russell Jones

"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."

- 21 years old
- In a relationship - no children
- 5 GCSEs
- Finished mechanic apprenticeship
- Recently diagnosed with Borderline Personality Disorder (BPD)
- Six months DBT
- Anger, depression, emotional outbursts & suicidality
- Risk-taking behaviours, self-harm

Goals

1. Complete the DBT course
2. Handle my emotions better
3. Dampen suicide/dangerous behaviour urges
4. Get a job as a mechanic

Fears

1. My girlfriend will leave me.
2. I'll never get better.

Background

I recently finished a mechanic apprenticeship. I'm a good mechanic, but they let me go because of poor attendance. I've had lots of time off because of being depressed, but I didn't want to tell them. I'm also moody & get upset and angry over small things. I feel irritable and agitated a lot of the time. I've seen a few therapists over the last few years, but I was diagnosed with BPD about nine months ago. My girlfriend, Maddie broke up with me after a row I threatened to kill myself if she left and she said if I didn't get help she would. Maddie is my main reason for doing DBT.

When I was 10, my dad's friend started taking me fishing; it was an excuse for him to abuse me. It lasted about a year until I told my parents. I was an emotional child, who got upset easily, and I was completely traumatised by what happened. My dad doesn't understand why I still get upset about the abuse though.

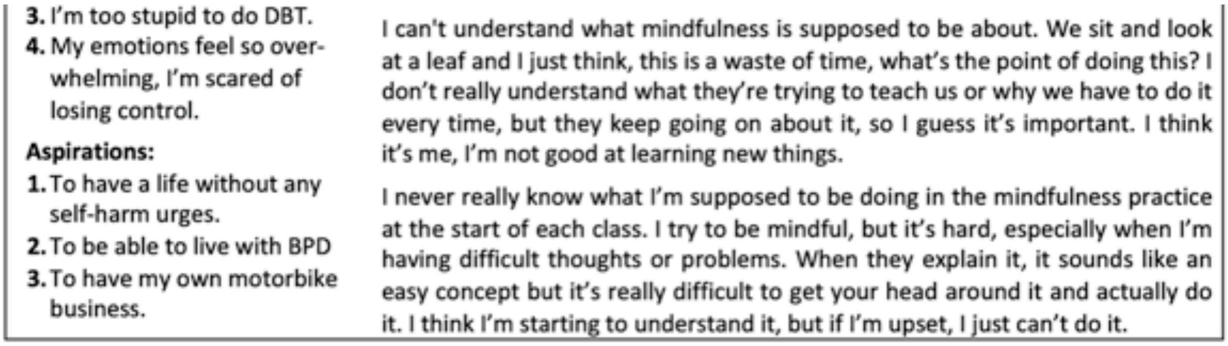
I started self-harming when I was a teenager. I fell off my bike after a row with my dad & the pain helped. I'd hit things and burn myself. Physical pain helps when I feel really bad. When I'm angry, I drive my motorbike too fast and put myself in danger. I don't care if I crash. I'm always falling out with my mates. I seem to get close to a mate and then they do something to annoy me & we fall out big time and stop talking. When I'm angry I bang my head on walls and punch myself.

I know I don't always treat Maddie well. I go between being very loving and pushing her away. I get really jealous. We've rowed a few times because I'm scared she'll leave me. I wanted to know where she'd been and grabbed her phone to see who'd called her. I'd never hurt her, but I get so angry, I'm scared I might lose control. She tried to break up with me after our last row. I punched a hole in the door. I told her I'd crash the bike and kill myself if she left me. Sometimes I think we'd both be better off if I were dead.

DBT

I've been going to DBT for six months. It's really helpful, but I still feel in a fog with it a lot of the time. I appreciate the time the therapists take, but I'm not very good at it. I almost never do the homework and I feel really guilty about that, but I forget. To be honest, often I don't understand the skills, and there's so many of them, it's overwhelming. When I feel like hurting myself, I get overcome with emotion & can't work out what else to do or use the skills. Maybe one day I will, but not at the moment. I know I need to be better for Maddie, but on bad days I feel so angry & depressed; I just want to make it stop. I hope DBT will help and stop the suicidal thoughts.

Mindfulness



3. I'm too stupid to do DBT.
4. My emotions feel so overwhelming, I'm scared of losing control.

Aspirations:

1. To have a life without any self-harm urges.
2. To be able to live with BPD
3. To have my own motorbike business.

I can't understand what mindfulness is supposed to be about. We sit and look at a leaf and I just think, this is a waste of time, what's the point of doing this? I don't really understand what they're trying to teach us or why we have to do it every time, but they keep going on about it, so I guess it's important. I think it's me, I'm not good at learning new things.

I never really know what I'm supposed to be doing in the mindfulness practice at the start of each class. I try to be mindful, but it's hard, especially when I'm having difficult thoughts or problems. When they explain it, it sounds like an easy concept but it's really difficult to get your head around it and actually do it. I think I'm starting to understand it, but if I'm upset, I just can't do it.

1. How far is Russell Jones' Background section representative of a typical early stage DBT client? *

	1	2	3	4	5	
Not at all like an early stage DBT client	○	○	●	○	○	Very much like an early stage DBT client

1.A Please say why you answered Question 1 as you did: *

N/A

2. How far is Russell's attitude to DBT representative of a typical early stage DBT client? *

	1	2	3	4	5	
Not at all like an early stage DBT client	○	○	●	○	○	Very much like an early stage DBT client

2.A Please say why you answered Question 2 as you did: *

N/A

3. How far is Russell's attitude to Mindfulness representative of a typical early stage DBT client? *

	1	2	3	4	5	
Not at all like an early stage client	○	○	●	○	○	Very much like an early stage client

3.A Please say why you answered Question 3 as you did: *

N/A

4. How far are Russell's Goals, Fears and Aspirations representative of a typical early stage DBT client? *

	1	2	3	4	5	
Not at all like an early stage DBT client	○	○	●	○	○	Very much like an early stage DBT client

4.A Please say why you answered Question 4 as you did: *

N/A

5. The personas were generated using data from observations and interviews with DBT clients; was there anything about the Russell Jones persona which was a surprise or gave you new information about an early stage DBT client? *

N/A

6. Are there any other parts of Russell Jones which seem either particularly insightful or misrepresentative of a typical early stage DBT client? *

N/A

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Part 1: Personas - Validating Requirements for a DBT App

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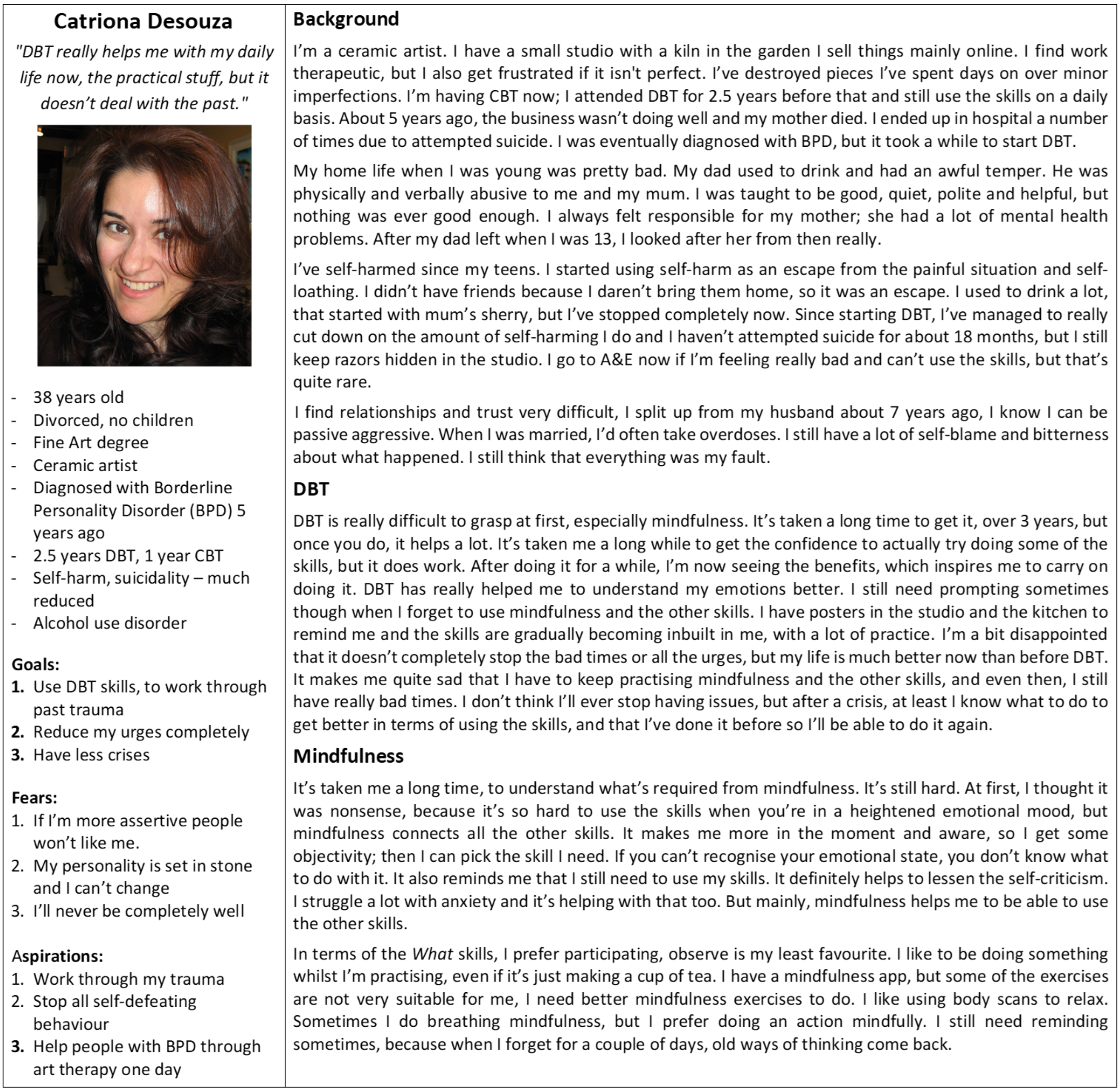
Persona 2 - Catriona Desouza

Catriona Desouza is a persona of a DBT client who has been acquiring and using DBT skills for 3+ years.

Please read the persona and answer the following questions. If the persona display is too small you can open the pdf using this link:

https://drive.google.com/file/d/1eh2Ui3z-OGvmVREE72HcMg2Ix1Q5GqE7/view?usp=sharing (opens in new tab)



Catriona Desouza

"DBT really helps me with my daily life now, the practical stuff, but it doesn't deal with the past."

- 38 years old
- Divorced, no children
- Fine Art degree
- Ceramic artist
- Diagnosed with Borderline Personality Disorder (BPD) 5 years ago
- 2.5 years DBT, 1 year CBT
- Self-harm, suicidality – much reduced
- Alcohol use disorder

Goals:

1. Use DBT skills, to work through past trauma
2. Reduce my urges completely
3. Have less crises

Fears:

1. If I'm more assertive people won't like me.
2. My personality is set in stone and I can't change
3. I'll never be completely well

Aspirations:

1. Work through my trauma
2. Stop all self-defeating behaviour
3. Help people with BPD through art therapy one day

Background

I'm a ceramic artist. I have a small studio with a kiln in the garden I sell things mainly online. I find work therapeutic, but I also get frustrated if it isn't perfect. I've destroyed pieces I've spent days on over minor imperfections. I'm having CBT now; I attended DBT for 2.5 years before that and still use the skills on a daily basis. About 5 years ago, the business wasn't doing well and my mother died. I ended up in hospital a number of times due to attempted suicide. I was eventually diagnosed with BPD, but it took a while to start DBT.

My home life when I was young was pretty bad. My dad used to drink and had an awful temper. He was physically and verbally abusive to me and my mum. I was taught to be good, quiet, polite and helpful, but nothing was ever good enough. I always felt responsible for my mother; she had a lot of mental health problems. After my dad left when I was 13, I looked after her from then really.

I've self-harmed since my teens. I started using self-harm as an escape from the painful situation and self-loathing. I didn't have friends because I daren't bring them home, so it was an escape. I used to drink a lot, that started with mum's sherry, but I've stopped completely now. Since starting DBT, I've managed to really cut down on the amount of self-harming I do and I haven't attempted suicide for about 18 months, but I still keep razors hidden in the studio. I go to A&E now if I'm feeling really bad and can't use the skills, but that's quite rare.

I find relationships and trust very difficult, I split up from my husband about 7 years ago, I know I can be passive aggressive. When I was married, I'd often take overdoses. I still have a lot of self-blame and bitterness about what happened. I still think that everything was my fault.

DBT

DBT is really difficult to grasp at first, especially mindfulness. It's taken a long time to get it, over 3 years, but once you do, it helps a lot. It's taken me a long while to get the confidence to actually try doing some of the skills, but it does work. After doing it for a while, I'm now seeing the benefits, which inspires me to carry on doing it. DBT has really helped me to understand my emotions better. I still need prompting sometimes though when I forget to use mindfulness and the other skills. I have posters in the studio and the kitchen to remind me and the skills are gradually becoming inbuilt in me, with a lot of practice. I'm a bit disappointed that it doesn't completely stop the bad times or all the urges, but my life is much better now than before DBT. It makes me quite sad that I have to keep practising mindfulness and the other skills, and even then, I still have really bad times. I don't think I'll ever stop having issues, but after a crisis, at least I know what to do to get better in terms of using the skills, and that I've done it before so I'll be able to do it again.

Mindfulness

It's taken me a long time, to understand what's required from mindfulness. It's still hard. At first, I thought it was nonsense, because it's so hard to use the skills when you're in a heightened emotional mood, but mindfulness connects all the other skills. It makes me more in the moment and aware, so I get some objectivity; then I can pick the skill I need. If you can't recognise your emotional state, you don't know what to do with it. It also reminds me that I still need to use my skills. It definitely helps to lessen the self-criticism. I struggle a lot with anxiety and it's helping with that too. But mainly, mindfulness helps me to be able to use the other skills.

In terms of the *What* skills, I prefer participating, observe is my least favourite. I like to be doing something whilst I'm practising, even if it's just making a cup of tea. I have a mindfulness app, but some of the exercises are not very suitable for me, I need better mindfulness exercises to do. I like using body scans to relax. Sometimes I do breathing mindfulness, but I prefer doing an action mindfully. I still need reminding sometimes, because when I forget for a couple of days, old ways of thinking come back.

7. How far is Catriona's Background representative of a typical longer-term user of DBT skills? *

	1	2	3	4	5	
Not at all like a longer-term DBT skills user	○	○	●	○	○	Very much like a longer-term DBT skills user

7.A Please say why you answered Question 7 as you did: *

N/A

8. How far is Catriona's attitude to DBT representative of a typical longer-term user of DBT skills? *

	1	2	3	4	5	
Not at all like a longer-term DBT skills user	○	○	●	○	○	Very much like a longer-term DBT skills user

8.A Please say why you answered Question 8 as you did: *

N/A

9. How far is Catriona's attitude to Mindfulness representative of a typical longer-term user of DBT skills? *

	1	2	3	4	5	
Not at all like a longer-term DBT skills user	○	○	●	○	○	Very much like a longer-term DBT skills user

9.A Please say why you answered Question 9 as you did: *

N/A

10. How far are Catriona's Goals, Fears and Aspirations representative of a typical longer-term user of DBT skills? *

	1	2	3	4	5	
Not at all like a longer-term DBT skills user	○	○	●	○	○	Very much like a longer-term DBT skills user

10.A Please say why you answered Question 10 as you did: *

N/A

11. The personas were generated using data from observations and interviews with DBT clients; was there anything about the Catriona Desouza persona which was a surprise or gave you new information about a longer-term DBT skills user? *

N/A

12. Are there any other parts of Catriona which seem either particularly insightful or misrepresentative of a typical longer-term DBT skills user? *

N/A

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Part 1: Personas - Validating Requirements for a DBT App

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Final section

13. Before this study, were you familiar with the use of personas as a design method? *

● Yes

○ No

14. Which did you find the most representative and realistic persona? *

○ Russell Jones

○ Catriona Desouza

● Both

○ Neither

15. Please add any other comments you have on the personas (optional):

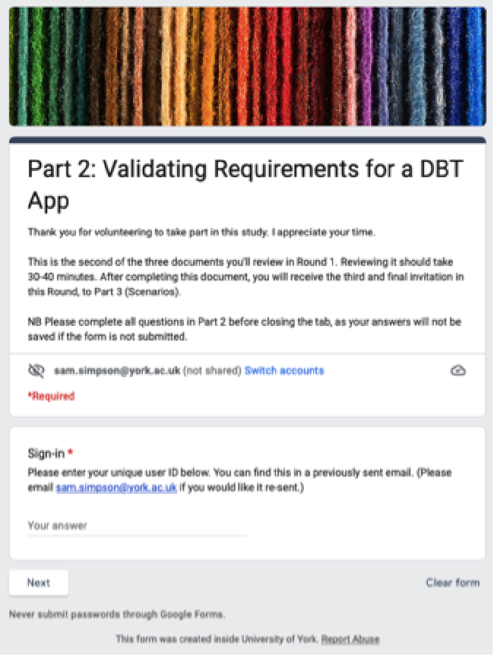
N/A

Back Submit

Appendix D

Study 4 Round 1 - Part 2 - UX Map

Putting a Google Form into a suitable format for presentation in the Appendices was difficult. Figures D.1 and D.2 show screenshots of the first two pages. The rest of the Round 1 Part 2 - UX Map questionnaire follows. The Part 2 questionnaire is also available online: https://bit.ly/Part2_UXmap



Part 2: Validating Requirements for a DBT App

Thank you for volunteering to take part in this study. I appreciate your time.

This is the second of the three documents you'll review in Round 1. Reviewing it should take 30-40 minutes. After completing this document, you will receive the third and final invitation in this Round, to Part 3 (Scenarios).

NB Please complete all questions in Part 2 before closing the tab, as your answers will not be saved if the form is not submitted.

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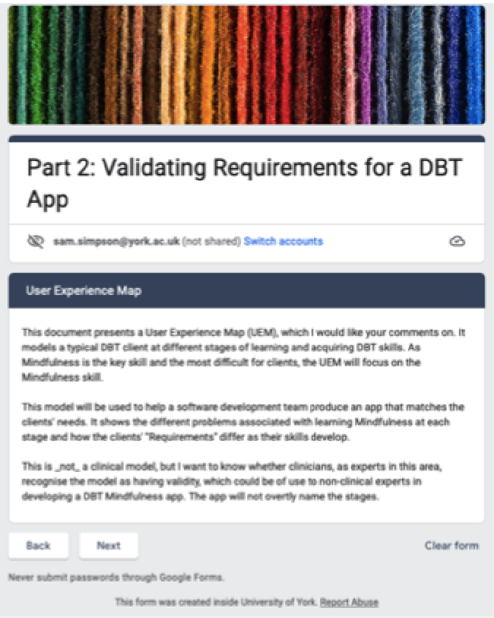
*Required

Sign-in *

Please enter your unique user ID below. You can find this in a previously sent email. (Please email sam.simpson@york.ac.uk if you would like it re-sent.)

