

**Self-disclosure**  
**in**  
**Mental Health Services**

Jonathan Lovell

PhD

University of York

Social Policy and Social Work

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## **Abstract**

Sharing lived experience of mental health experiences by mental health practitioners is a topic of increasing relevance in statutory UK mental health settings, in part because of the rise in recent years of the employment of peer workers who share their lived experience by default. Literature to date has suggested that self-disclosure can have a range of benefits and risks, but existing studies have tended to focus on general rather than mental health disclosure, have not taken place in statutory settings, have studied a narrow section of the workforce, or have used analogue methodology.

The current study used quantitative and qualitative methods through surveys and focus groups to explore statutory UK mental health practitioners' and service-users' views about the helpfulness of sharing personal mental health lived experience versus other types of lived experience.

Service-users indicated that personal mental health lived experience was the most helpful disclosure topic, was valued when disclosed by all types of qualified practitioner, but it was shared least often. Practitioners who rate disclosure as helpful may be more reflective than practitioners who rate disclosure as unhelpful. Practitioners may be deterred from disclosing by a range of pressures, including risk of negative disclosure effects; adherence to therapeutic models; negative judgements from colleagues; pre-qualifying training; and perceived direction from professional codes of conduct and ethics. Despite perceived risks associated with hypothetical disclosure, most practitioners disclosed to some extent. Respondents gave almost 500 examples of real life disclosures which were almost exclusively helpful.

It is recommended that practitioners are afforded greater autonomy, respect and permission to make decisions about disclosure without fear of judgment about professionalism. Training and guidance may be beneficial to help practitioners make best use of disclosures in statutory mental health service delivery.

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## **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 an award at this, or any other, University. All sources are acknowledged as References.

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## Chapter 1: Sharing Lived Experience

### 1.1 Introduction

This thesis explores whether it is helpful or unhelpful for mental health practitioners to share their lived experience when working with service-users. Primarily, it concentrates on the sharing of mental health lived experience, but also considers other types of non-mental health lived experience, such as beliefs, activities and identities, that practitioners may or may not choose to share with the people they work with. The subject is explored from multiple perspectives to include the views of both practitioners and service-users, in the UK and in Australia.

This chapter explores some of the key ideas, terms and concepts that will be referred to or explored in more depth in subsequent chapters. An outline of this chapter is as follows:

**Section 1.2** outlines what is meant by 'sharing lived experience' and the related term 'self-disclosure'. It considers the contribution of 'lived experience' to knowledge production, why the term 'lived experience' may be important to marginalised and disempowered groups of people, what counts as lived experience, and briefly introduces the practitioner dilemma of whether to share.

**Section 1.3** gives a brief introduction to the history of peer support, its emergence in current statutory mental health settings, and some of the key elements of peer support including role modelling, providing hope for recovery, stigma reduction, what is meant by the therapeutic relationship in mental health provision, and whether it might be affected by self-disclosure. It also considers whether peer support is considered effective and on what criteria.

**Section 1.4** looks at the prevalence and visibility of lived experience in the non-peer mental health workforce, and how group cultures and identities might contribute to professional attitudes towards disclosure.

**Section 1.5** draws these themes together to present a justification for the research described in this thesis.

## 1.2 Background and Aims

In 2013, the researcher undertook research into self-disclosure by social workers as part of the social work Masters course at the University of York which was published as an article in Community Care online magazine. As a result, a peer worker in a recovery team in a nearby NHS Foundation Trust requested help to undertake research on self-disclosure of personal mental health lived experience by mental health practitioners. They reported anecdotally that while disclosure of mental illness experience was seen as inherently beneficial to service-users when undertaken by peer workers, there was much controversy about whether it was helpful for other mental health practitioners to disclose their lived experience. Anecdotal evidence suggested that while psychologists, occupational therapists and counsellors were more accepting of self-disclosure as legitimate professional practice, in other professional roles, in particular among nurses, doctors, and social workers, sharing lived-experience was seen as inappropriate, unprofessional, risky, or unhelpful and best restricted to peer workers. It was felt that this may be to whether there is visible support for self-disclosure by senior managers in particular directorates, but may also be related to different perceptions of whether self-disclosure supported or deterred by professional roles and codes of conduct.

Peer workers have become increasingly prevalent in mental health services in recent years (Repper & Carter, 2010; Reidy & Webber, 2013), and either by choice or default they regularly disclose information to service-users, while other mental health professionals tend to maintain traditional user/practitioner boundaries (Repper and Carter, 2010). There is some evidence to suggest that general self-disclosure may be of benefit to service-users, but disclosures of mental illnesses may be more controversial (Henretty & Levitt, 2010). Mental health practitioners therefore potentially face a practice dilemma, where some professionals feel that self-disclosure of mental illness experience should be used with caution, while disclosure is central to the peer worker role. Since up to 1 in 4 people have experienced mental illness at some point in their lives (McManus et al, 2007; Singleton et al, 2000), it is likely that lived-experience is prevalent to some extent across the workforce, so the decision about whether to disclose may be one that many practitioners face.

This thesis describes the research that was undertaken in one UK NHS mental health Trust to gauge whether it was seen as helpful for peer workers to disclose their personal mental health lived experience, and whether it was seen as helpful for other mental health

practitioners to disclose such information too. It examines the issue from the perspectives of both service-users and practitioners, and explores whether findings are unique to the UK through additional research activities with Australian comparators. Specifically, the research aimed to explore:

- What kinds of disclosures practitioners had made in the past, whether they were seen as helpful, and in what ways.
- Whether service-users and practitioners found disclosure of mental illness lived experience helpful when undertaken by peer workers and other mental health professionals.
- Whether other types of self-disclosure were viewed as helpful, in what ways, and who by.
- Professional codes of conduct and standards to identify any policy directives on the use of self-disclosure in different professional roles/bodies.

### **1.2.1 Involving service-users**

Service-user involvement in research is widely encouraged by a range of researchers and organisations for a variety of reasons (see section 4.7) and is argued to bring a range of benefits from improving research design and increasing the credibility of findings (National Institute for Health research, 2013;) to ensuring that appropriate language is used to describe service-users' experiences (Shaw, 2012). To this end, service-users involved throughout the research process, from pre-research consultation around language and methodology, to involving service-users in the analysis of qualitative data. As part of this process, the concept of 'helpfulness' of disclosure was chosen over other potential terms (see section 4.3.4.2,) and the term 'sharing lived experience' was used where possible in preference to 'self-disclosure.' However, since most of the existing literature refers to 'self-disclosure', and because self-revealing disclosure is arguably synonymous with sharing lived experience (see section 2.6.1) the two terms are also used interchangeably in this thesis.

### 1.3 Sharing Lived Experience and Self-Disclosure

The term 'lived experience' is used in a wide range of research literature, especially those based on ethnographic and phenomenological methods (see section 1.3), and refers to in-the-moment, direct personal experiences that may only be understood through later reflection (Van Manen, 1990). In health contexts, phenomenology also emphasises the importance of understanding the lived experience of others, and has become a dominant methodology in nursing research, enabling nurses to develop the subjective lived experiences of patients in order to improve care (Matua, 2015). There is also some acknowledgement in nursing literature to suggest that nurses bring their own lived experience into the workplace (Oates et al, 2017) and that this insider knowledge can also help to improve care (Byrne et al, 2013). However, while lived experience might inform practice without being disclosed, for example, by providing the practitioner with additional insight and knowledge, this experience might not be shared through verbal disclosure. The current research focused on the dynamics associated with explicit sharing of lived experience with others, mostly through direct, deliberate, verbally articulated means. This approach was chosen because of the explicit expectation that peer workers should verbally share their experiences for the benefit of service-users (see peer worker job description, Appendix 1), as opposed to the possibility that other practitioners might usefully have, but not necessarily share (or verbalise) their lived experience (see community psychiatric nurse job description, Appendix 2).

In the literature, sharing lived experience is usually referred to as 'self-disclosure' and describes not only the conscious, reflective ways in which people, including mental health practitioners, make aspects of their identities, feelings and experiences known to others, but also the unconscious and unavoidable ways in which lived experience might come to be known by others.

#### 1.3.1 What counts as lived experience

Lived experience primarily refers to people who have *first-hand* experience of a particular phenomenon, but it is difficult to define precisely what counts as first-hand because many researchers do not define such terms. For example, lived experience is referred to throughout *Sharing Experience Learned Firsthand (SELF): Self-Disclosure of Lived Experience in Mental Health Services and Supports* (Marino et al, 2015) and *Uncovering the Lived Experience of Well-Being*

(Healey-Ogden & Austin, 2011), but neither offers an explicit definition of what counts as experience learned 'firsthand'.