Your answer

Figure D.1: Page 1



Part 2: Validating Requirements for a DBT App

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User Experience Map

This document presents a User Experience Map (UEM), which I would like your comments on. It models a typical DBT client at different stages of learning and acquiring DBT skills. As Mindfulness is the key skill and the most difficult for clients, the UEM will focus on the Mindfulness skill.

This model will be used to help a software development team produce an app that matches the clients' needs. It shows the different problems associated with learning Mindfulness at each stage and how the clients' "Requirements" differ as their skills develop.

This is _not_ a clinical model, but I want to know whether clinicians, as experts in this area, recognise the model as having validity, which could be of use to non-clinical experts in developing a DBT Mindfulness app. The app will not overtly name the stages.

Figure D.2: Page 2

Part 2: Validating Requirements for a DBT App

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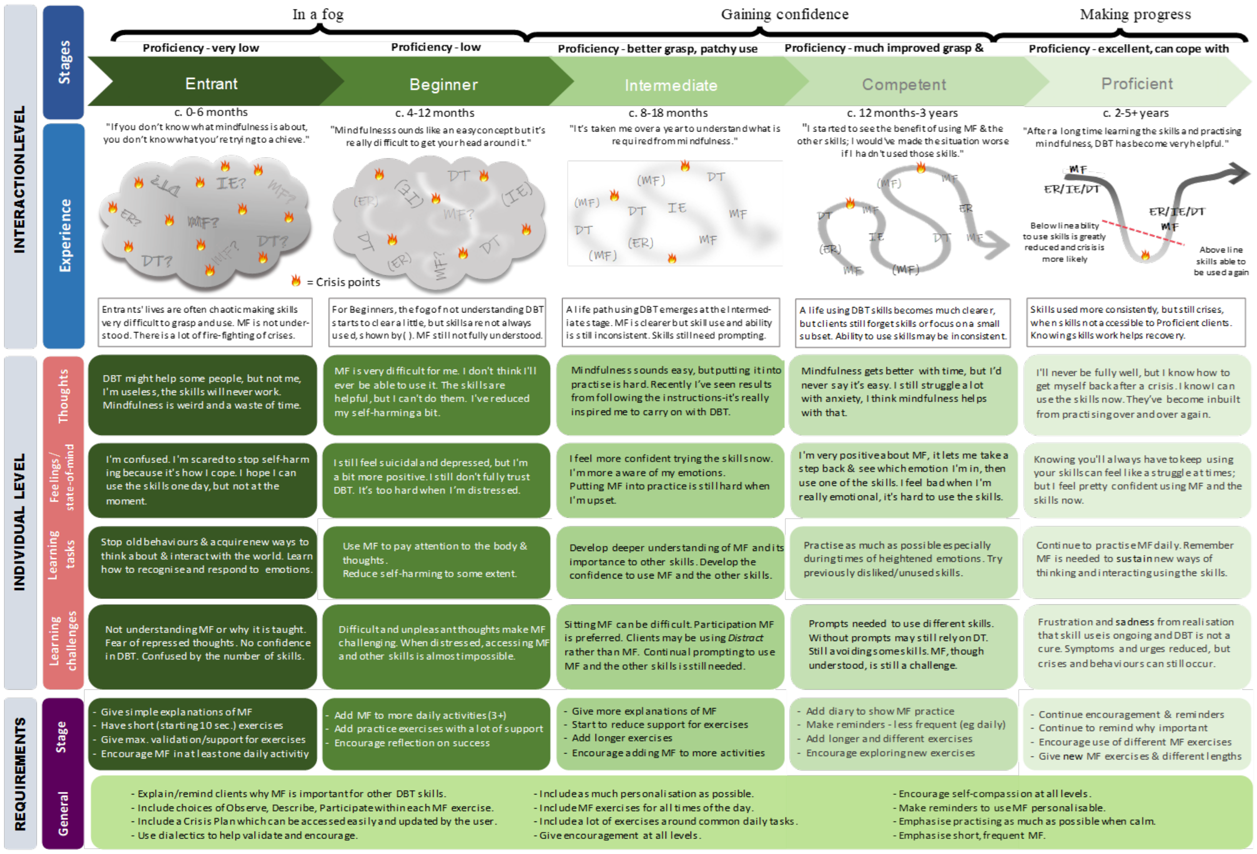
Questions on the UEM

Please look at the User Experience Map below. You can also open the map as a pdf (opens in new tab): https://bit.ly/2YRSR7Y

You may find it easier to leave the PDF open for reference in the questions below. After reading the document, please answer the following questions:



		Entrant	Beginner	Intermediate	Competent	Proficient
INTERACTION LEVEL		In a fog		Gaining confidence		Making progress
		Proficiency - very low	Proficiency - low	Proficiency - better grasp, patchy use	Proficiency - much improved grasp &	Proficiency - excellent, can cope with
	Stages	Entrant	Beginner	Intermediate	Competent	Proficient
	Experience	c. 0-6 months "If you don't know what mindfulness is about, you don't know what you're trying to achieve."	c. 4-12 months "Mindfulness sounds like an easy concept but it's really difficult to get your head around it."	c. 8-18 months "It's taken me over a year to understand what is required from mindfulness."	c. 12 months-3 years "I started to see the benefit of using MF & the other skills; I would've made the situation worse if I hadn't used those skills."	c. 2-5+ years "After a long time learning the skills and practising mindfulness, DBT has become very helpful."
		Entrants' lives are often chaotic making skills very difficult to grasp and use. MF is not understood. There is a lot of fire-fighting of crises.	For Beginners, the fog of not understanding DBT starts to clear a little, but skills are not always used, shown by ( ). MF still not fully understood.	A life path using DBT emerges at the Intermediate stage. MF is clearer but skill use and ability is still inconsistent. Skills still need prompting.	A life using DBT skills becomes much clearer, but clients still forget skills or focus on a small subset. Ability to use skills may be inconsistent.	Skills used more consistently, but still crises, when skills not accessible to Proficient clients. Knowing skills work helps recovery.
INDIVIDUAL LEVEL	Thoughts	DBT might help some people, but not me, I'm useless, the skills will never work. Mindfulness is weird and a waste of time.	MF is very difficult for me. I don't think I'll ever be able to use it. The skills are helpful, but I can't do them. I've reduced my self-harming a bit.	Mindfulness sounds easy, but putting it into practise is hard. Recently I've seen results from following the instructions-it's really inspired me to carry on with DBT.	Mindfulness gets better with time, but I'd never say it's easy. I still struggle a lot with anxiety, I think mindfulness helps with that.	I'll never be fully well, but I know how to get myself back after a crisis. I know I can use the skills now. They've become inbuilt from practising over and over again.
	Feelings / state-of-mind	I'm confused. I'm scared to stop self-harming because it's how I cope. I hope I can use the skills one day, but not at the moment.	I still feel suicidal and depressed, but I'm a bit more positive. I still don't fully trust DBT. It's too hard when I'm distressed.	I feel more confident trying the skills now. I'm more aware of my emotions. Putting MF into practice is still hard when I'm upset.	I'm very positive about MF, it lets me take a step back & see which emotion I'm in, then use one of the skills. I feel bad when I'm really emotional, it's hard to use the skills.	Knowing you'll always have to keep using your skills can feel like a struggle at times; but I feel pretty confident using MF and the skills now.
	Learning tasks	Stop old behaviours & acquire new ways to think about & interact with the world. Learn how to recognise and respond to emotions.	Use MF to pay attention to the body & thoughts. Reduce self-harming to some extent.	Develop deeper understanding of MF and its importance to other skills. Develop the confidence to use MF and the other skills.	Practise as much as possible especially during times of heightened emotions. Try previously disliked/unused skills.	Continue to practise MF daily. Remember MF is needed to sustain new ways of thinking and interacting using the skills.
	Learning challenges	Not understanding MF or why it is taught. Fear of repressed thoughts. No confidence in DBT. Confused by the number of skills.	Difficult and unpleasant thoughts make MF challenging. When distressed, accessing MF and other skills is almost impossible.	Sitting MF can be difficult. Participation MF is preferred. Clients may be using *Distract* rather than MF. Continual prompting to use MF and the other skills is still needed.	Prompts needed to use different skills. Without prompts may still rely on DT. Still avoiding some skills. MF, though understood, is still a challenge.	Frustration and sadness from realisation that skill use is ongoing and DBT is not a cure. Symptoms and urges reduced, but crises and behaviours can still occur.
REQUIREMENTS	Stage	- Give simple explanations of MF - Have short (starting 10 sec.) exercises - Give max. validation/support for exercises - Encourage MF in at least one daily activitiy	- Add MF to more daily activities (3+) - Add practice exercises with a lot of support - Encourage reflection on success	- Give more explanations of MF - Start to reduce support for exercises - Add longer exercises - Encourage adding MF to more activities	- Add diary to show MF practice - Make reminders - less frequent (eg daily) - Add longer and different exercises - Encourage exploring new exercises	- Continue encouragement & reminders - Continue to remind why important - Encourage use of different MF exercises - Give new MF exercises & different lengths
	General	- Explain/remind clients why MF is important for other DBT skills. - Include choices of Observe, Describe, Participate within each MF exercise. - Include a Crisis Plan which can be accessed easily and updated by the user. - Use dialectics to help validate and encourage.		- Include as much personalisation as possible. - Include MF exercises for all times of the day. - Include a lot of exercises around common daily tasks. - Give encouragement at all levels.	- Encourage self-compassion at all levels. - Make reminders to use MF personalisable. - Emphasise practising as much as possible when calm. - Emphasise short, frequent MF.	

LEGEND: MF - Mindfulness IE - Interpersonal Effectiveness ER - Emotion Regulation DT - Distress Tolerance

1. Overall, how far does the User Experience Map match your experience of clients' typical progress in acquiring DBT Mindfulness skills?" *

	1	2	3	4	5	
Not at all	○	○	○	○	○	Very well

Please elaborate on the above answer: *

Your answer

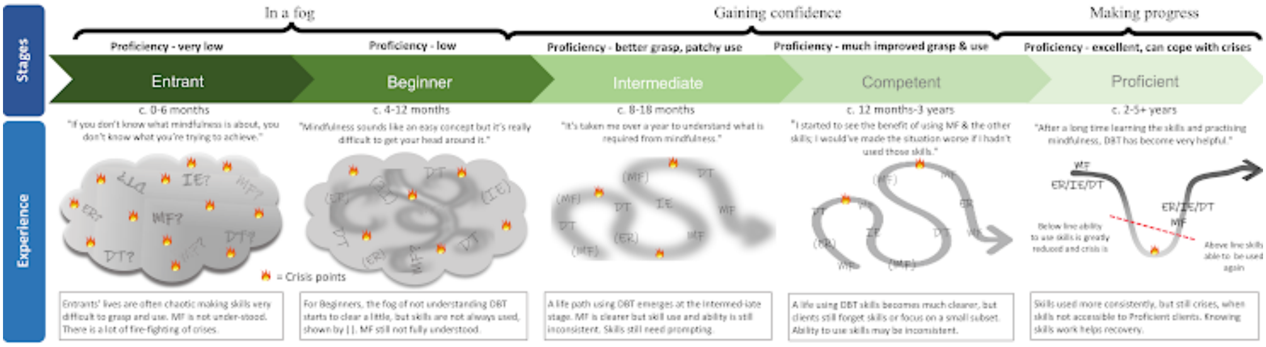
2. Looking specifically at the Stages (see extract below): how far do the progression stages, from Entrant to Proficient (in green), the timeline, proficiency and high-level categories (In a fog, etc.) represent the clients' progress in acquiring DBT Mindfulness skills? Please use the PDF if this extract is too small. (https://bit.ly/2YRSR7Y) *

	1	2	3	4	5	
Poor representation	○	○	○	○	○	Excellent representation

Please elaborate on the above answer: *

Your answer

3. Looking at the Experience level: how well do the quotes, graphical representations and short explanations represent the experience of acquiring DBT Mindfulness skills from Entrant to Proficient? Please use the PDF if this extract is too small. *



"If you don't know what mindfulness is about, you don't know what you're trying to achieve."

"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."

"It's taken me over a year to understand what is required from mindfulness."

"I started to see the benefit of using MF & the other skills; I would've made the situation worse if I hadn't used those skills."

"After a long time learning the skills and practising mindfulness, DBT has become very helpful."

Entrants' lives are often chaotic making skills very difficult to grasp and use. MF is not under-stood. There is a lot of fire-fighting of crises.

For Beginners, the fog of not understanding DBT starts to clear a little, but skills are not always used, shown by | |. MF still not fully understood.

A life path using DBT emerges at the intermed-iate stage. MF is clearer but skill use and ability is still inconsistent. Skills still need prompting.

A life using DBT skills becomes much clearer, but clients still forget skills or focus on a small subset. Ability to use skills may be inconsistent.

Skills used more consistently, but still crises, when skills not accessible to Proficient clients. Knowing skills work helps recovery.

	1	2	3	4	5	
Poor representation	○	○	○	○	○	Exellent representation

Please elaborate on the above answer: *

Your answer

4. Looking at the Individual Level (below): how well does it represent clients' needs, issues and experiences around acquiring DBT Mindfulness skills? Please refer to the PDF if this is too small: (https://bit.ly/2YRSR7Y) *

Thoughts	DBT might help some people, but not me, I'm useless, the skills will never work. Mindfulness is weird and a waste of time.	MF is very difficult for me. I don't think I'll ever be able to use it. The skills are helpful, but I can't do them. I've reduced my self-harming a bit.	Mindfulness sounds easy, but putting it into practise is hard. Recently I've seen results from following the instructions-it's really inspired me to carry on with DBT.	Mindfulness gets better with time, but I'd never say it's easy. I still struggle a lot with anxiety, I think mindfulness helps with that.	I'll never be fully well, but I know how to get myself back after a crisis. I know I can use the skills now. They've become inbuilt from practising over and over again.
Feelings / state-of-mind	I'm confused. I'm scared to stop self-harm-ing because it's how I cope. I hope I can use the skills one day, but not at the moment.	I still feel suicidal and depressed, but I'm a bit more positive. I still don't fully trust DBT. It's too hard when I'm distressed.	I feel more confident trying the skills now. I'm more aware of my emotions. Putting MF into practice is still hard when I'm upset.	I'm very positive about MF, it lets me take a step back & see which emotion I'm in, then use one of the skills. I feel bad when I'm really emotional, it's hard to use the skills.	Knowing you'll always have to keep using your skills can feel like a struggle at times; but I feel pretty confident using MF and the skills now.
Learning tasks	Stop old behaviours & acquire new ways to think about & interact with the world. Learn how to recognise and respond to emotions.	Use MF to pay attention to the body & thoughts. Reduce self-harming to some extent.	Develop deeper understanding of MF and its importance to other skills. Develop the confidence to use MF and the other skills.	Practise as much as possible especially during times of heightened emotions. Try previously disliked/unused skills.	Continue to practise MF daily. Remember MF is needed to sustain new ways of thinking and interacting using the skills.
Learning challenges	Not understanding MF or why it is taught. Fear of repressed thoughts. No confidence in DBT. Confused by the number of skills.	Difficult and unpleasant thoughts make MF challenging. When distressed, accessing MF and other skills is almost impossible.	Sitting MF can be difficult. Participation MF is preferred. Clients may be using *Distract* rather than MF. Continual prompting to use MF and the other skills is still needed.	Prompts needed to use different skills. Without prompts may still rely on DT. Still avoiding some skills. MF, though understood, is still a challenge.	Frustration and sadness from realisation that skill use is ongoing and DBT is not a cure. Symptoms and urges reduced, but crises and behaviours can still occur.

	1	2	3	4	5	
Poor representation	○	○	○	○	○	Excellent representation

Please elaborate on the above answer: *

Your answer

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Part 2: Validating Requirements for a DBT App

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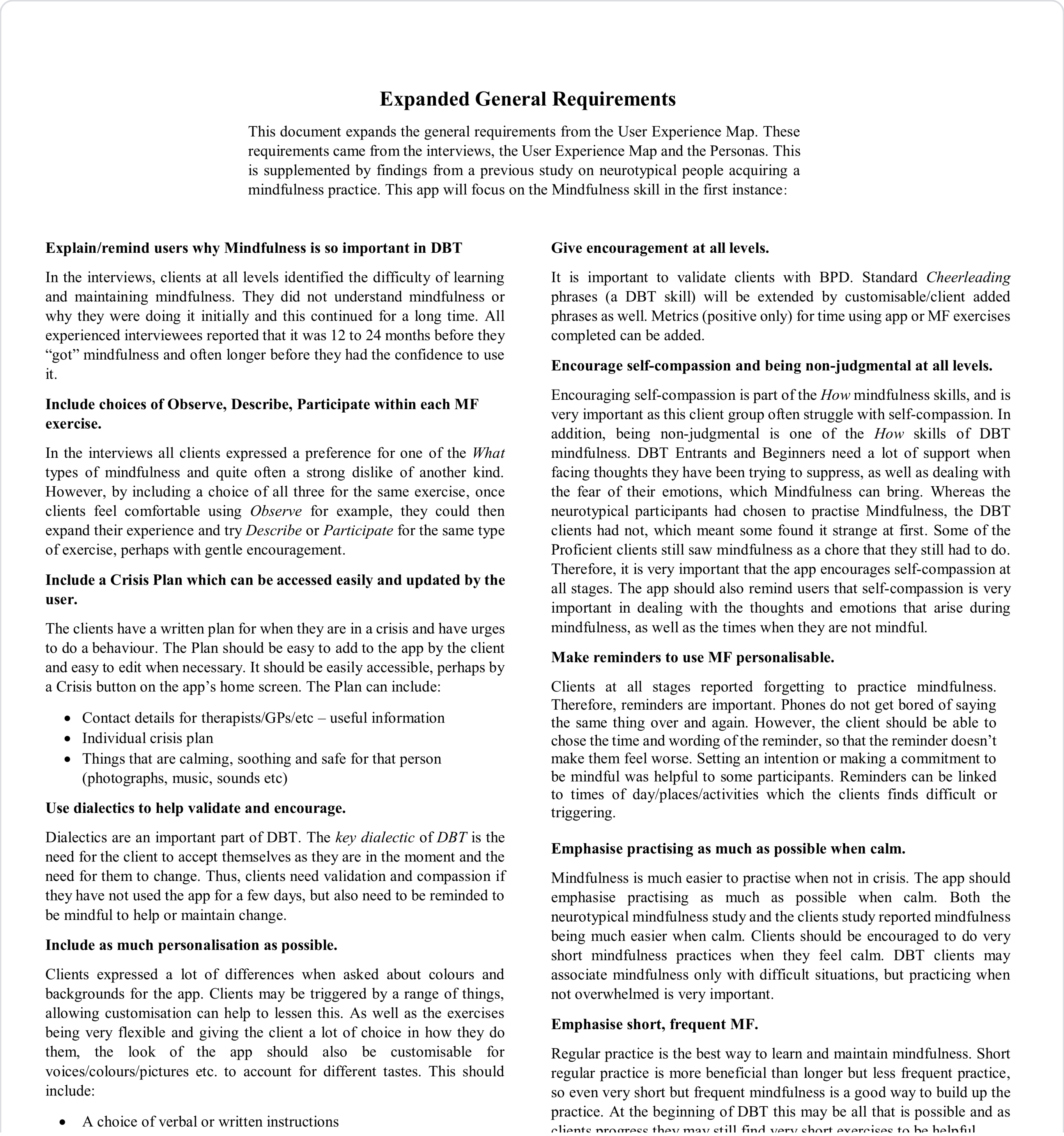
*Required

General Requirements

The User Experience Map (UEM) includes General Requirements for the overall application (bottom line of the UEM). 'Requirements' is a term from software development. Requirements are instructions to the software design team about what the final product should look like and what the users want and need from the software application.