In the literature, the term 'lived experience' is not only used in relation to mental health but also in relation to a range of other identities and experiences, including gender, ethnicity, disability, and sexual orientation, among others, as well as general life experience not related to minority issues. Lived experience, then, may refer to one, or more than one, identity or experience for any individual, and such identities are not stand-alone entities, but relate to and affect one another. The Government's strategic document *No Health Without Mental Health* (Department of Health, 2011) highlights the interconnections between mental health, physical health and a wide range of life outcomes. Focusing solely on mental illness is reductive; ignores the multiplicity of identities and roles that a person may associate with; reduces 'people' to 'patients'; and focuses conversation on abnormality instead of normality (Perkins & Repper, 2001).

Lived experience in this thesis refers to an individual's direct, first-hand experiences regarding their own mental illness and other identities and experiences, rather than observation of and interaction with other people who have lived experience. However, the absence of diagnosed mental illness does not necessarily indicate mental health (Keyes, 2005) so those without a formal diagnosis may nevertheless have their own direct experience and understanding of varying degrees of mental ill-health. Further, those without lived experience of mental illness may have varying degrees of distance or closeness to mental illness which may contribute to their insight and understanding. Some may have little or no personal contact with people who have experienced a mental illness while others may work with, live with, care for, or support people with mental illness, presenting them with opportunities to learn first-hand about mental illness, rather than through training.

### **1.3.2 Types of lived experience**

Since the presence of mental illness is the primary reason for mental health trusts to engage with service-users, and since mental illness is likely to be the single most common lived experience across the service-user population, it may be assumed that the most relevant type of disclosure would be mental health experiences. However, there are several reasons why



other aspects of lived experience and identity might be important to practitioners and service users, particularly in the contexts of research and recovery.

One of the criticisms of researcher-led research is that the researcher chooses which questions to ask, and this restricts the variety of possible responses (Beresford, 2002). In the delivery of mental health services, over-identification with mental illness as an inescapable identity may impede recovery (Yanos et al, 2010), and a central pillar of the recovery approach is that service-users are able to identify what aspects of their lives are most important to them (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010; Coleman, 2011).

Taking account of the cultural and spiritual strengths of individuals forms part of peer worker job descriptions in mental health trusts in England (Skills for Health 2010), including, for example, Leeds and York Partnership NHS Foundation Trust's job description for peer support workers (see Appendix 1). Leamy et al (2011) also highlight the interconnectedness and multiplicity of identity as an important feature of recovery approaches, especially regarding black and minority ethnic communities, spirituality and faith, and in a subsequent more detailed paper based on the same systematic review, this is expanded to include other identities and cultures including sexual orientation (Bird et al, 2014).

In light of this, attempts were made steer away from pre-determined assumptions that the sharing of *mental health* lived experience would be the most relevant, important, or helpful type of lived experience for service-users. Instead, it was decided that, as far as possible, service-users would be able to select which identities and experiences were most relevant to them.

### **1.3.3 The status of lived experience in knowledge production**

The delivery of current health and social care policy and practice has become increasingly evidence-based since the 1970s with the rise of Cochrane systematic reviews, and evidence-based practice became a government priority in the 1990s (Sheldon & Macdonald, 2009). What counts as evidence has been contested for much longer than this, and such debates have given rise to a wide range of research approaches with competing philosophies, ranging from positivistic, quantitative, scientific approaches to qualitative, subjective approaches that seek to understand the how individuals experience the world (Glasby et al, 2007). At the two extremes,

knowledge can either be learned from the outside by observation, experimentation, and formal learning (for example, from textbooks), the gold standard for medical inquiry being randomised control trials (Kirmayer, 2012) and systematic reviews (Newman et al, 2005), or it can be learned first-hand, from the inside, through experience of being in the world (Mapp, 2008). While both forms of knowledge are represented in research literature, with their credibility and validity being assessed according to competing criteria, it is arguable that medical and social work practice tends to be dominated by quantitative, objective, scientific approaches that suppress the importance of subjective, insider knowledge or lived experience (Glasby et al, 2007), so professional views of what counts as evidence favour positivist, scientific knowledge over the lived experience of service-users.