I would like your comments on the document below which expands the General Requirements from the bottom line of the UEM. You can also open and read the Expanded General Requirements using this link: https://bit.ly/2EyYNej (opens in new tab).



Expanded General Requirements

This document expands the general requirements from the User Experience Map. These requirements came from the interviews, the User Experience Map and the Personas. This is supplemented by findings from a previous study on neurotypical people acquiring a mindfulness practice. This app will focus on the Mindfulness skill in the first instance:

Explain/remind users why Mindfulness is so important in DBT

In the interviews, clients at all levels identified the difficulty of learning and maintaining mindfulness. They did not understand mindfulness or why they were doing it initially and this continued for a long time. All experienced interviewees reported that it was 12 to 24 months before they "got" mindfulness and often longer before they had the confidence to use it.

Include choices of Observe, Describe, Participate within each MF exercise.

In the interviews all clients expressed a preference for one of the *What* types of mindfulness and quite often a strong dislike of another kind. However, by including a choice of all three for the same exercise, once clients feel comfortable using *Observe* for example, they could then expand their experience and try *Describe* or *Participate* for the same type of exercise, perhaps with gentle encouragement.

Include a Crisis Plan which can be accessed easily and updated by the user.

The clients have a written plan for when they are in a crisis and have urges to do a behaviour. The Plan should be easy to add to the app by the client and easy to edit when necessary. It should be easily accessible, perhaps by a Crisis button on the app's home screen. The Plan can include:

- Contact details for therapists/GPs/etc – useful information
- Individual crisis plan
- Things that are calming, soothing and safe for that person (photographs, music, sounds etc)

Use dialectics to help validate and encourage.

Dialectics are an important part of DBT. The *key dialectic* of *DBT* is the need for the client to accept themselves as they are in the moment and the need for them to change. Thus, clients need validation and compassion if they have not used the app for a few days, but also need to be reminded to be mindful to help or maintain change.

Include as much personalisation as possible.

Clients expressed a lot of differences when asked about colours and backgrounds for the app. Clients may be triggered by a range of things, allowing customisation can help to lessen this. As well as the exercises being very flexible and giving the client a lot of choice in how they do them, the look of the app should also be customisable for voices/colours/pictures etc. to account for different tastes. This should include:

- A choice of verbal or written instructions

Give encouragement at all levels.

It is important to validate clients with BPD. Standard *Cheerleading* phrases (a DBT skill) will be extended by customisable/client added phrases as well. Metrics (positive only) for time using app or MF exercises completed can be added.

Encourage self-compassion and being non-judgmental at all levels.

Encouraging self-compassion is part of the *How* mindfulness skills, and is very important as this client group often struggle with self-compassion. In addition, being non-judgmental is one of the *How* skills of DBT mindfulness. DBT Entrants and Beginners need a lot of support when facing thoughts they have been trying to suppress, as well as dealing with the fear of their emotions, which Mindfulness can bring. Whereas the neurotypical participants had chosen to practise Mindfulness, the DBT clients had not, which meant some found it strange at first. Some of the Proficient clients still saw mindfulness as a chore that they still had to do. Therefore, it is very important that the app encourages self-compassion at all stages. The app should also remind users that self-compassion is very important in dealing with the thoughts and emotions that arise during mindfulness, as well as the times when they are not mindful.

Make reminders to use MF personalisable.

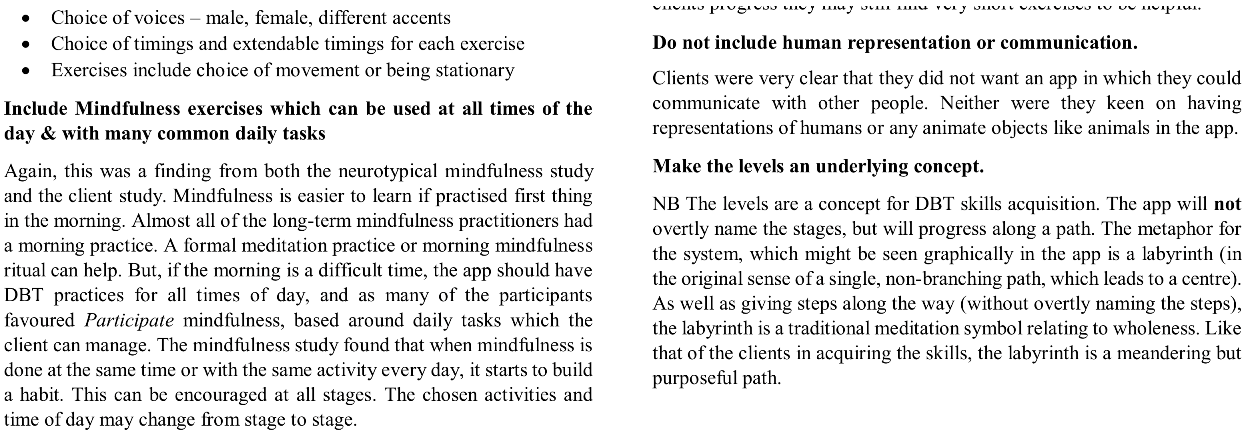
Clients at all stages reported forgetting to practice mindfulness. Therefore, reminders are important. Phones do not get bored of saying the same thing over and again. However, the client should be able to chose the time and wording of the reminder, so that the reminder doesn't make them feel worse. Setting an intention or making a commitment to be mindful was helpful to some participants. Reminders can be linked to times of day/places/activities which the clients finds difficult or triggering.

Emphasise practising as much as possible when calm.

Mindfulness is much easier to practise when not in crisis. The app should emphasise practising as much as possible when calm. Both the neurotypical mindfulness study and the clients study reported mindfulness being much easier when calm. Clients should be encouraged to do very short mindfulness practices when they feel calm. DBT clients may associate mindfulness only with difficult situations, but practicing when not overwhelmed is very important.

Emphasise short, frequent MF.

Regular practice is the best way to learn and maintain mindfulness. Short regular practice is more beneficial than longer but less frequent practice, so even very short but frequent mindfulness is a good way to build up the practice. At the beginning of DBT this may be all that is possible and as clients progress they may still find very short exercises to be helpful.



- Choice of voices – male, female, different accents
- Choice of timings and extendable timings for each exercise
- Exercises include choice of movement or being stationary

Include Mindfulness exercises which can be used at all times of the day & with many common daily tasks

Again, this was a finding from both the neurotypical mindfulness study and the client study. Mindfulness is easier to learn if practised first thing in the morning. Almost all of the long-term mindfulness practitioners had a morning practice. A formal meditation practice or morning mindfulness ritual can help. But, if the morning is a difficult time, the app should have DBT practices for all times of day, and as many of the participants favoured *Participate* mindfulness, based around daily tasks which the client can manage. The mindfulness study found that when mindfulness is done at the same time or with the same activity every day, it starts to build a habit. This can be encouraged at all stages. The chosen activities and time of day may change from stage to stage.

clients progress they may still find very short exercises to be helpful.

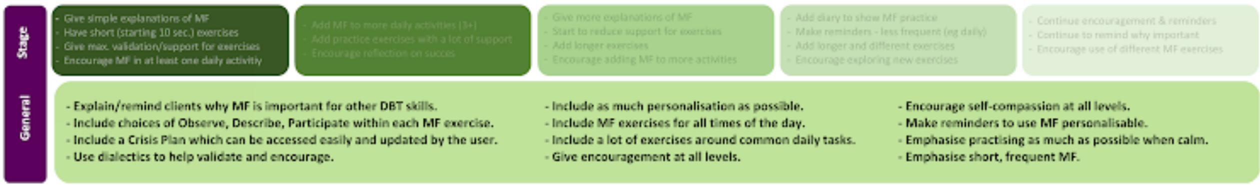
Do not include human representation or communication.

Clients were very clear that they did not want an app in which they could communicate with other people. Neither were they keen on having representations of humans or any animate objects like animals in the app.

Make the levels an underlying concept.

NB The levels are a concept for DBT skills acquisition. The app will **not** overtly name the stages, but will progress along a path. The metaphor for the system, which might be seen graphically in the app is a labyrinth (in the original sense of a single, non-branching path, which leads to a centre). As well as giving steps along the way (without overtly naming the steps), the labyrinth is a traditional meditation symbol relating to wholeness. Like that of the clients in acquiring the skills, the labyrinth is a meandering but purposeful path.

5. After reading the Expanded General Requirements, how appropriate do you think the General Requirements are for clients acquiring DBT Mindfulness skills? *



Stage

- Give simple explanations of MF
- Have short (starting 10 sec.) exercises
- Give max. validation/support for exercises
- Encourage MF in at least one daily activitiy

- Add MF to more daily activities (3+)
- Add practice exercises with a lot of support
- Encourage reflection on succes

- Give more explanations of MF
- Start to reduce support for exercises
- Add longer exercises
- Encourage adding MF to more activities

- Add diary to show MF practice
- Make reminders - less frequent (eg daily)
- Add longer and different exercises
- Encourage exploring new exercises

- Continue encouragement & reminders
- Continue to remind why important
- Encourage use of different MF exercises

General

- Explain/remind clients why MF is important for other DBT skills.
- Include choices of Observe, Describe, Participate within each MF exercise.
- Include a Crisis Plan which can be accessed easily and updated by the user.
- Use dialectics to help validate and encourage.

- Include as much personalisation as possible.
- Include MF exercises for all times of the day.
- Include a lot of exercises around common daily tasks.
- Give encouragement at all levels.

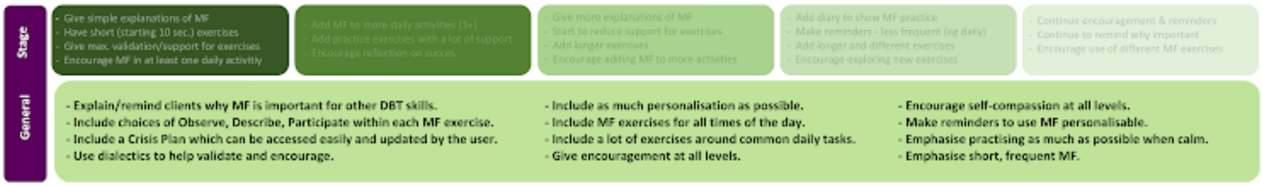
- Encourage self-compassion at all levels.
- Make reminders to use MF personalisable.
- Emphasise practising as much as possible when calm.
- Emphasise short, frequent MF.

	1	2	3	4	5	
Not at all appropriate	○	○	○	○	○	Very appropriate

Please elaborate on the above answer: *

Your answer

6. Again referring to the General Requirements, below and in the Expanded Requirements Document (above): how complete are the General Requirements for clients acquiring DBT Mindfulness skills? Do you think any important Requirements have been overlooked? *



Stage

- Give simple explanations of MF
- Have short (starting 10 sec.) exercises
- Give max. validation/support for exercises
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- Encourage self-compassion at all levels.
- Make reminders to use MF personalisable.
- Emphasise practising as much as possible when calm.
- Emphasise short, frequent MF.

	1	2	3	4	5	
Incomplete	○	○	○	○	○	Complete

Please elaborate on the above answer: *

Your answer

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Part 2: Validating Requirements for a DBT App

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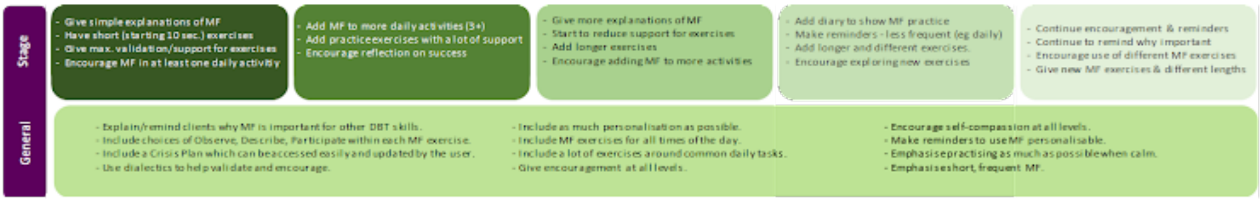
*Required

Stage Level Requirements

7. Looking now at the Requirements for each of the five Stages (top line below): how far do the Stage Requirements seem appropriate for clients acquiring DBT Mindfulness skills at each stage? Please refer to the PDF if this image is too small: https://bit.ly/2YRSR7Y *



- Give simple explanations of MF
- Have short (starting 10 sec.) exercises
- Give max. validation/support for exercises
- Encourage MF in at least one daily activity

- Add MF to more daily activities (3+)
- Add practice exercises with a lot of support
- Encourage reflection on success

- Give more explanations of MF
- Start to reduce support for exercises
- Add longer exercises
- Encourage adding MF to more activities

- Add diary to show MF practice
- Make reminders - less frequent (eg daily)
- Add longer and different exercises.
- Encourage exploring new exercises

- Continue encouragement & reminders
- Continue to remind why important
- Encourage use of different MF exercises
- Give new MF exercises & different lengths

- Explain/remind clients why MF is important for other DBT skills.
- Include choices of Observe, Describe, Participate within each MF exercise.
- Include a Crisis Plan which can be accessed easily and updated by the user.
- Use dialectics to help validate and encourage.

- Include as much personalisation as possible.
- Include MF exercises for all times of the day.
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- Give encouragement at all levels.

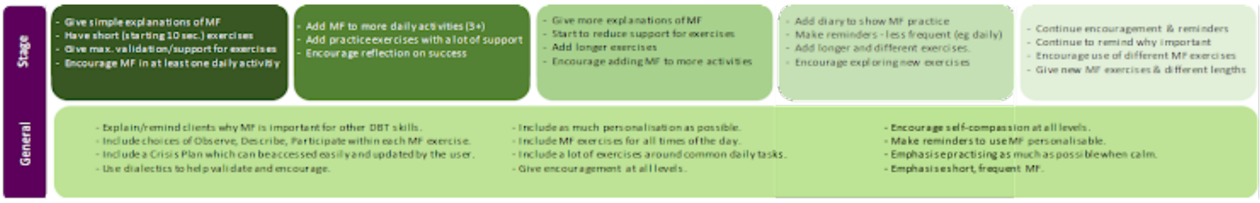
- Encourage self-compassion at all levels.
- Make reminders to use MF personalisable.
- Emphasise practising as much as possible when calm.
- Emphasise short, frequent MF.

	1	2	3	4	5	
Not at all appropriate	○	○	○	○	○	Very appropriate

Please elaborate on the above answer: *

Your answer

8. Again, in the Stage Requirements (top line below): how complete are the Stage Requirements for clients acquiring DBT Mindfulness skills at each stage? Do you think any important Stage level Requirements have been overlooked? *



Stage

- Give simple explanations of MF
- Have short (starting 10 sec.) exercises
- Give max. validation/support for exercises
- Encourage MF in at least one daily activity

- Add MF to more daily activities (3+)
- Add practice exercises with a lot of support
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- Give encouragement at all levels.

- Encourage self-compassion at all levels.
- Make reminders to use MF personalisable.
- Emphasise practising as much as possible when calm.
- Emphasise short, frequent MF.

	1	2	3	4	5	
Incomplete	○	○	○	○	○	Complete

Please elaborate on the above answer: *

Your answer

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Final section

9. Before doing this study, were you aware of User Experience Maps as a design method? *

○ Yes

○ No

10. Imagine you had to explain to a software developer the typical path of a client learning DBT Mindfulness skills and what an application would need to do to support them. How useful would you find the present User Experience Map for that explanation? (Link here: https://bit.ly/2YRSR7Y) *

	1	2	3	4	5	
Not useful at all	○	○	○	○	○	Very useful

Please elaborate on the above answer: *

Your answer

11. Are there any parts of the experience map which you thought seemed either particularly insightful or misrepresentative of a typical DBT client's learning experience? *

Your answer

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Part 2: Validating Requirements for a DBT App

Thank you for taking time to complete Part 2 of this study, your response has been recorded.

If you would like to do Part 3 now, please click this link:
https://forms.gle/EvxKgf14Fae8nRLQ6 (10-15 minutes)

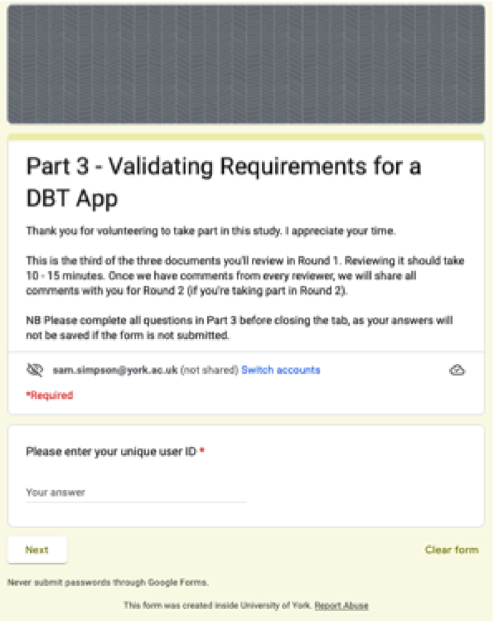
Otherwise the link can be found in my email.

Please contact me (sam.simpson@york.ac.uk) with any questions or issues about the study.

Appendix E

Study 4 Round 1 - Part 3 - Scenarios

Putting a Google Form into a suitable format for presentation in the Appendices was difficult. Figures G.1 and E.2 show screenshots of the first two pages. This is followed by the persona of India Birch and the scenario for India Birch linked to in Figure E.2. The Round 1 Part 3 - Scenarios questionnaire follows. The Part 3 questionnaire is also available online:



Part 3 - Validating Requirements for a DBT App

Thank you for volunteering to take part in this study. I appreciate your time.

This is the third of the three documents you'll review in Round 1. Reviewing it should take 10 - 15 minutes. Once we have comments from every reviewer, we will share all comments with you for Round 2 (if you're taking part in Round 2).

NB Please complete all questions in Part 3 before closing the tab, as your answers will not be saved if the form is not submitted.