#### **1.3.4 Lived experience, knowledge production and disempowered groups**

Objective scientific knowledge may be more dominant compared to knowledge gained from lived experience. However, subjective, qualitative approaches to knowledge production are increasingly pursued within nursing, particularly through phenomenological approaches that seek to understand the internal, experiential worlds of patients (Finlay, 2009; Tuohy et al, 2013).

While objective approaches to research might seek to minimise researchers' personality in the pursuit of unbiased knowledge production, scientific enquiry is nevertheless influenced by personal and political aims (Wilton, 2004), and subjective life experiences and identities impact on the lived experience of both researchers and those who are researched (Tuohy et al, 2013). Making the researcher's personal identity and lived experience explicit in scientific inquiry, rather than seeking to limit, ignore, or avoid it, arguably increases objectivity and transparency (Mapp, 2008).

Identity, lived experience and subjectivity in knowledge production are particularly relevant to research involving marginalised and minority concerns, such as feminist (Bryman, 2012), black and minority ethnic (Scheurich & Young 1997), disability (Beresford, 2007) and lesbian and gay (Stanley and Wise, 1993) research, because such research has integral political objectives (Stanley and Wise, 1993). The lived experience of people who have experienced mental illness is important to knowledge production for similar reasons (Kirmayer, 2012).

## 1.4 Peers and Peer Support

### 1.4.1 Who are peers?

Peers, peer groups and peer relationships refer to associations and relationships that people have with others based on a wide range of personal characteristics, identities and attributes, and which tend to operate with some level of interpersonal expectation, reciprocity and equality (Reitz et al, 2014). Within mental health services (or indeed any services) practitioners and service-users may form part of a number of different peer groups that develop according to various criteria. Practitioners may form one peer group and service-users another, and within such groups other sub-groups may exist based, for example, on practitioner role, service-user diagnosis or treatment, or on personal characteristics such as their ethnicity or sexual orientation. Membership of peer groups may also overlap. Peer support workers are visible as both workers and as previous or current users of services, but for other practitioners dual status may be less obvious.

Members of a particular group may assume, correctly or incorrectly, that because members of their peer group share their own characteristics they will also share their beliefs, even where there is no natural connection between beliefs and the group's defining characteristics (Wagner, 1995). Members of peer groups may also experience pressure from which "it is often very difficult for individuals either to extricate themselves... or to change group thinking" (Mason et al, 2001, p.4).

Practitioners may receive support through membership of formal and informal peer group activities, such as chatting with colleagues over tea, and more formal systems such as clinical supervision (Aston & Molassiotis, 2002; Cheater & Hale, 2001). Functions of formal peer support groups among mental health professionals include consultation and support that may lead to professional growth (Zins & Murphy, 1996). As members of such groups, practitioners may be subject to pressure from their colleagues and organisations to conform to established working practices and doctrines.

### **1.4.2 What is peer support?**

There are a wide range of definitions of peer support in the literature relating to different types of peer support in different contexts. Repper & Carter's (2010) systematic review of the literature on formal peer support roles as they operate in mental health services suggests that there are common elements across definitions, and broadly peer support may be defined as "mutual support provided by people with similar life experiences as they move through difficult situations" p.4), focusing on strengths, recovery, and wellness.

There are numerous models of peer support, due to the rich history of peer involvement in service instigation, management, facilitation and delivery, and the proliferation of settings in which peer support may take place in one way or another (Repper & Carter, 2010). As a result, various terms that have been used to describe those who provide peer support on a paid or unpaid basis, including 'prosumers' (Schiff, 2004), 'peer providers' (Solomon, 2004), 'peer support workers' (Repper & Carter, 2010), and 'peer workers' (Gillard et al, 2013).

This thesis uses the term 'peer support worker' to describe the employment of people with experience of mental illness to provide support to service-users within traditional mental health services, rather than self-help or consumer-run services (Repper & Carter, 2010).

### **1.4.3 The emergence of peer support**

Peer support has a long history in both formal and informal settings. Forms of peer support may be found in Jean Baptiste Pussin's involvement of mental health patients in looking after other mental health patients in the 1790s (Davidson et al, 2012); in the work of Harry Stack Sullivan's similar patient involvement in the 1920s (Reidy & Webber, 2013); and in a variety self-help organisations and groups over recent decades (Gartner & Riessman, 1982).