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*Required

Please enter your unique user ID *

Your answer

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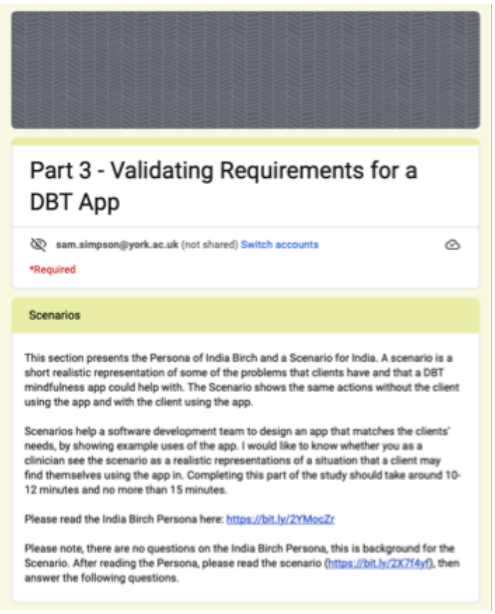
Figure E.1: Part 3 Page 1



Part 3 - Validating Requirements for a DBT App

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Scenarios

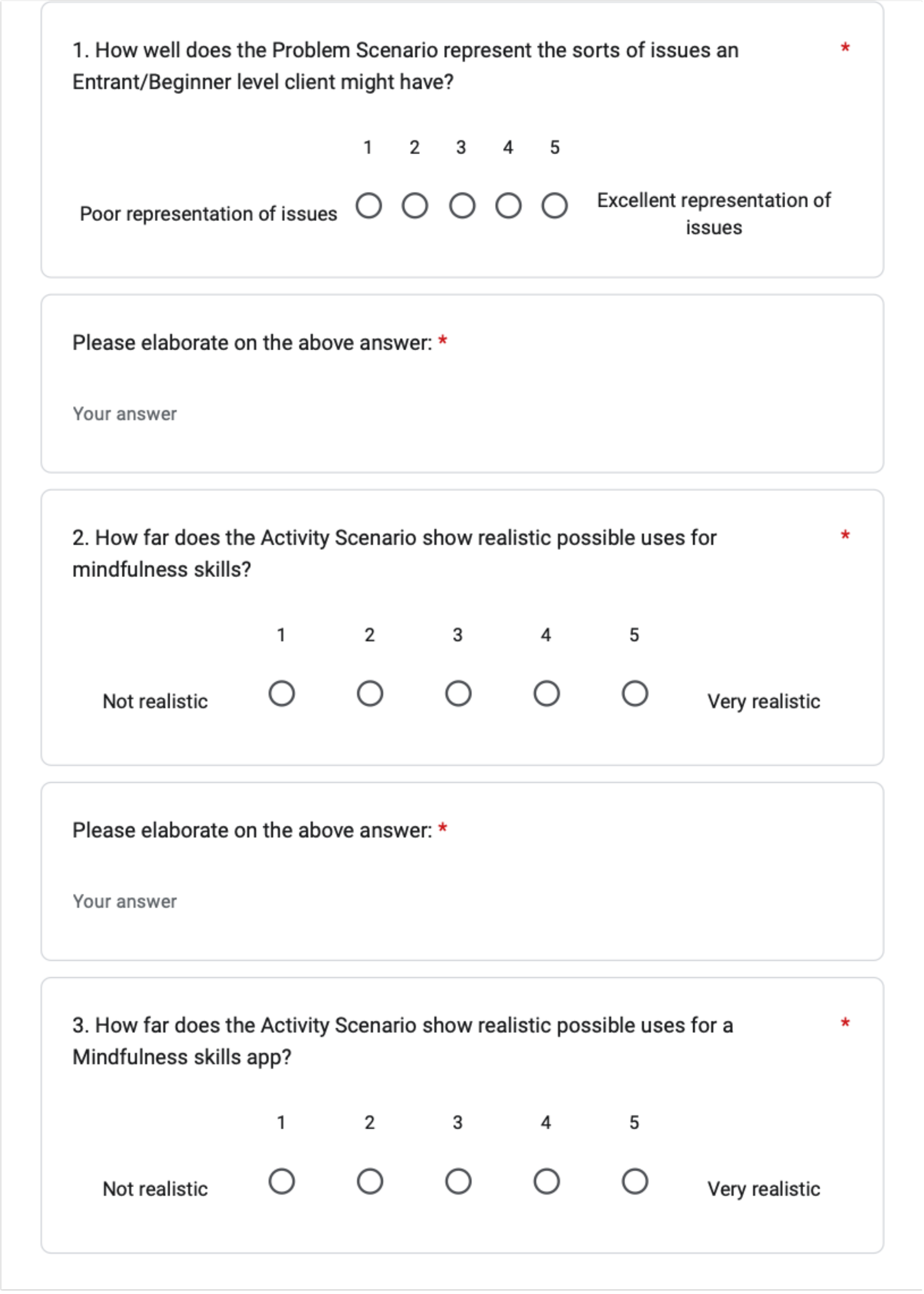
This section presents the Persona of India Birch and a Scenario for India. A scenario is a short realistic representation of some of the problems that clients have and that a DBT mindfulness app could help with. The Scenario shows the same actions without the client using the app and with the client using the app.

Scenarios help a software development team to design an app that matches the clients' needs, by showing example uses of the app. I would like to know whether you as a clinician see the scenario as a realistic representations of a situation that a client may find themselves using the app in. Completing this part of the study should take around 10-12 minutes and no more than 15 minutes.

Please read the India Birch Persona here: https://bit.ly/2YMocZr

Please note, there are no questions on the India Birch Persona, this is background for the Scenario. After reading the Persona, please read the scenario (https://bit.ly/2X7f4yf), then answer the following questions.

Figure E.2: Part 3 Page 2



1. How well does the Problem Scenario represent the sorts of issues an Entrant/Beginner level client might have? *

	1	2	3	4	5	
Poor representation of issues	○	○	○	○	○	Excellent representation of issues

Please elaborate on the above answer: *

Your answer

2. How far does the Activity Scenario show realistic possible uses for mindfulness skills? *

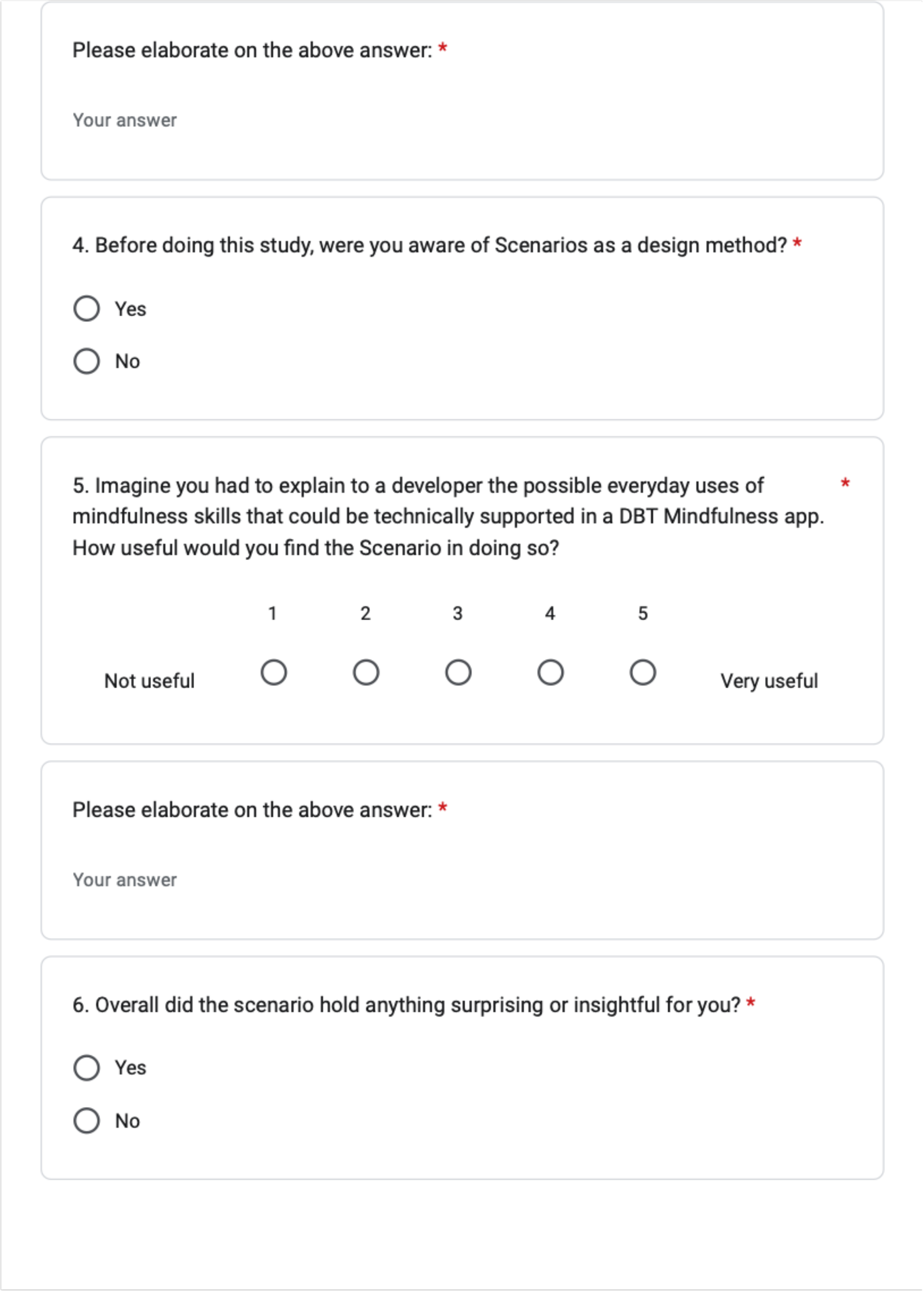
	1	2	3	4	5	
Not realistic	○	○	○	○	○	Very realistic

Please elaborate on the above answer: *

Your answer

3. How far does the Activity Scenario show realistic possible uses for a Mindfulness skills app? *

	1	2	3	4	5	
Not realistic	○	○	○	○	○	Very realistic



Please elaborate on the above answer: *

Your answer

4. Before doing this study, were you aware of Scenarios as a design method? *

○ Yes

○ No

5. Imagine you had to explain to a developer the possible everyday uses of mindfulness skills that could be technically supported in a DBT Mindfulness app. How useful would you find the Scenario in doing so? *

	1	2	3	4	5	
Not useful	○	○	○	○	○	Very useful

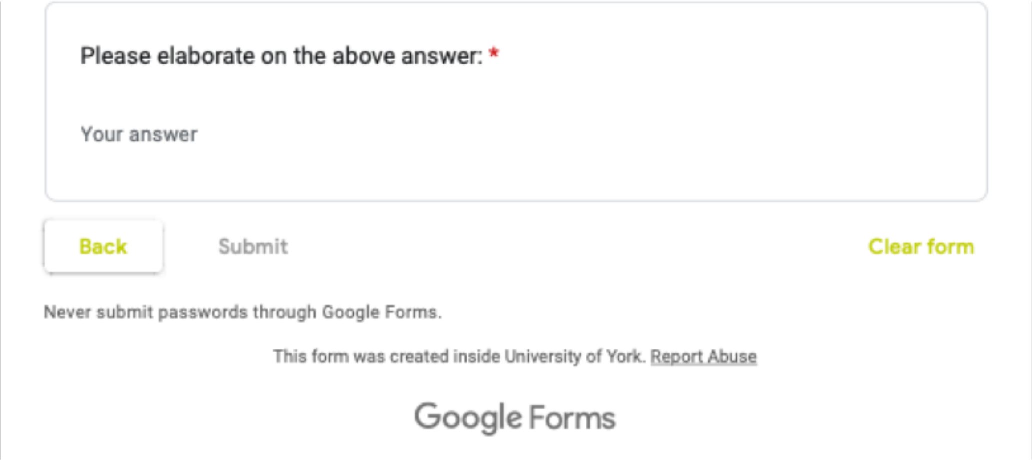
Please elaborate on the above answer: *

Your answer

6. Overall did the scenario hold anything surprising or insightful for you? *

○ Yes

○ No



Please elaborate on the above answer: *

Your answer

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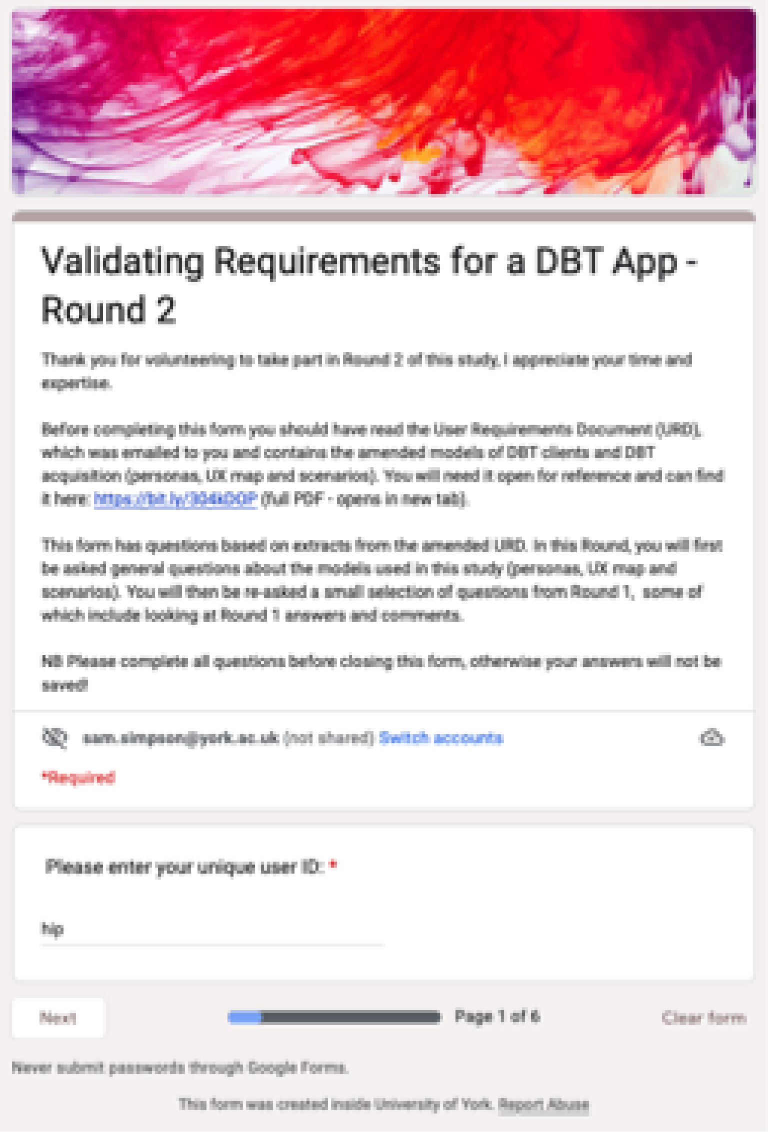
Appendix F

Study 4 – Round 2

Putting a Google Form into a suitable format for presentation in the Appendices was difficult. Figure F.1 shows a screenshot of the first page. Figures F.3 and **??** show page 2. The rest of the Round 2 questionnaire follows. The Round 2 questionnaire is also available online: https://bit.ly/Round2_Questionnaire



Validating Requirements for a DBT App - Round 2

Thank you for volunteering to take part in Round 2 of this study, I appreciate your time and expertise.

Before completing this form you should have read the User Requirements Document (URD), which was emailed to you and contains the amended models of DBT clients and DBT acquisition (personas, UX map and scenarios). You will need it open for reference and can find it here: https://bit.ly/304kDOP (full PDF - opens in new tab).

This form has questions based on extracts from the amended URD. In this Round, you will first be asked general questions about the models used in this study (personas, UX map and scenarios). You will then be re-asked a small selection of questions from Round 1, some of which include looking at Round 1 answers and comments.

NB Please complete all questions before closing this form, otherwise your answers will not be saved!

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Please enter your unique user ID: *

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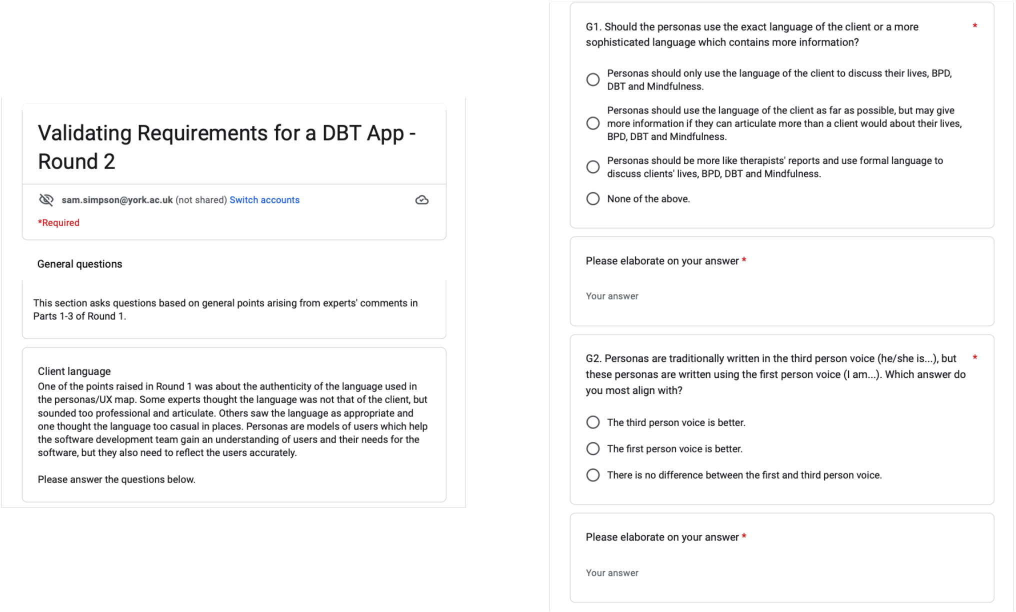
Figure F.1: Round 2 questionnaire - Page 1



Validating Requirements for a DBT App - Round 2

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General questions

This section asks questions based on general points arising from experts' comments in Parts 1-3 of Round 1.

Client language

One of the points raised in Round 1 was about the authenticity of the language used in the personas/UX map. Some experts thought the language was not that of the client, but sounded too professional and articulate. Others saw the language as appropriate and one thought the language too casual in places. Personas are models of users which help the software development team gain an understanding of users and their needs for the software, but they also need to reflect the users accurately.

Please answer the questions below.

G1. Should the personas use the exact language of the client or a more sophisticated language which contains more information? *

○ Personas should only use the language of the client to discuss their lives, BPD, DBT and Mindfulness.

○ Personas should use the language of the client as far as possible, but may give more information if they can articulate more than a client would about their lives, BPD, DBT and Mindfulness.

○ Personas should be more like therapists' reports and use formal language to discuss clients' lives, BPD, DBT and Mindfulness.

○ None of the above.

Please elaborate on your answer *

Your answer

G2. Personas are traditionally written in the third person voice (he/she is...), but these personas are written using the first person voice (I am...). Which answer do you most align with? *

○ The third person voice is better.

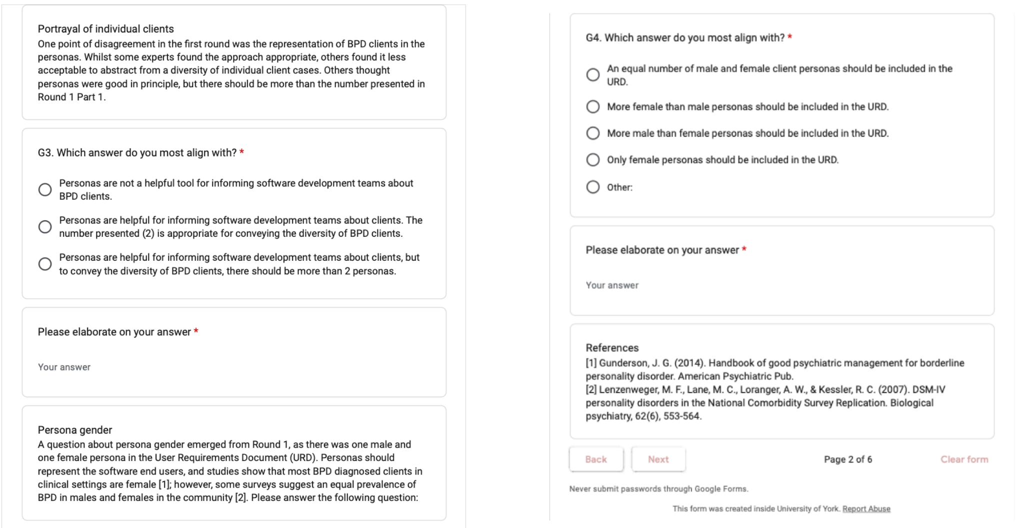
○ The first person voice is better.