The employment of peer support workers in the delivery of mental health services is a relatively recent phenomenon in UK statutory mental health settings (Barker et al 2011), but it has increased dramatically in that time and "over the last twenty years, the practice of peer support has virtually exploded around the globe" (Davidson et al, 2012, p.123).

A range of UK mental health policy initiatives support, embed and drive forward the inclusion of peer workers in UK mental health systems and settings (Gillard et al, 2013, Repper & Carter,

2010; Reidy & Webber, 2013). In the UK, one of the targets set by the NHS Mental Health Taskforce in its *Five Year Forward View for Mental Health* is to reduce the stigma of mental illness, which service-users may face from the general public as well as from mental health staff. A key contributor to stigma reduction is the provision of peer support services:

“A number of people described encountering stigmatising attitudes from some staff within mental health services, as well as staff in the wider NHS (including GP surgeries and non-clinical staff). Developing a paid peer support workforce had considerable support.”

(Mental Health Taskforce, 2016, p. 43)

#### **1.4.4 Functions of peer support for service-users**

Peer support workers are seen as central to a shift from traditional medicalised models of mental health intervention towards recovery models where wider quality-of-life goals are more prominent, and peer support is valued by service-users because of the social inclusion, self-efficacy and hope that it offers (Repper & Carter, 2010; Reidy & Webber, 2013).

A peer support job description obtained from one mental health NHS Foundation Trust in 2013 (see Appendix 1) suggests various central elements of the peer support role, which might broadly fit within the headings of *recovery*, *hope*, *role modelling*, *reducing stigma*, and *relationships*. These key elements of the peer support role have also been identified by other mental health trusts in England (Skills for Health, 2010), in systematic and other reviews of personal recovery in mental health (Leamy et al, 2011; Bird et al, 2014), and in the literature on peer support (Solomon, 2004; Repper & Carter, 2010; Repper et al, 2013; Davidson et al, 2006). Although the literature identifies many other features of peer support roles, these five elements are explored below because they represent common and recurrent themes across a wide range of sources, and because other elements might arguably fit within them, for example, helping service-users to develop new knowledge and skills (Davidson et al, 2006) may fit within the broad heading of *recovery*.

#### **1.4.4.1 Recovery**

In the USA, the “vision” of mental health recovery emerged in the 1990s as a result of the rise of community mental health models in the 1980s (Anthony, 1993). Antecedents of the emergence of recovery concept may be traced to deinstitutionalisation in the 1960s, and service-user campaigns for greater control over service delivery and for their voices to be heard by service providers in the 1970s (Austin et al, 2014). In Australia, the recovery concept emerged around the same time as in the USA, initially in non-governmental and service-user-led organisations, then more formally in public health literature and policies from the late 1990s (Ramon et al, 2009). The concept of recovery in the UK has similar historical antecedents to the USA (Bonney & Stickley, 2008; Ramon et al, 2009). Recovery emerges in UK public health policy and practice from the 2000s, draws on US literature and models, and is embedded in public health policy more strongly than in Australia (Ramon et al, 2009).

A single definition of recovery is difficult to find because of the variety of ways in which recovery has been described, observed, and measured. For some, recovery may be indicated by a lack of visible symptoms of mental illness, while for others it may mean the ability to take control of aspects of their lives (Austin et al, 2014). One definition suggests recovery is “the subjective experience of hope, empowerment, independence, and strengths as key ingredients to adapting to illness and living a full and meaningful life despite the limitations of illness” (Ahmed et al, 2012, p.700). In the UK, Implementing Recovery through Organisational Change (ImROC), a partnership set up by the Department of Health to promote recovery-focused initiatives, in their briefing paper *Making Recovery a Reality*, defines recovery as “a set of values about a person’s right to build a meaningful life for themselves, with or without the continuing presence of mental health symptoms” (Shepherd et al, 2008, p.1). Inherent in these concepts is the idea that it is service-users, rather than practitioners, who decide what counts as recovery, and what counts as a recovery outcome.

#### **1.4.4.2 Hope**

There is some evidence to suggest that peer support interventions are highly valued by service-users (Gillard et al, 2013); that lived experience is a “critical ingredient” of peer support programmes (Cabral et al, 2014); that being aware of a variety of potential positive futures may increase resilience and recovery when people face adverse circumstances (Katz, 1997); and that

peer support can increase hope and optimism for the future among mental health service-users (Repper et al, 2013).