○ There is no difference between the first and third person voice.

Please elaborate on your answer *

Your answer

Figure F.2: Round 2 Page 2-1 and 2-2



Portrayal of individual clients

One point of disagreement in the first round was the representation of BPD clients in the personas. Whilst some experts found the approach appropriate, others found it less acceptable to abstract from a diversity of individual client cases. Others thought personas were good in principle, but there should be more than the number presented in Round 1 Part 1.

G3. Which answer do you most align with? *

○ Personas are not a helpful tool for informing software development teams about BPD clients.

○ Personas are helpful for informing software development teams about clients. The number presented (2) is appropriate for conveying the diversity of BPD clients.

○ Personas are helpful for informing software development teams about clients, but to convey the diversity of BPD clients, there should be more than 2 personas.

Please elaborate on your answer *

Your answer

Persona gender

A question about persona gender emerged from Round 1, as there was one male and one female persona in the User Requirements Document (URD). Personas should represent the software end users, and studies show that most BPD diagnosed clients in clinical settings are female [1]; however, some surveys suggest an equal prevalence of BPD in males and females in the community [2]. Please answer the following question:

G4. Which answer do you most align with? *

○ An equal number of male and female client personas should be included in the URD.

○ More female than male personas should be included in the URD.

○ More male than female personas should be included in the URD.

○ Only female personas should be included in the URD.

○ Other:

Please elaborate on your answer *

Your answer

References

[1] Gunderson, J. G. (2014). Handbook of good psychiatric management for borderline personality disorder. American Psychiatric Pub.

[2] Lenzenweger, M. F., Lane, M. C., Loranger, A. W., & Kessler, R. C. (2007). DSM-IV personality disorders in the National Comorbidity Survey Replication. Biological psychiatry, 62(6), 553-564.

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Figure F.3: Round 2 Page 2-3 and 2-4

Validating Requirements for a DBT App - Round 2

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Personas

Please look at the amended Russell Jones and Catriona Desouza personas: https://bit.ly/304kDOP (full PDF, opens in new tab) and answer the questions below.

Russell Jones
Please look at the experts' scores and comments on Part 1 Question 3: http://bit.ly/Russell1_3 (PDF - opens in a new tab)

Once you have read the comments and the Russell Jones persona, which was amended based on the comments, please re-answer Part 1 Question 3:

P1.3 How far is Russell's attitude to Mindfulness representative of a typical early stage DBT client? *

	1	2	3	4	5	
Not at all like an early stage DBT client	○	○	○	○	○	Very much like an early stage DBT client

Please elaborate on your answer *

Your answer

Catriona Desouza
Please look at the experts' scores and comments on Part 1 Question 9:
http://bit.ly/Catriona1_9 (PDF - opens in a new tab)

Once you have read the comments and the Catriona Desouza persona, which was amended based on the comments, please re-answer Part 1 Question 9:

P1.9 How far is Catriona's attitude to Mindfulness representative of a typical longer-term user of DBT skills? *

	1	2	3	4	5	
Not at all like a longer-term DBT skills user	○	○	○	○	○	Very much like a longer-term DBT skills user

Please elaborate on your answer *

Your answer

Back Next Page 3 of 6 Clear form

Validating Requirements for a DBT App - Round 2

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User Experience Map

One of the biggest criticisms of the User Experience Map, and to some extent the personas and scenario, was the timeline. In the amended UX Map, the timeline has been removed and other changes have also been made, as detailed in the URD.

Please look at the amended UX Map (p.8): https://bit.ly/304kDOP (full PDF - opens in new tab) and re-answer the questions below.

P2.1 Overall, how far does the User Experience Map match your experience of clients' typical progress in acquiring DBT Mindfulness skills? *

	1	2	3	4	5	
Not at all	○	○	○	○	○	Very well

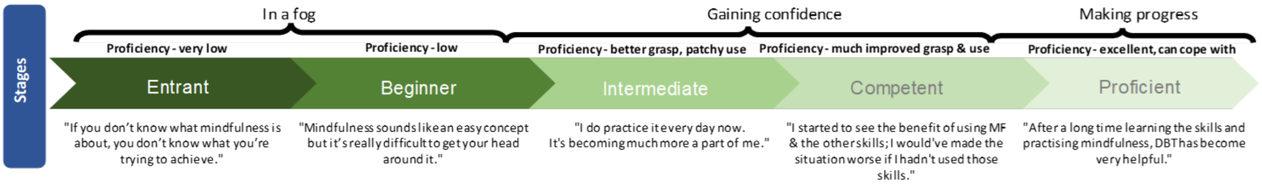
Please elaborate on your answer: *

Your answer

Stages level

Please look at the experts' scores and comments on Part 2 Question 2: https://bit.ly/323AcZ7 (PDF opens in a new tab)

Once you have read the comments, please look at the Stages level of the UX map below or in the URD: https://bit.ly/304kDOP (full PDF - opens in new tab), which was amended based on some of the comments. Please then re-answer Part 2 Question 2:



"If you don't know what mindfulness is about, you don't know what you're trying to achieve."

"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."

"I do practice it every day now. It's becoming much more a part of me."

"I started to see the benefit of using MF & the other skills; I would've made the situation worse if I hadn't used those skills."

"After a long time learning the skills and practising mindfulness, DBT has become very helpful."

P2.2 Looking specifically at the Stages level: How far do the progression stages (in green), the proficiency and high-level categories represent the clients' progress in acquiring DBT Mindfulness skills? *

	1	2	3	4	5	
Poor representation	○	○	○	○	○	Excellent representation

Please elaborate on your answer: *

Your answer

Back Next

Clear form

Validating Requirements for a DBT App - Round 2

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Scenarios

Please look at the experts' scores and comments on Part 3 Question 2: https://bit.ly/2LvCD0Q (PDF opens in a new tab)

Once you have read the comments and looked at the scenarios, which were amended based on some of the comments, please re-answer Part 3 Question 2:

P3.2 How far does the Activity Scenario show realistic possible uses for mindfulness skills? *

	1	2	3	4	5	
Not realistic possible uses	○	○	○	○	○	Very realistic possible uses

Please elaborate on your answer *

Your answer

P3.5 Imagine you had to explain to a developer the possible everyday uses of mindfulness skills that could be technically supported in a DBT Mindfulness app. How useful would you find the Scenario in doing so? *

	1	2	3	4	5	
Not useful	○	○	○	○	○	Very useful

Please elaborate on your answer *

Your answer

Back Next Page 5 of 6 Clear form

Validating Requirements for a DBT App - Round 2

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Conclusion

You have almost finished Round 2 of Validating Requirements for a DBT App: a Delphi study. One more question, which is optional:

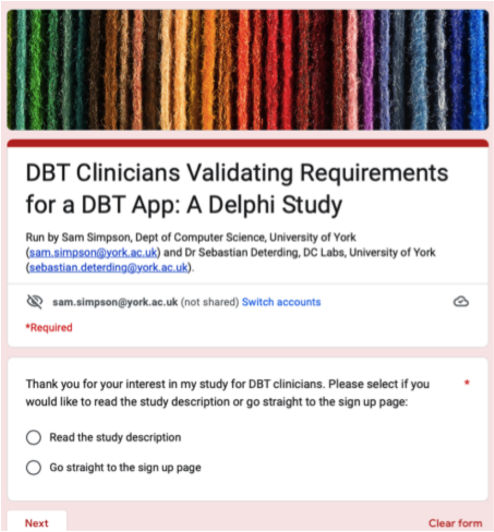
Do you have any other thoughts or comments on the amended URD?

Your answer

Back Submit Page 6 of 6 Clear form

Appendix G

Study 4 Clinicians sign up and screening


DBT Clinicians Validating Requirements for a DBT App: A Delphi Study

Run by Sam Simpson, Dept of Computer Science, University of York (sam.simpson@york.ac.uk) and Dr Sebastian Deterding, DC Labs, University of York (sebastian.deterding@york.ac.uk).

sam.simpson@york.ac.uk (not shared) Switch accounts

*Required

Thank you for your interest in my study for DBT clinicians. Please select if you would like to read the study description or go straight to the sign up page: *

○ Read the study description

○ Go straight to the sign up page

Figure G.1: Screening/sign up Page 1

Validating Requirements for a DBT App: A Delphi Study

Background

I'm a doctoral student in Computer Science at the University of York working with clients and clinicians at The Take Centre, an established York-based counselling, therapy and psychological assessment service. I'm supervised by Dr Sebastian Deterding. I'm working on digital interventions to support Dialectical Behaviour Therapy (DBT) for patients with Borderline Personality Disorder.

My research is focused on user-centred design, which models the potential users of a digital system, to make the design and development, and therefore the user experience of the technology, better and more effective. Healthcare professionals (HCPs) are currently very interested in digital interventions; however, there have been varying degrees of success with such interventions. The literature shows that many HCPs are unaware of the benefits that user-centred design can bring to a digital intervention. My research looks at bridging the gap between HCPs and software developers, using and extending existing user-centred design methods.

To do this I have developed a User Requirements Document (URD) for a digital intervention supporting DBT skills, focusing on the skill of Mindfulness. The URD models clients and the DBT process in a way that a software development team would find useful and helpful.

What we ask of you

To validate the User Requirements Document, making sure it is plausible and useful, I'm running a web-based Delphi study with around 15 DBT-trained clinicians. A Delphi study tries to produce a consensus about a document, based on the results of several rounds of questions from a panel of experts. The responses are anonymised and shared with the group after each round. This study has 2 rounds:

1. In Round 1, the Requirements Document will be split into 3 Parts, all online. There are questions about the text in each section. Part 1 takes around 20 minutes, Part 2 30-40 minutes and Part 3 10-15 minutes. You'll have a week for completion of this Round. If you are only able to commit to Round 1, you can still take part.
2. In Round 2, you'll read the anonymised comments made by your fellow experts in an online document, again in three Parts of approximately 20 minutes, and comment on those, guided by questions. Again a week is allowed for completion of this Round.

This study has ethical approval from the University of York Physical Sciences Ethics Committee. If you have any ethical queries or complaints about this study, please contact Dr Daniel Kudenko (daniel.kudenko@york.ac.uk), Physical Sciences Ethics Committee.

Inclusion criteria

I'm looking for clinicians who have DBT skills training and are experienced in helping clients with Borderline Personality Disorder.

Figure G.2: Screening/sign up Page 2

DBT Clinicians Validating Requirements for a DBT App: A Delphi Study

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Sign up page

This is the sign up page for a Delphi study** to validate a User Requirements Document for a Dialectical Behaviour Therapy (DBT) app. This study has ethical approval from the University of York Physical Sciences Ethics Committee***.

Thank you for your interest in my study, if you would like to take part please enter your details below:

Name: *

Your answer

Email address: *

Your answer

Please describe briefly your DBT training and your experience using DBT with clients: *

Your answer

Please indicate which parts of the Study you are able to take part in:

○ Round 1 only

○ Round 1 and Round 2

Footnotes
**For more information on Delphi studies - https://thepsychologist.bps.org.uk/volume-22/edition-7/delphi-method

*** If you have any ethical queries or complaints please contact Dr Daniel Kudenko (daniel.kudenko@york.ac.uk), Physical Sciences Ethics Committee, Computer Science Department, University of York.

Thank you
I'll be in touch very soon - Sam Simpson (sam.simpson@york.ac.uk)

Back Submit Clear form

Appendix H

Adlin and Pruitt persona creation process

A&P Process Step 1 – Create assumption personas

In developing the assumption personas, A&P recommend the following steps:

1. Gather the persona development team.
2. Clarify the user experience (UX) goals.
3. Identify the language which is used to describe different categories of users. Make sure the terms are consistent in terms of categories, for example, reflecting roles/goals/characteristics etc.
4. Create a number of short, possible system end-users and a short situation/problem to go with each of them.
5. Identify which of the UX categories in number 2 the end-users fit into using affinity diagramming.[1] At this stage new categories may arise. If full personas are to be created, these categories can then be used in Step 2 when organising the research data.
6. Otherwise, give each assumption persona some goals, wants and needs.

A&P Process Step 2 – Process the data

The second stage in the process assumes the collection of research data on the customers/end-users. This data is then processed for relevant information. The following steps are suggested by A&P:

1. Gather the persona development team.
2. Identify individual pieces of data (termed factoids by A&P) in the data source.
3. Write the factoids on post-it notes.
4. Place user category labels (from Step 1) in different places to allow the factoids to be sorted by user category.
5. Process the factoids using affinity diagramming, sorted into the user categories found in Step 1.
6. In each category sort the factoids into "clusters" which identify groups of facts and subcategories which identify groups of people.

---

[1] Affinity diagramming is a way of recording ideas onto cards or post-it notes, then sorting ideas that seem to be related into groups until all cardsnotes have been used.

Subcategories should be users that are important to the design and unique compared to the other subcategories. It is important to create as many categories and sub-categories as it takes to capture the data. However, not all of them will necessarily become personas.

A&P Process Step 3 - Establish and verify categories of users. Create skeleton personas

Having identified the most important categories and subcategories, in this step skeleton personas are created. These are short personas using bullet lists of attributes and information found in the data.

1. Create one persona for each sub-category, using the clusters as sub-headings in each skeleton.
2. The skeletons will be compared and prioritised in Step 4, so they need to contain similar information to aid this.
3. The key characteristics which form the essence of the subcategory should be used.
4. The skeleton personas are not given names or other personal details at this stage.
5. Only create skeletons for interesting/important users. However, a large number of skeletons can be reduced in Step 4.

A&P Process Step 4 - Evaluate and prioritise the skeleton personas

In this step, consensus is reached on which skeleton personas will be prioritised, in order to reduce the set of skeletons to the ones which are critical to the immediate design goals.

1. Gather stakeholders to evaluate the skeleton personas.
2. Before starting, remind the team of the goal of the meeting and the impact their decisions will have on the project.
3. Some issues which may be considered when ranking the personae:
    - Importance
    - Frequency of use
    - Size of market
    - Potential revenue
    - Strategic importance
    - Is there a key persons who must be made “ridiculously” happy
    - Other relevant attributes
4. Score each skeleton from a total of 100 points with no two having the same score.

A&P Process Step 5 - Develop the selected skeleton personas into full personas

In this step, the skeleton personas that were picked in Step 4 are augmented to become full personas. Data about the individuals and the context they are sited within is added. Storytelling elements and a photograph are also added at this point to make them more lifelike.

A persona document is created which contains all the information about the persona (and may also contain scenarios). These can be many pages long and contain footnotes linking the data in the document to factoids and other data sources, and comments, including where characteristics are fictitious.

The process is as follows:

1. Start with the skeleton persona
2. Add in data based on three things:
   - Labels for clusters that came out of the assimilation exercise.
   - Topics relevant to the domain
   - Common headings to create a realistic, well-rounded persona. These include: demographics like name, gender, age, a quote which highlights an important persona characteristic, a photograph; roles and tasks such as job or responsibilities; goals; context/environment; and, skills and knowledge.
3. Add in the factoids.

A&P Process Step 6 - Validation

A&P recommend validating the personas using one or more of the following methods:

- Review against the original data sources.
- Have experts who are close to the personas review them.
- Have representative users of each persona review their persona.
- Conduct reality-check site visits.
- Conduct large-sample surveys or interviews.

Appendix I

URD

User Requirements Document

For an adjunctive digital intervention to support acquisition and use of the DBT Mindfulness skills module for people with BPD

Abbreviations

BPD	Borderline Personality Disorder
DMHI	Digital Mental Health Intervention
DBT	Dialectical Behaviour Therapy
UCD	User-centred design
URD	User Requirements Document
UX	User experience

1. Introduction

Purpose of the URD

This document describes the user requirements for a DMHI to deliver DBT skills, initially focused on Mindfulness skills. The URD reflects information derived from interviews with stakeholders, including end users. It shows the derived requirements for the end users, with respect to the design and development of a DMHI. In a later stage it can be used as a reference for verification.

The DMHI will sit alongside therapy for clients undertaking DBT, but it is anticipated that it will be mainly used outside the programme; it can also be used by those who have completed the DBT programme and still want to use the DBT skills.

Contents overview

The user requirements were established using data from observations of inpatient and outpatient DBT skills groups and Consultation meetings, and interviews with DBT clients of varying times in DBT (from 3 months to 5+ years), as well as DBT clinicians as stakeholders.

The document contains four personas, which are archetypes of users; a User Experience (UX) Map of the DBT skills acquisition journey, a 24-hour UX map of an early-stage persona; and, two scenarios, which are goal-driven interactions between early stage personas and the proposed system.

The research showed that acquisition of the skills was difficult, especially at the start of therapy. The model of DBT skills acquisition found in this document is based on an underlying assumption of acquisition being divided into five stages SORT THIS:

1. Entrant
2. Beginner
3. Gaining confidence - Intermediate / Competent
4. Proficient

At this stage the clinical requirements have not been incorporated.

Contents verifiication

The stages detailed above, which were used as a basis for the requirements, and the tools used to model the users and their requirements were verified using a nationwide panel of DBT clinicians, working privately and in the public sector. The verification methodology was a two-round Delphi-type study, with changes made after Round 1 and re-presented to achieve AGREEMENT in Round 2.

Scope of the software

The software to be made consists of a DMHI to help deliver the DBT skills modules. The DMHI will be developed incrementally, starting with Mindfulness then adding the three other skills, as the other skills are designed to be used with Mindfulness as the foundation. This document describes the Mindfulness skills requirements only.

The direct stakeholders, who will be using the system, are the DBT clients. The indirect stakeholders are the clinicians, partners, parents and significant others of the clients. They have an interest in the system, and in the system being used, but do not use the system themselves. For clients in the early stages of acquiring DBT, the DMHI will sit alongside formal DBT. For clients who have completed a course of DBT, who wish to continue using Mindfulness skills and language familiar from DBT, the DMHI will be familiar, using DBT terminology and DBT mindfulness-type exercises.

The DMHI should also incorporate a Crisis Plan, as this was requested by a number of clients in the interviews. A Crisis Plan is not part of DBT Mindfulness, but taught as part of Distress Tolerance skills; however, including it at this stage may encourage use of the DMHI in clients at the start of DBT, as it gives them additional support structures, as well as being a very important resource for clients at all stages of DBT.

2. Personas

Personas are data-driven models of users which allow the development team to talk about the design in terms of the users' expectations, to have empathy for the users and to see the design from the user's point of view, and a well-established UCD tool. The team can talk about design features in terms of what a persona wants/needs, rather than a nebulous group of users.

Personas are archetypes which represent end-users, therefore they use language which the design team can understand to illustrate the important points, rather than using completely accurate client language. This means personas may be more articulate and give more information than a typical client might, especially at the beginning of treatment.

Stages

The research showed learning DBT as having 5 stages, which are reflected in the user experience journey. For the personas, the middle two stages are covered by one persona. The scenarios reflect India's use of the DMHI as a possible starting point for the design. The personas and stages are:

1. India Birch – Entrant
2. Russell Jones – Beginner
3. Catriona Desouza – Intermediate / Competent
4. Gayle Foster – Proficient

Persona sections

The personas presented in this URD consist of different sections:

Quotation - This is a real quote taken from a person at this stage, from the client interviews.

Photograph - Helps to bring them to life for the design team.

Demographics - Quickly establish who the persona is. Unlike personas usually given to software developers, these personas have details of their diagnosis, therapy undertaken and disorder presentations. Whilst very common in people with a BPD diagnosis, co-morbidities were not included because they would make the personas too complex and might confuse the developers.

Goals, Fears & Aspirations - Establish the persona quickly for the design team.

Background - More detailed in the DBT client personas than in a standard persona, to help a development team with no experience of BPD or DBT to understand the persona and how they might have got to this point.

Attitude to DBT - Allows the software development team to see the acquisition of DBT through the eyes of the end-users, rather than how they, or an expert like a therapist, might imagine it feels.

Attitude to mindfulness - Allows the software development team to focus in on the Mindfulness skill through the eyes of an end-user, rather than how they, or an expert like a therapist, might imagine it feels.

Overview of personas

In this section we can see the four personas developed from the client interview data, clinician formal and informal discussions and interviews, and incorporating observations of clients and general reading about BPD and DBT. Two of the personas, Russell and Catriona went through the validation process with a nationwide panel of DBT clinicians.

Living with a diagnosis of BPD means the clients face a lot of challenges, as was seen in the data. The personas discuss abuse, self-harming and thoughts of suicide. The personas try to capture how the clients saw themselves. This includes, as the interviews revealed, they did not always have a stable self-image and were not always consistent in their evaluation of learning DBT, especially in the early stages. Therefore, the personas speak in the first person. They are some of the most challenging personas at each stage, as I hypothesised following Cooper et al. (2014) that in designing for DBT end-users who are facing the most challenges, those users with less challenging etiologies, who take less time to acquire Mindfulness, will be covered. The Entrant and Beginner personas need the most support. The DMHI could start by designing for these early stages and then expand and build on these for the other personas. It is envisaged that the rest of the DMHI would build up in stages from the Entrant stage. However, this would be decided by the design team.

India Birch

India (see Figure I.1) discusses self-harming, which is complicated and has a number of functions. As well as helping clients to manage their emotional dysfunction, it can also have an occupational aspect, which can become more hidden over time. The care and nurturing aspect of having wounds tended to and healed may be the only compassion and kindness that clients experience, so can be very powerful. However, like India, clients also feel a great shame around this, as they do about many of their self-harming behaviours, and hide them from friends and other acquaintances. Self-harming can take many forms, India uses some of the more common ones. She feels a lot of shame about her self-harming behaviours, but also realises that it makes her mother more caring towards her and sometimes shows her mother what she has done, in order to get sympathy and care.

Due to her shyness, reticence and lack of self-confidence in using DBT, India cannot yet imagine herself using the skills to get the results she wants out of a situation where she needs to communicate her needs effectively. India has intense shame about her illness, self-harm and the negative things that have happened in her life. Consequently she hides her illness even from close friends. She also gets frustrated with herself when she does not learn or get better as quickly as she wants to. She blames herself for not being able to learn the Mindfulness skills. India's attitude to her illness and behaviour shows a major characteristic typical of those with BPD: self-blaming when unable to understand or use DBT in the beginner stages. She has great faith in DBT, as shown in the interview data, and reports its helpfulness, but cannot yet produce mindfulness, showing a tension in her narrative about the treatment, as well as reflecting the difficulty of the therapy.

India cannot understand why mindfulness is being taught. She has not yet understood what is required in mindfulness and she is not able to try being mindful when she is feeling intense emotions. India reflects clients who like to distract themselves by keeping busy. The mindfulness *Participate* skill was seen as the easiest for her, because she was focused on a task. However, she may have been using the *distract* skill rather than participating mindfully.

India Jones

"If you don't know what mindfulness is about, you don't know what you're trying to achieve"

- 22 years old
- Single. No children
- Studying foundation course at FE college.
- History of self-harm, cutting and overdosing
- Diagnosed with Borderline personality disorder (BPD) 18 months ago
- Five months DBT

Goals:

1. To cut down self-harming to less than 3 times a week.
2. To stand up to my mum better.
3. To get good marks in my foundation course, so I can go and study Psychology.

Fears:

1. I'll never get better.
2. I'm too stupid to do DBT.
3. I won't be able to cope away from my parents at university.

Aspirations:

1. To have a life without any self-harm urges.
2. To be able to live with BPD

Goals & tasks relevant to learning DBT/getting better:

1. Get to grips with mindfulness.
2. Understand and practise IE.
3. Worry less about other peoples' judgments.
4. Understand better which skills are needed in which situation.

Background

I'm doing a foundation course and I work part-time in a shop. I attend DBT skills and therapy sessions weekly. I was lucky to get NHS funding after being in hospital, after I took another overdose of my prescription meds. When I was 14, my dad's friend started abusing me. The first time, my parents were downstairs. It lasted about a year until I told my parents. I was always a very emotional child, who was upset easily, I still am, but I was completely traumatised by what happened. I live at home with my parents, but my mum gets really annoyed that I'm still upset about the abuse. I was diagnosed with Borderline Personality Disorder recently, but I've seen quite a few therapists over the last few years.

I started self-harming when I was a teenager. It started when I fell off my bike after a row with my mum. The pain helped. I pull out my hair and cut myself. Then I started taking overdoses as well. The physical pain helps when I feel really bad. I usually hide my arms, but sometimes I show my mum because it makes her want to take care of me for a bit. She's scared I'll accidentally kill myself when self-harming.

I'm quite shy and don't like people noticing me really. I find it hard to stand up for myself. My mum is a bit controlling and domineering. She wants me to leave college & get a full-time job. I want to go to university and study Psychology, but my parents don't want me to live away from home, as they worry about what might happen. I have friends at college, but we're not close and none of them know about the BPD. I get so ashamed of self-harming, all my faults, my illness and making my parents so upset. It makes me frustrated and sad. Sometimes I feel both me and my parents would be better off if I were dead.

DBT

I've been going to DBT for 5 months. It's great, really helpful. I really appreciate the time the therapists take, but I'm not very good at it. I almost never do the homework and I feel really guilty about that, but I forget. To be honest, often I don't understand the skills, and there's so many skills, it's overwhelming. When I feel like cutting myself or other self-defeating behaviours as my therapist calls them, I'm just too flooded with feelings to work out what to do or use the skills. Maybe one day I will, but not at the moment. I know I need to be better in order to go to university, but on bad days I feel so depressed and exhausted. I just want to make it stop. I hope DBT will help and stop the suicidal thoughts, although I'm not sure what giving up suicide as an option would mean.

Mindfulness

I don't get the point of mindfulness. It just seems really silly and a bit rubbish and pointless. I just don't understand what they are trying to teach us or why we have to do it every time. We sit and look at a leaf and I just think, this is weird, what's the point of doing this? I don't look forward to the group mindfulness exercise because it makes me anxious, I think they're going to judge me and judge what I say, so I think about what I'm going to say rather than doing the mindfulness. I think it's me, I'm not very good at learning new things. Also, I can't practise on my own because I'm very busy. I don't have time to sit and dwell for 2 or 3 minutes. I like the participate ones, it's easier when you're doing something. The worst is observe, I especially hate focusing on my breath, it's so boring. What I really want is someone to help me, someone who knows what they're doing, not the group, like a therapist.

Other DBT skills

ER was really challenging. I find it hard to work out what emotion I'm feeling. I can't really understand when they talk about different emotions, they're really hard to separate. Often I'd rather think than feel, because I'm really scared of my emotions. My emotions are so intense, when they tried to teach us the six core emotions, I was thinking that what I feel is not one of those, it's much more intense than that. So, I don't use these skills very often; I don't even try.

I wish I could use IE when speaking to my mum, the problem is, she isn't DBT-trained and I find challenging her hard, she doesn't respond like in the practices we do in skills group, then I get frustrated and upset. I don't have confidence that they'll work, so I don't use these skills.

I use DT skills, but I don't get Self-soothe. If I feel like self-harming, I don't want to have a bath or to light a candle. I also don't get the half-smile stuff. Why would I do that? I distract myself most of the time, it's the main skill I use, but it doesn't always work.

Figure I.1: India Birch - Entrant stage persona

Russell Jones

The Russell personas can be seen in Figure I.2. The interview data showed a lot of inconsistency in clients' attitude to DBT in the early days and this is reflected in Russell's wanting to do DBT, his hope for DBT, but also his lack of faith in his own abilities. Russell is more articulate than an early stage client might be; however, this was done in order to help the design team to understand the issues at this stage.

Like India, he is fairly new to DBT and is really struggling to understand the therapy. Like almost all clients, Russell has struggled with a mental illness for a long time, and it has affected all aspects of his life, including work. Details about Russell's mood swings were added, as described in the interviews. A history of sexual abuse and starting to self-harm at a young age are recurring themes in DBT clients with BPD. Russell has a lot of anger issues. The anger in BPD often appears in response to perceived rejection . Male clients, whilst not unknown, are less common than female. However, anger issues, whilst a possible symptom of BPD, are not typical, with anger more likely to be internalised as self-criticism or self-harm than reflected outwards, especially in female clients. Self-harming can often start with an accidental injury when the client is upset. Russell's father not being understanding about his son's ongoing trauma is based on reported incidents from the Tuke.

In terms of Russell's relationship, many clients want to be able to have better relationships with people, as evidenced by the interviews. In relationships, people with BPD may cause fights because they have feelings for partners that rapidly cycle between adoration and extreme dislike. They instigate arguments but when the partner tries to leave they frantically try to avoid being abandoned.

Russell also exhibits risk-taking behaviours, in the form of driving at speed. He also self-harms through head-banging and self-hitting, all acts that were discussed during the DBT placement. As with the other personas, DBT is often about getting people to reduce the number of times they self-harm or engage in self-defeating behaviours, rather than getting them to stop altogether, especially in the early stages of DBT.

Catriona Desouza

The interview data showed that even clients who had been learning the DBT skills for a year or longer, could still struggle to consistently use them, which is reflected in Catriona's attitude to DBT. Catriona may be more articulate than a client at this stage might be; however, the language was persevered in order to help the design team to understand the issues. People with BPD often have very dramatic lives and have often had a number of terrible things happen to them, which can seem unrealistic or excessive when modelled using personas. The personas were check with a senior clinician to ensure they are realistic and grounded in realistic client-type experiences. Catriona was also validated with a panel of clinicians over 2 rounds.

Many clients have experienced numerous hospitalisations, often for extended periods. Parenting-of-parents, included in Catriona to show an invalidating childhood environment, is often found in those with a diagnosis of BPD. In addition, many of the female clients had been brought up to be 'good girls', becoming distressed when they fail to meet unreachable perfectionist standards.

Russell Jones

"Mindfulness sounds like an easy concept, but it's really difficult to get your head around it."

- 21 years old
- In a relationship - no children
- 5 GCSEs
- Unemployed mechanic
- Recently diagnosed with Borderline Personality Disorder (BPD)
- Four months DBT
- Depression, anger, emotional outbursts & suicidality
- Risk-taking behaviours, self-harm

Goals

1. Handle my emotions better
2. Have better relationships with people
3. Get a job as a mechanic

Fears

1. My girlfriend will leave me
2. I worry that DBT won't work for me
3. My emotions are over-whelming, I'm scared of losing control

Aspirations:

1. To have a better life and be able to live with BPD
2. To have my own motorbike business

Background

I was doing a mechanic apprenticeship. I'm a good mechanic, but they let me go because of poor attendance. I've had lots of time off because of being depressed, but I didn't want to tell them. I'm also moody & get upset and angry over small things. I feel irritable and agitated a lot of the time. I was diagnosed with BPD about nine months ago. I was rowing a lot with my girlfriend, Maddie and she said she would break up with me if I didn't get help. My main reason for doing DBT is to have a good life with her.

When I was 10, my dad's friend started taking me fishing; it was an excuse for him to abuse me. It lasted about a year until I told my parents. I was an emotional child, who got upset easily, and I was completely traumatised by what happened. My dad doesn't understand why I still get upset about the abuse though.

I started self-harming when I was a teenager. I fell off my bike after a row with my dad & the pain helped. I'd hit things and burn myself. Physical pain helps when I feel really bad. When I'm angry, I drive my motorbike too fast and put myself in danger. I don't care if I crash. I'm always falling out with my mates. I seem to get close to a mate and then they do something to annoy me & we fall out big time and stop talking. When I'm angry I bang my head on walls and punch myself.

I know I don't always treat Maddie well. I go between being very loving and pushing her away. I get really jealous. We've rowed a few times because I'm scared she'll leave me. I wanted to know where she'd been and grabbed her phone to see who'd called her. I'd never hurt her, but I get so angry, I'm scared I might lose control. She tried to break up with me after our last row. I punched a hole in the door. I told her I'd crash the bike and kill myself if she left me. Sometimes I think we'd both be better off if I were dead.

Personal assessment of DBT

I've been going to DBT for four months. It's really helpful, but I still feel in a fog with it a lot of the time. I appreciate the time the therapists take, but I'm not very good at it. I don't always do the homework and I feel really guilty about that, but I forget. To be honest, often I don't understand the skills, and there's so many of them, it's overwhelming. When I feel like hurting myself, I get overcome with emotion & can't work out what else to do or use the skills. Maybe one day I will, but not at the moment. I want to get better, but on bad days I feel so angry & depressed; I just want to make it stop. I hope DBT will help with the suicidal thoughts.

Personal assessment of Mindfulness

I can't understand what mindfulness is supposed to be about. I never really know what I'm supposed to be doing in the mindfulness practice at the start of each class. We sit and look at a leaf or play a game and I just think, this is a waste of time, what's the point of doing this? I don't really understand what they're trying to teach us or why we have to do it every time, but they keep going on about it, so I guess it's important. I think it's me, I'm not good at learning new things.

I mean, when they explain it, it sounds like an easy concept, but when I try it, it's really difficult to actually do it. Sometimes, I think I'm starting to understand it; but if I'm upset, I just can't do it, especially when I'm having difficult thoughts or problems.

Figure I.2: Russell Jones Persona - Beginner stage persona

Catriona Desousa

"I see the benefit of using Mindfulness & the other skills; I would have made the situation worse if I hadn't used my skills."

- 38 years old
- Divorced, no children
- Fine Art degree
- Ceramic artist
- Diagnosed with Borderline Personality Disorder (BPD) five years ago
- Three years DBT
- Self-harm, suicidality – much reduced
- Alcohol use disorder

Goals:

1. Use DBT skills to work through past trauma
2. Increase types of mindfulness practice
3. Reduce amount of prompting to remember skills

Fears:

1. That me and my work are not `good enough’
2. I’d like to meet a partner but worry a little about being in a relationship

Aspirations:

1. Work through my trauma
2. Keep reducing self-defeating behaviours
3. Help people with BPD through art therapy one day

Background

I’m a ceramic artist. I have a small studio with a kiln in the garden I sell things mainly online. I find work therapeutic, but I also get frustrated if it isn't perfect. I’ve destroyed pieces I’ve spent days on over minor imperfections. About five years ago, the business wasn’t doing so well and then my mother died. I ended up in hospital a number of times due to attempted suicide. I was eventually diagnosed with BPD, but it took a while to start DBT. I’ve attended DBT for over three years. Now I’ve learnt the skills and I’m more stable, I’m processing some of the things that happened in my past.

My home life when I was young was pretty bad. My dad used to drink and had an awful temper. He was physically and verbally abusive to me and my mum. I was taught to be good, quiet, polite and helpful, but nothing was ever good enough. I always felt responsible for my mother; she had a lot of mental health problems. After my dad left when I was 13, I looked after her from then really.

I’ve self-harmed since my teens. I started using self-harm as an escape from the painful situation and self-loathing. I didn’t have friends because I daren’t bring them home, so it was an escape. I used to drink a lot, that started with mum’s sherry, but I’ve stopped completely now. Since starting DBT, I’ve managed to really cut down on the amount of self-harming I do and I haven’t attempted suicide for about 18 months. I go to A&E now if I’m feeling really bad and can’t use the skills, but that’s quite rare.

Personal assessment of DBT

DBT was difficult to grasp at first, especially mindfulness. It’s taken me a long time to completely embed the DBT skills, over two years, but now I have, it helps a lot. It took me a long while to get the confidence to actually try doing some of the skills, but it does work. I now see the benefits, which inspires me to carry on doing it.

DBT has really helped me to understand my emotions better. I still need prompting sometimes though, when I forget to use mindfulness and the other skills. I have posters in the studio and the kitchen to remind me and the skills have gradually become inbuilt in me, with a lot of practice. Sometimes I’m a bit sad that it doesn’t completely stop the bad times or all the urges, but my life is so much better now than before DBT. I still have bad times, I don’t think I’ll ever stop having issues, but after a crisis, at least I now know how to get better by using the DBT skills, and that I’ve used the skills to do it before, so I’ll be able to do it again.

Personal assessment of Mindfulness

It took me a long time to understand what was required from mindfulness, around a year. It’s still hard to practice sometimes, depending on my mood. I still need reminding to use mindfulness now and again, because sometimes I forget for a couple of days, then the old ways of thinking come back.

At first, it was hard to use the skills in a heightened emotional mood, but I know mindfulness connects all the other skills. It makes me more in the moment and aware, so I get some objectivity and I can recognise my emotional state; then I can pick the skill I need. Being mindful also reminds me that I still need to use my skills. It definitely helps to lessen the self-criticism. I struggle with anxiety and it helps with that too, but mainly, it helps me to use the other skills.

In terms of the mindfulness *What* skills, I prefer participating, O*bserve* is my least favourite. I like to be doing something whilst I’m practising, even if it’s just making a cup of tea. I have a mindfulness app, but I don’t think some of the exercises are right for me. For example, I sometimes do breathing mindfulness, but I don’t like the breath ones very much.

Figure I.3: Catriona Desouza - Competent stage persona

Mental health often gets worse at times when life is very difficult. In those with BPD, self-harming at such times is used as a way of replacing mental pain with physical pain. Regarding self-harm, as with India and Russell, DBT is often about getting people to gradually reduce the number of times they self-harm or engage in other therapy-interfering behaviours, rather than getting them to stop altogether, which may be too difficult. This also shows one of the dialectics which is inherent within DBT: that the therapy-interfering and self-harming behaviours are understandable given the client's background, but that clients are nevertheless encouraged to reduce and eventually stop the behaviours.

Difficulty in personal relationships, especially provoking partners into leaving through passive-aggressive behaviour, then begging them not to go, is seen as typical behaviour of a person with BPD. Likewise, Catriona's relationship with her partner gives a better idea of the trust issues and other effects that emotional issues can have in personal relationships.

Catriona's attitude and engagement with DBT, the slow learning and trying out of skills is based on the interview data. Several clients said it took a long time to understand and start using the skills properly. Catriona has been in DBT for several years, which is not atypical. Although she has been undertaking DBT for 2.5 years, she struggled to understand Mindfulness for some time. This reflects the interview data, with clients saying they found understanding and practising Mindfulness difficult for over a year.

Gayle

Gayle Foster can be seen in Figure I.4. Gayle has been undertaking DBT for 4 years. In the Gayle persona, the use of DBT and mindfulness skills have given a person who perceived her life as painful and not worth living, a chance to develop the necessary skills to solve the problems that cause them deep distress. By gaining experience in the skills, suicide is no longer one of the options considered by Gayle in deciding how to deal with a problem.

However, a DMHI can still help clients like Gayle, as they still face challenges from time to time, need to be reminded to practise sometimes, or may want to try different Mindfulness exercises or skills that they dismissed as too difficult or unpleasant when they were in the early stages of DBT.

Gayle is a client who represses their emotions rather than being overly emotional. Gayle also reflects that many people with a diagnosis of BPD only attend DBT after a breakdown in their mental health, as described by a number of the study participants.

Gayle still struggles with self-compassion, which is extremely difficult for most clients, as they have often experienced an invalidating environment in their childhood.

Gayle Foster

“Even after 4 years, I try to practise DBT every day.”

- 31 years old
- Single - divorced, no children
- MSc maths / PGCE
- FE college maths teacher
- Diagnosed with BPD 4 years ago
- Multiple overdoses, promiscuity
- 2.5 years DBT
- 1.5 years Trauma processing

Goals

1. Reduce my urges completely
2. Have less crises
3. Retrain for a new career, running my own gardening business

Fears

1. I’ll never be completely well
2. I’ll feel so bad I’ll kill myself either accidently or intentionally.
3. I’ll never meet someone who gets me and can love the real me

Aspirations

1. Continue to practise the DBT skills as much as possible
2. To have a life without self-harm urges.
3. To not fear my emotions.
4. To have a healthy relationship with a new partner and a child.
5. Practice mindfulness and be more self-compassionate
6. Keep using Emotion Regulation skills

Background

I’m a maths teacher at an FE college. I married my university boyfriend when we were 22. The marriage was happy at first, but my ex got frustrated with my coolness and inconsistency of feelings towards him. I was very insecure. I always thought he’d leave me, although I was desperate for him not to. Eventually he left. It was awful and I had a complete breakdown, I lost the house and my job and became really depressed and suicidal. I had a lot of partners. I just wanted to feel something. After the breakdown, I got a proper diagnosis and I did a couple of years of DBT. Now I have therapy for trauma processing once a week.

My parents were reserved and unaffectionate. I was bright, swotty and encouraged to be well-behaved. When I was walking home from school one day, I was seriously sexually assaulted. I didn’t tell my parents or anyone else what had happened for years afterwards. I thought it was my fault. I just closed down. As I got older, I realised that I didn't feel emotions like other people. Friends would describe intense emotions about the things they loved or hated, but I often felt very empty inside or found it hard to know what I was feeling.

I had first started self-harming as a result of being bullied, but it got a lot worse after the assault. I started by burning myself and taking more than the recommended amount of painkillers. I controlled my marriage by threatening and taking overdoses. I still have a lot of self-blame and bitterness about what happened. I think that everything was my fault.

DBT

After a long time learning the skills and trying to practice mindfulness, DBT has become very helpful. DBT has helped me to understand my emotions better.I know I can use the skills now and they’ve become inbuilt from practising over and again. I don’t think I’ll ever stop having issues, but at least I know what to do to get better, in terms of using the skills and that I’ve done it before so I am able to do it again. It makes me quite sad that I have to keep doing mindfulness and the skills. I still have really bad times. But now I know I can use the skills to get better.

Mindfulness

Even after 4 years, I still try to do this every day. I sometimes forget I need to keep training myself, even though it’s built in, but then I use old ways of thinking and realise I need to keep up my practise. I find the grounding aspect of mindfulness really helpful if I start to dissociate. Mindfulness also connects all the other skills, if you can’t recognise your emotional state, you don’t know what to do with it. I find it also helps me to get more in touch with my body and how it feels and what I’m thinking. Compassion can still be very hard, I try to be more self-compassionate and that helps with my critical voice. It’s still not always easy.

Mindfulness really helps with the other skills, because it makes me more in the moment and aware, so I get some objectivity. Then I can pick the skill I need. It also reminds me that I still need to use my skills. Sometimes, I keep myself very busy, rather than being mindful or trying to work out which emotion I’m feeling. Once I realise what I’m doing I take a step back and use my mindfulness to see if it’s an appropriate response to the situation.

Figure I.4: Gayle Foster - proficient stage persona

3. User Experience Maps

There are two UX Maps, which capture and present the DBT process and the complex client interactions that occur. Firstly, Figure I.5 shows a user-journey map following the progression of DBT, from beginning therapy to finishing DBT and mastering the skills modules. The user-journey map is based on observations and client interview analysis and shows a range of users. By looking at the clients' requirements at each stage, design and development will be more suitable and usable for clients at all stages. Secondly, in Figure I.6, a 24-hour journey map showing the use of Mindfulness skills over 24 hours for India Birch, an Entrant-stage client.

The design/development team should be aware that the process shown in the DBT journey map may not be a linear one; clients could go forwards or backwards within the process. The purpose of the UX map is to allow the team to understand that the end users may be at different stages in the acquisition process, so that this can be incorporated into the DMHI design. However, if the DMHI is to be used by all those who are trying to use DBT in their lives, both ends of the spectrum, as well as those in between need to be considered. If the DMHI is designed only for early stage clients and patients, the requirements of those at the end of the process would not be covered. The UX map will not be translated directly into the DMHI, but is an abstraction of the process which can be translated into a design and a finished product.

DBT UX journey map

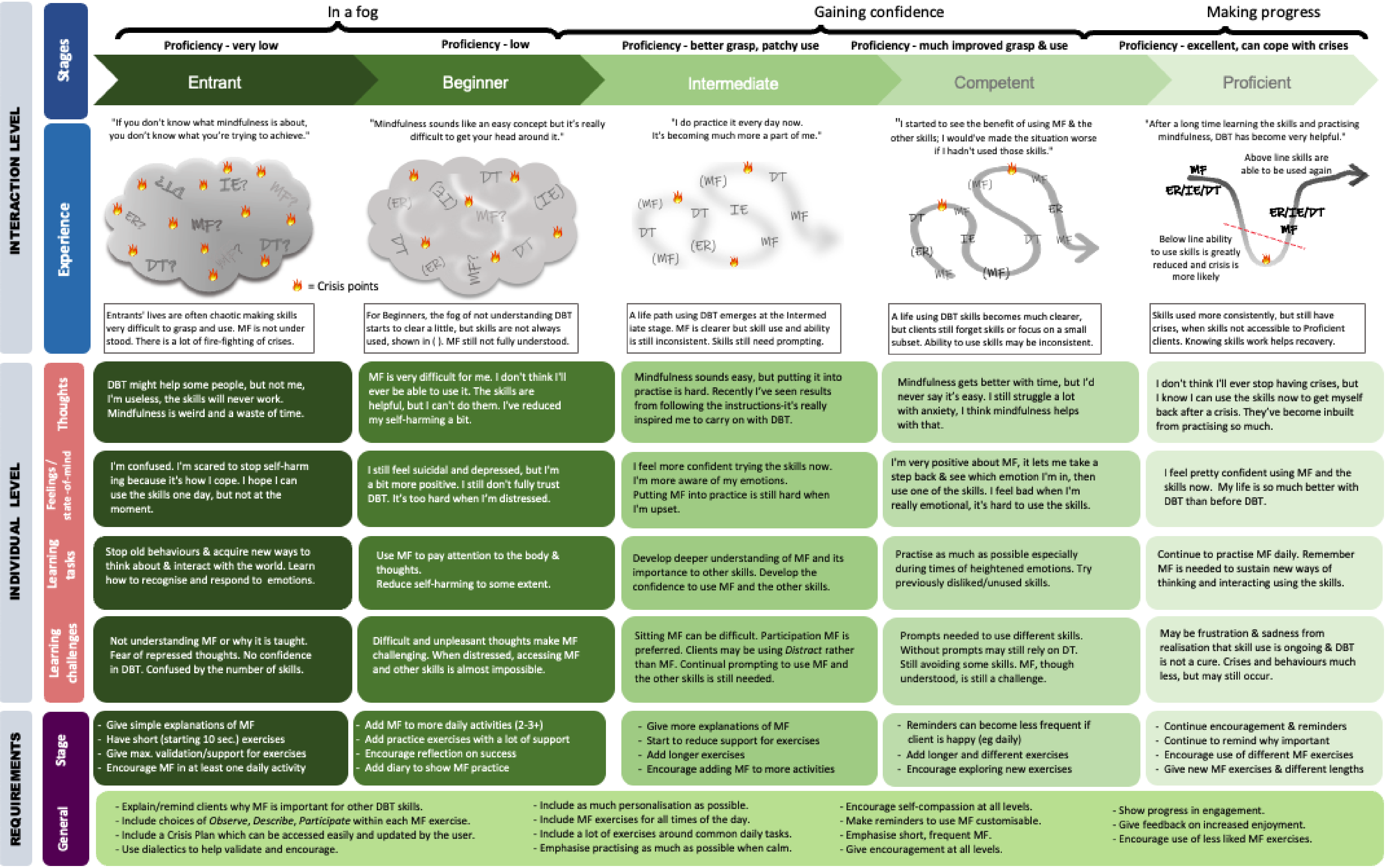
The UX journey map has different sections, as follows:

Stages The map reads both down and across. At the top are the categories of users, showing a progression from *Entrant* level to *Proficient* level.

Thoughts and Feelings Reading down the map, for each stage in the DBT acquisition process, the thoughts and feelings of clients are shown. These are expressed in the first person and are quotes or paraphrased from the client interviews.

Learning tasks and challenges The learning tasks and learning challenges were informed by the client and the clinician interviews.

Requirements The Requirements level is the most important in some ways. Extrapolated from the rest of the document, this tells the software development team which are the key requirements (i.e. user needs) that the DMHI must cover. These are expanded in Section 4.

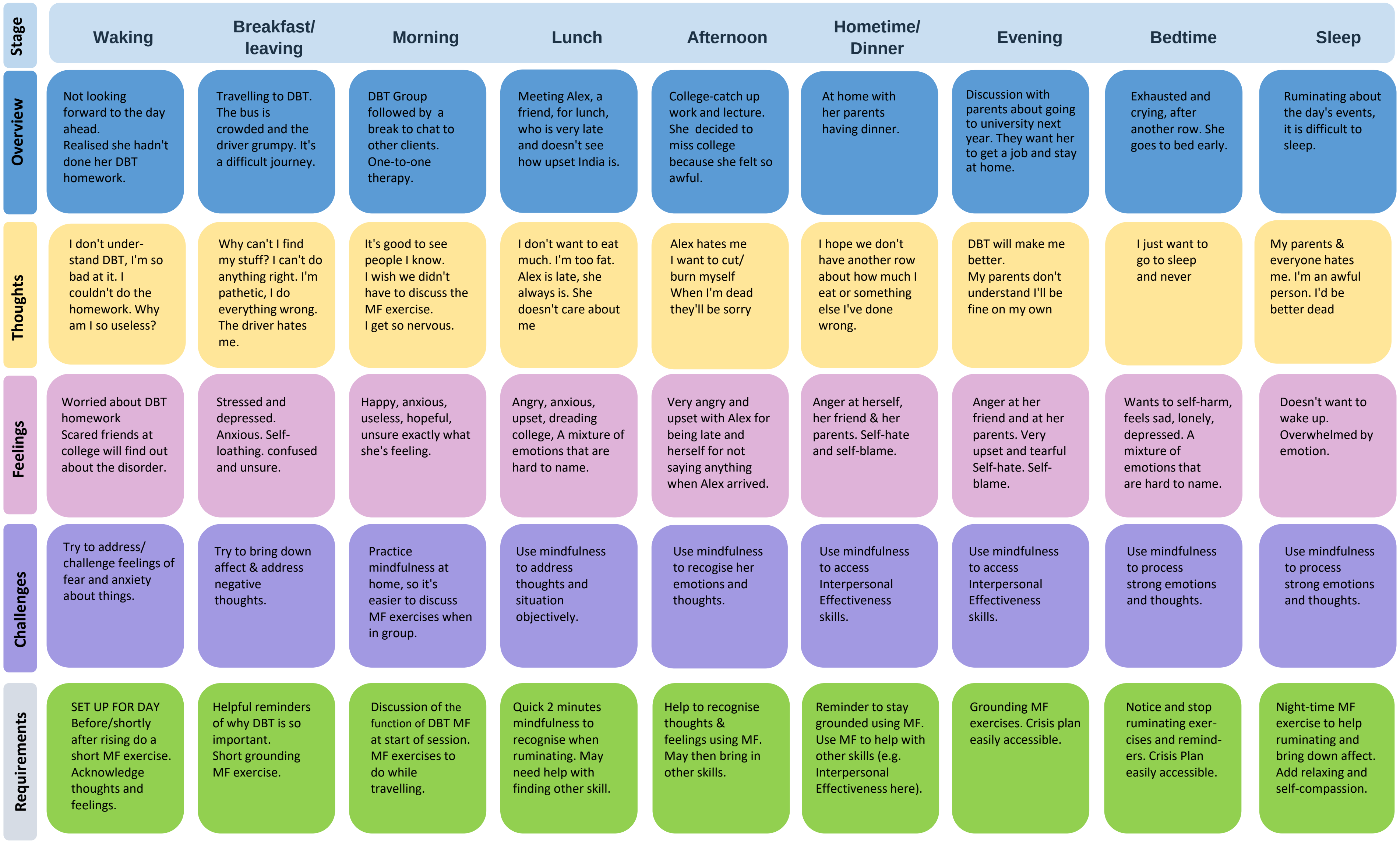


		Entrant	Beginner	Intermediate	Competent	Proficient
INTERACTION LEVEL	Stages	In a fog		Gaining confidence		Making progress
		Proficiency - very low	Proficiency - low	Proficiency - better grasp, patchy use	Proficiency - much improved grasp & use	Proficiency - excellent, can cope with crises
	Experience	"If you don't know what mindfulness is about, you don't know what you're trying to achieve."	"Mindfulness sounds like an easy concept but it's really difficult to get your head around it."	"I do practice it every day now. It's becoming much more a part of me."	"I started to see the benefit of using MF & the other skills; I would've made the situation worse if I hadn't used those skills."	"After a long time learning the skills and practising mindfulness, DBT has become very helpful."
		Entrants' lives are often chaotic making skills very difficult to grasp and use. MF is not understood. There is a lot of fire-fighting of crises.	For Beginners, the fog of not understanding DBT starts to clear a little, but skills are not always used, shown in ( ). MF still not fully understood.	A life path using DBT emerges at the Intermediate stage. MF is clearer but skill use and ability is still inconsistent. Skills still need prompting.	A life using DBT skills becomes much clearer, but clients still forget skills or focus on a small subset. Ability to use skills may be inconsistent.	Skills used more consistently, but still have crises, when skills not accessible to Proficient clients. Knowing skills work helps recovery.
INDIVIDUAL LEVEL	Thoughts	DBT might help some people, but not me, I'm useless, the skills will never work. Mindfulness is weird and a waste of time.	MF is very difficult for me. I don't think I'll ever be able to use it. The skills are helpful, but I can't do them. I've reduced my self-harming a bit.	Mindfulness sounds easy, but putting it into practise is hard. Recently I've seen results from following the instructions-it's really inspired me to carry on with DBT.	Mindfulness gets better with time, but I'd never say it's easy. I still struggle a lot with anxiety, I think mindfulness helps with that.	I don't think I'll ever stop having crises, but I know I can use the skills now to get myself back after a crisis. They've become inbuilt from practising so much.
	Feelings / state-of-mind	I'm confused. I'm scared to stop self-harming because it's how I cope. I hope I can use the skills one day, but not at the moment.	I still feel suicidal and depressed, but I'm a bit more positive. I still don't fully trust DBT. It's too hard when I'm distressed.	I feel more confident trying the skills now. I'm more aware of my emotions. Putting MF into practice is still hard when I'm upset.	I'm very positive about MF, it lets me take a step back & see which emotion I'm in, then use one of the skills. I feel bad when I'm really emotional, it's hard to use the skills.	I feel pretty confident using MF and the skills now. My life is so much better with DBT than before DBT.
	Learning tasks	Stop old behaviours & acquire new ways to think about & interact with the world. Learn how to recognise and respond to emotions.	Use MF to pay attention to the body & thoughts. Reduce self-harming to some extent.	Develop deeper understanding of MF and its importance to other skills. Develop the confidence to use MF and the other skills.	Practise as much as possible especially during times of heightened emotions. Try previously disliked/unused skills.	Continue to practise MF daily. Remember MF is needed to sustain new ways of thinking and interacting using the skills.
	Learning challenges	Not understanding MF or why it is taught. Fear of repressed thoughts. No confidence in DBT. Confused by the number of skills.	Difficult and unpleasant thoughts make MF challenging. When distressed, accessing MF and other skills is almost impossible.	Sitting MF can be difficult. Participation MF is preferred. Clients may be using *Distract* rather than MF. Continual prompting to use MF and the other skills is still needed.	Prompts needed to use different skills. Without prompts may still rely on DT. Still avoiding some skills. MF, though understood, is still a challenge.	May be frustration & sadness from realisation that skill use is ongoing & DBT is not a cure. Crises and behaviours much less, but may still occur.
REQUIREMENTS	Stage	- Give simple explanations of MF - Have short (starting 10 sec.) exercises - Give max. validation/support for exercises - Encourage MF in at least one daily activity	- Add MF to more daily activities (2-3+) - Add practice exercises with a lot of support - Encourage reflection on success - Add diary to show MF practice	- Give more explanations of MF - Start to reduce support for exercises - Add longer exercises - Encourage adding MF to more activities	- Reminders can become less frequent if client is happy (eg daily) - Add longer and different exercises - Encourage exploring new exercises	- Continue encouragement & reminders - Continue to remind why important - Encourage use of different MF exercises - Give new MF exercises & different lengths
	General	- Explain/remind clients why MF is important for other DBT skills. - Include choices of *Observe*, *Describe*, *Participate* within each MF exercise. - Include a Crisis Plan which can be accessed easily and updated by the user. - Use dialectics to help validate and encourage.	- Include as much personalisation as possible. - Include MF exercises for all times of the day. - Include a lot of exercises around common daily tasks. - Emphasise practising as much as possible when calm.		- Encourage self-compassion at all levels. - Make reminders to use MF customisable. - Emphasise short, frequent MF. - Give encouragement at all levels.	- Show progress in engagement. - Give feedback on increased enjoyment. - Encourage use of less liked MF exercises.

LEGEND: MF - Mindfulness IE - Interpersonal Effectiveness ER - Emotion Regulation DT - Distress Tolerance

Figure I.5: DBT UX Journey Map

Figure I.6: Map of twenty-four hours in India’s life



Stage	Waking	Breakfast/ leaving	Morning	Lunch	Afternoon	Hometime/ Dinner	Evening	Bedtime	Sleep
Overview	Not looking forward to the day ahead. Realised she hadn't done her DBT homework.	Travelling to DBT. The bus is crowded and the driver grumpy. It's a difficult journey.	DBT Group followed by a break to chat to other clients. One-to-one therapy.	Meeting Alex, a friend, for lunch, who is very late and doesn't see how upset India is.	College-catch up work and lecture. She decided to miss college because she felt so awful.	At home with her parents having dinner.	Discussion with parents about going to university next year. They want her to get a job and stay at home.	Exhausted and crying, after another row. She goes to bed early.	Ruminating about the day's events, it is difficult to sleep.
Thoughts	I don't understand DBT, I'm so bad at it. I couldn't do the homework. Why am I so useless?	Why can't I find my stuff? I can't do anything right. I'm pathetic, I do everything wrong. The driver hates me.	It's good to see people I know. I wish we didn't have to discuss the MF exercise. I get so nervous.	I don't want to eat much. I'm too fat. Alex is late, she always is. She doesn't care about me	Alex hates me I want to cut/ burn myself When I'm dead they'll be sorry	I hope we don't have another row about how much I eat or something else I've done wrong.	DBT will make me better. My parents don't understand I'll be fine on my own	I just want to go to sleep and never	My parents & everyone hates me. I'm an awful person. I'd be better dead
Feelings	Worried about DBT homework Scared friends at college will find out about the disorder.	Stressed and depressed. Anxious. Self-loathing. confused and unsure.	Happy, anxious, useless, hopeful, unsure exactly what she's feeling.	Angry, anxious, upset, dreading college, A mixture of emotions that are hard to name.	Very angry and upset with Alex for being late and herself for not saying anything when Alex arrived.	Anger at herself, her friend & her parents. Self-hate and self-blame.	Anger at her friend and at her parents. Very upset and tearful Self-hate. Self-blame.	Wants to self-harm, feels sad, lonely, depressed. A mixture of emotions that are hard to name.	Doesn't want to wake up. Overwhelmed by emotion.
Challenges	Try to address/ challenge feelings of fear and anxiety about things.	Try to bring down affect & address negative thoughts.	Practice mindfulness at home, so it's easier to discuss MF exercises when in group.	Use mindfulness to address thoughts and situation objectively.	Use mindfulness to recogise her emotions and thoughts.	Use mindfulness to access Interpersonal Effectiveness skills.	Use mindfulness to access Interpersonal Effectiveness skills.	Use mindfulness to process strong emotions and thoughts.	Use mindfulness to process strong emotions and thoughts.
Requirements	SET UP FOR DAY Before/shortly after rising do a short MF exercise. Acknowledge thoughts and feelings.	Helpful reminders of why DBT is so important. Short grounding MF exercise.	Discussion of the function of DBT MF at start of session. MF exercises to do while travelling.	Quick 2 minutes mindfulness to recognise when ruminating. May need help with finding other skill.	Help to recognise thoughts & feelings using MF. May then bring in other skills.	Reminder to stay grounded using MF. Use MF to help with other skills (e.g. Interpersonal Effectiveness here).	Grounding MF exercises. Crisis plan easily accessible.	Notice and stop ruminating exercises and reminders. Crisis Plan easily accessible.	Night-time MF exercise to help ruminating and bring down affect. Add relaxing and self-compassion.

Figure 1.8: UX map - 24 hours in India Birch's (Entrant) life

India Birch - 24-hour DBT Entrant UX map

The 24-hour DBT UX map is based on a day in India's life. It is helpful as a starting point for India's scenario. It is necessarily different from the longer-term map, because the learning challenge is the same throughout, so is not explicitly modelled. This map focuses on where in the day Mindfulness skills would be helpful.

The headings show: the time of day, a brief overview of what is happening at that time, India's thoughts about what is happening, India's feelings towards what is happening (NB one of the key presentations of BPD is strong emotive affect and emotional dysregulation), how India can use DBT to address the challenges, and dropping out of this, in the final row, some possible requirements.

4. General Requirements

This document expands the general requirements from the last row of the DBT UX journey map. These are the main requirements for the design team to have in mind when designing and developing. These requirements are a result of the interviews, the DBT UX journey map, the 24-hour DBT Entrant UX map and the personas. They are supplemented by findings from a previous study with non-clinical mindfulness practitioners. The DMHI will focus on the Mindfulness skills module in the first instance.

Explain/remind users why Mindfulness is so important in DBT

In the interviews, clients at all levels identified the difficulty of learning and maintaining mindfulness. They did not understand mindfulness or why they were doing it initially and this continued for a long time. The models deliberately do not use timelines in order not to stigmatise the end-users, but this can be 3-9 months and up to 1 year+. All experienced interviewees (Proficient level clients) reported that it was 12+ months before they really "got" mindfulness *and* had the confidence to use it.

Include choices of *Observe*, *Describe*, *Participate* for each exercise

In the interviews all clients expressed a preference for one of the *What* types of Mindfulness execise (see DBT Mindfulness module skills explanation) and quite often a strong dislike of another kind. However, by including a choice of all three for the same exercise, once clients feel comfortable using *Observe* for example, they could then expand their experience and try *Describe* or *Participate* for the same type of exercise, perhaps with gentle encouragement. In later stages gently encourage the use of less-liked Mindfulness exercises to help clients tolerate negative feelings when they arise, which can help in moving towards acceptance (see Dialectics - Acceptance and Change).

Include a Crisis Plan which can be accessed easily and updated

The clients have a written Crisis Plan for when they are in a crisis and have urges to do a self-harming or therapy-interfering behaviour. The Plan should be easy to add to the DMHI by the client and easy to edit when necessary. It should be easily accessible from the home screen and might include:

- Contact details for therapists/GPs/etc – useful information
- Individual crisis plan
- Things that are calming, soothing and safe for that person (photographs, music, sounds etc)

Use dialectics to help validate and encourage

Dialectics are an important part of DBT. The key dialectic of DBT is the need for the client to accept themselves as they are in the moment and the need to change. Thus, clients need validation and compassion if they have not used the DMHI for a few days, but also need to be reminded to be mindful to help or maintain change.

Include as much personalisation as possible

Clients expressed a lot of differences when asked about colours and backgrounds for the app. Clients may be triggered by a range of things, allowing customisation can help to lessen this. The look of the DMHI should be customisable for voices/colours/pictures etc. to account for different tastes. The exercises should give the client a lot of choice in how they are done and be as flexible as possible. This should include for each exercise:

- A choice of *Observe*, *Describe* or *Participate*.
- A choice of verbal or written instructions.
- A choice of voices – male, female, different accents.
- A choice of timings and extendable timings for each exercise.
- Exercises should include a choice of moving or being stationary.

In the interviews clients were shown seven different pictures which might become backgrounds, themes or even Mindfulness focuses. The most popular was Figure I.7 followed by Figure I.8, although there was an objection to the human figures, endorsing the widely expressed view that no human depictions should be included. Overall clients expressed a liking for colours.

Include Mindfulness exercises for different times of day & common daily tasks

This came from a finding from both Study 1 and Study 2. Mindfulness is easier to learn if practised first thing in the morning. Almost all of the long-term mindfulness practitioners had a morning practice. A formal meditation practice or morning mindfulness ritual can help. But, in case the morning is a difficult time for some clients, the DMHI should have DBT practices for all times of day. As many of the participants favoured *Participate* Mindfulness, the mindfulness exercises should be based around different daily tasks which the client can manage.

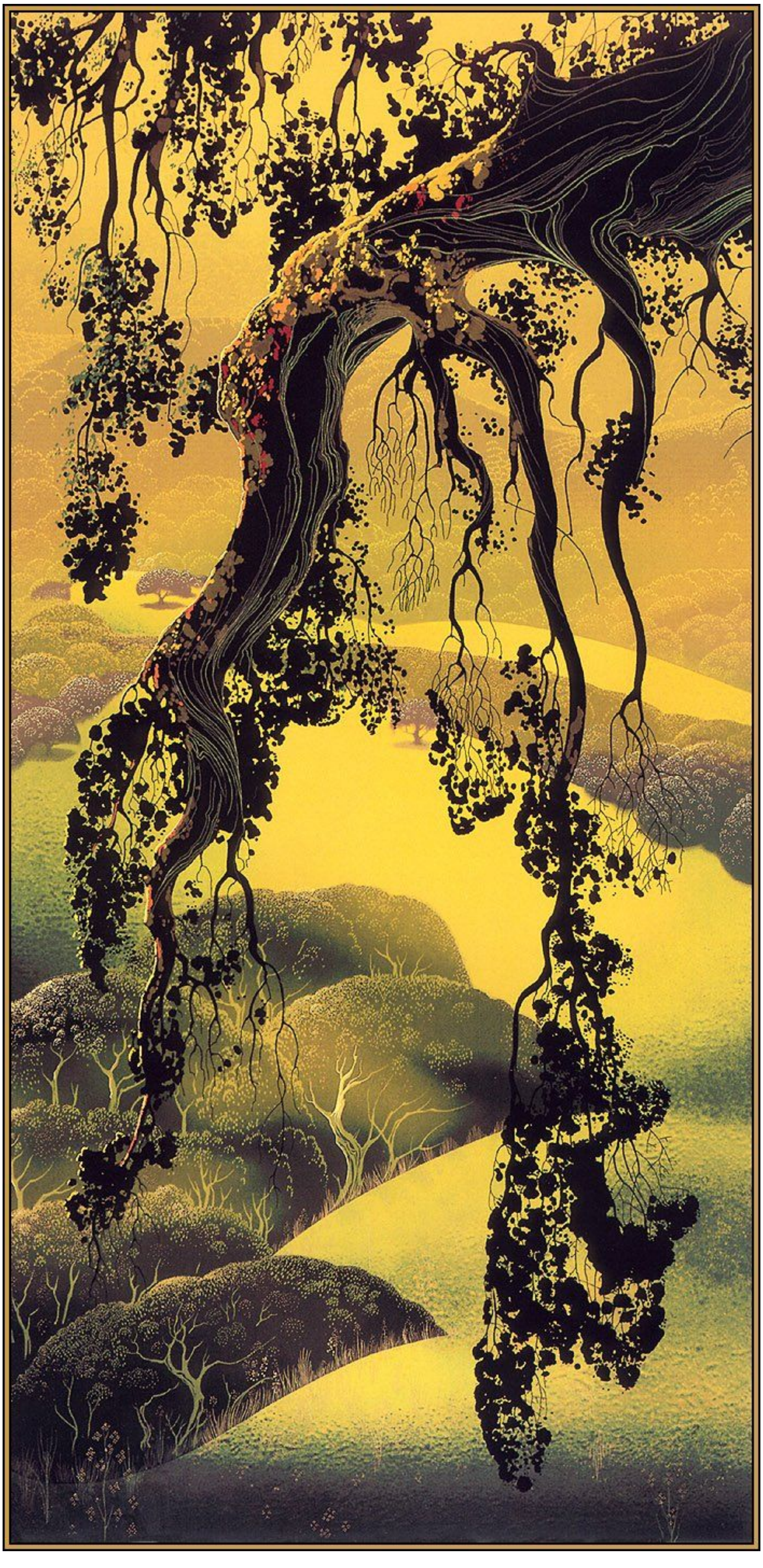


Figure I.7: Background Choice 7

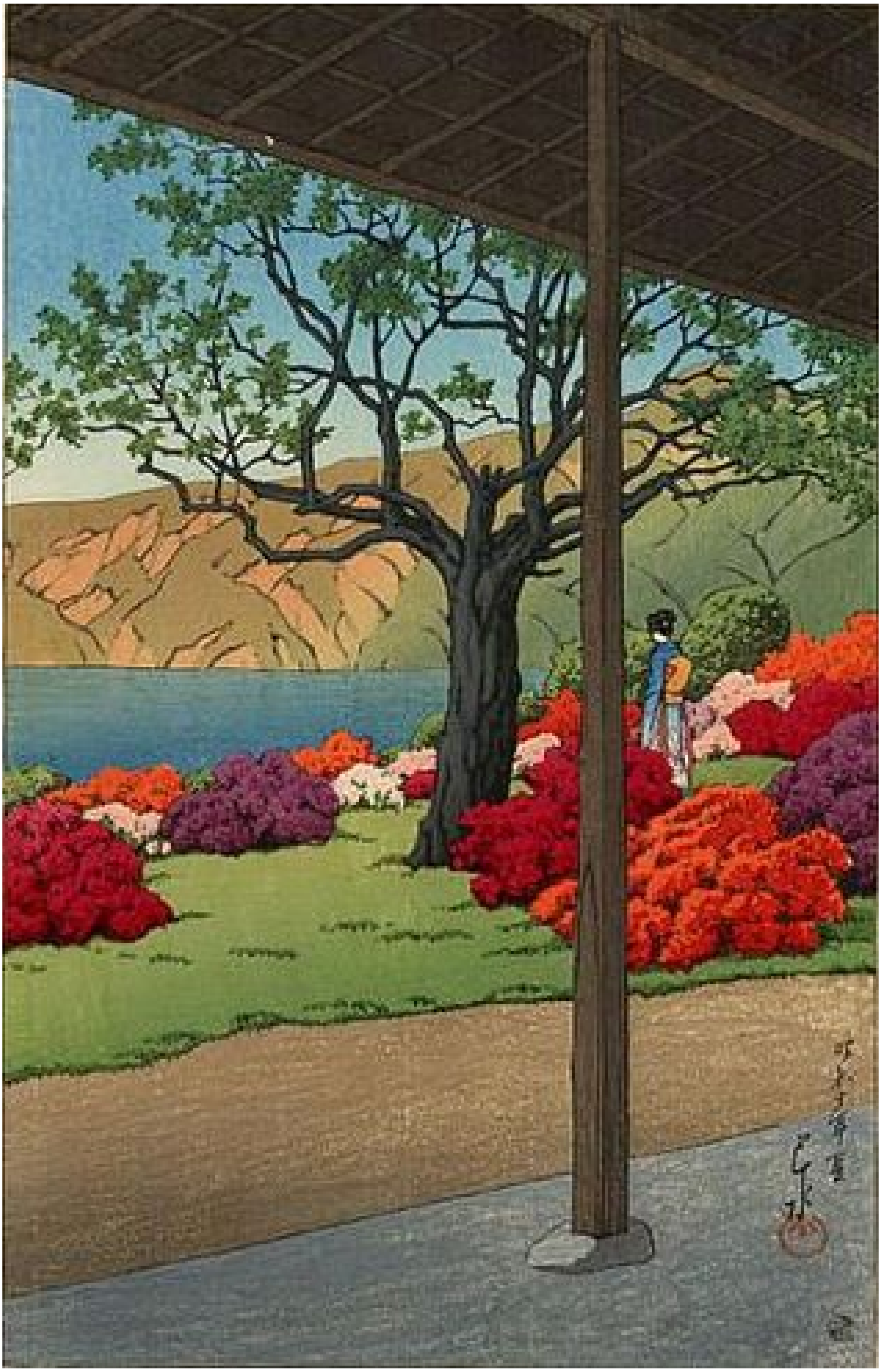


Figure I.8: Background Choice 1

The mindfulness study found that when mindfulness is done at the same time or with the same activity every day, it starts to build a habit. This can be encouraged at all stages. The chosen activities and time of day may change from stage to stage.

Give encouragement at all levels

It is extremely important to validate clients with BPD. Standard encouraging phrases will be extendable with customisable/client added phrases as well, so that the praise does not sound patronising.

Encourage self-compassion non-judgment

Encouraging self-compassion at all levels is part of the *How* Mindfulness skills, and is very important as this client group often struggle with self-compassion. In addition, being non-judgemental is another of the *How* skills of DBT Mindfulness. DBT Entrants and Beginners need a lot of support when facing thoughts they have been trying to suppress, as well as when dealing with the fear of being overwhelmed by their emotions; Mindfulness can help with this support.

The DBT clients often had not chosen to practise Mindfulness as part of a therapy, and may have started the therapy not knowing anything about it or not having previously heard of it. They therefore found it very strange at first. Some of the Proficient clients still saw mindfulness as a chore that they still had to do. Therefore, it is very important that the DMHI encourages self-compassion at all stages. The DMHI should also remind users that self-compassion is very important in dealing with the thoughts and emotions that arise during mindfulness, as well as the times when they are not mindful.

Make reminders to use Mindfulness customisable

Clients at all stages said that they forget to practice mindfulness. Reminders are important. Phones do not get bored of saying the same thing over and again. However, the client should be able to chose the time and wording of the reminder, so that the reminder does not make them feel worse. Setting an intention or making a commitment to be mindful was found to be helpful to some participants. Reminders can be linked to times of day/places/activities which the clients finds difficult or triggering.

Emphasise practising as much as possible when calm

Mindfulness is much easier to practise when not in crisis. The DMHI should emphasise practising as much as possible when calm. Both Study 1 and the clients in Study 2 reported mindfulness being much easier when calm. Clients should be encouraged to do very short Mindfulness skills practices when they feel calm. DBT clients may associate mindfulness only with difficult situations, but practising when not overwhelmed is very important.

Emphasise short, frequent Mindfulness

Regular practice is the best way to learn and maintain Mindfulness skills. Short regular practice is more beneficial than longer but less frequent practice, so even very short (even 30 seconds), but frequent mindfulness is a good way to build up the practice. At the beginning of DBT this may be all that is possible and as clients progress they may still find very short exercises to be helpful.

Show progress and give feedback in engagement and enjoyment

Metrics (positive only) for time using the app, different mindfulness exercises completed or enjoyment of the DMHI can also be added to show clients the progress they are making which will help with engagement and encouragement.

Encourage use of less liked Mindfulness exercises

See section on *Include choices of* Observe*,* Describe*,* Participate *for each exercise*.

Do not include human representation or communication

Clients were very clear that they did not want a DMHI in which they could communicate with other people. Neither were they keen on having representations of humans or any animate objects like animals in the DMHI.

Make the levels an underlying concept

It is important to note that the levels are a concept for DBT skills acquisition. The DMHI will not overtly name the stages, but will progress along a path through exercises that grow with the stages. The metaphor for the system, which might be seen graphically in the app, is a labyrinth (in the original sense of a single, non-branching path, which leads to a centre). As well as giving steps along the way (without overtly naming the steps), the labyrinth is a traditional meditation symbol relating to wholeness. Like that of the clients in acquiring the skills, the labyrinth is a meandering but purposeful path.

Conclusion

The requirements listed in the URD are not a collection of inflexible directions, but rather guidelines which keep the user requirements for the DMHI consistent (Rogers et al., 2012).

The tools and models detailed in this URD are based on UCD methods for creating personas, scenarios and experience maps. However, as the users have a mental health disorder, in this research the "standard" UCD methods were extended and used slightly differently, incorporating high-level details of the challenges brought by the disorder. The personas use the first-person voice to reflect the seriousness of their illness and make them more empathetic and are more detailed than usual. This also allows a reflection of the early stage clients' inability to construct a narrative about their agency to bring about a deep understanding and control of the skills (Section **??**, which becomes resolved in later stage clients. Experience maps are used as part of the requirements document, because, whilst the four personas give good snapshots of clients at different stages in the process, the journey is not as straightforward as that of the non-clinical population in acquiring and embedding mindfulness. This needed to be reflected in a DMHI which is appropriate for clients at all stages of the DBT therapeutic process. The scenarios work as illustrations where early stage clients might use to DMHI to help in difficut circumstances.

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