Fostering hope is an important aim in promoting recovery for mental as well as physical illness, and is believed to “promote self-healing capacity” (Harding and Zahniser, 1994, p.141). Ross (1995) suggests that hope leads to motivation and vitality, and that lack of hope is linked with learned helplessness. As such, lack of hope appears to be antithetical to clinical and non-clinical recovery outcomes.

#### ***1.4.4.3 Role modelling***

Role modelling may be described as acting as a positive real life example to inspire and motivate others, and help people to achieve goals, improve their self-efficacy, and gain new skills and knowledge (Cleary et al, 2013). Self-efficacy and a belief that change is possible are seen as central components of both social learning theory, regarding how behaviours are determined, and the health belief model, regarding how health-related actions are influenced (Rosenstock et al, 1988).

Perry’s (2009) qualitative nursing study suggests that role modelling plays an important part in experienced nurses sharing skills and knowledge with less experienced nurses that “cannot be learned by reading a textbook (Perry, 2009, p.40). Drawing on the social learning theory of Bandura, Perry identifies three major principles of role modelling that are important to its success, including the visible demonstration of behaviours that the observer may emulate independently, demonstrating outcomes that are of value to the observer, and coupling the nurses’ “admired status” (p.43) with their similarity to the observer. Since the theoretical basis on which conclusions are drawn is not nursing-specific, the findings may also be applicable to relationships that nursing staff have outside of nurse-nurse mentor relationships, perhaps with other colleagues and patients. Being visible and open about experience of mental illness, demonstrating positive behaviour and condition management, and demonstrating similarity of experience, might enable practitioners to be effective role models for service-users.

Role modelling is an explicit element of the peer support role, but other practitioners may also be expected, explicitly or implicitly, to act as role models themselves, either to the general public and patients (Blake & Harrison, 2013) or, within mental health settings, to other mental health

professionals (Cleary et al, 2013). For example, the *NHS Health and Wellbeing Report* (Department of Health, 2009) encourages NHS staff to take responsibility for and improve their own physical health. While nurses may be expected to act as healthy role models to patients and the general public, not least in order to maintain credibility when imparting health promotion advice, their actual health behaviours and status (such as smoking, maintaining a healthy weight, and drinking alcohol) may be at odds with the idealistic image they project (Blake & Harrison, 2013). The credibility of advice may be undermined where health practitioners are not seen to implement themselves what they recommend to others (Peate, 2012).

Campaigns such as “Time to Talk” (Time to Change, 2017), endorsed and funded by the Department of Health, discourage silence and encourage people to talk about their mental health problems. If mental health campaigners want people to talk about their experiences of mental illness, and to not feel stigmatised by them, having a silent mental health workforce might convey a lack of lived experience among practitioners, or an unwillingness to be open about it, either of which may potentially compound feelings of stigma among service-users.

#### **1.4.4.4 Reducing stigma**

Mental health stigma may be described as negative stereotyping, discrimination and prejudice towards people with mental illness, which may lead to inequitable access to resources and opportunities such as health, employment, and housing; feelings of shame and blame; discrimination and disrespect; and early mortality (Thorncroft et al, 2016). Stigma may affect people who have a mental illness, and those who associate with people who have a mental illness (Thorncroft et al, 2016). Stigmatising attitudes may be found among the general public as well as among mental health professionals (Corrigan, 2000). Stigmatising views may be held about people with mental illness as well as by people with mental illness (Department of Health, 2011), and mental health staff may feel pressured to conceal mental illness and avoid seeking help as a result (Department of Health, 2009).

Covariation theory (Kelley, 1973, adapted by and cited in Ingleby, 2010) suggests that prejudice occurs where blame is attached to individuals, for example, people who are addicted to drugs, based on three covarying concepts: consistency, distinctiveness, and consensus. Discrimination is more likely to occur where behaviours are highly consistent (they happen repeatedly, for example, taking drugs regularly), of low distinctiveness (they are not unique, or one-offs, but



occur alongside other undesirable behaviours, such as problematic or criminal behaviour), and of low consensus (most people are not addicted to drugs). Neither Ingleby (2010) or Kelley (1973, cited in Ingleby, 2010) make any suggestion of applicability of this model to prejudice regarding mental health, but it is feasible that similar processes might occur there too.

Several UK initiatives have sought to reduce stigma and ameliorate its effects. Thornicroft et al's (2016) narrative review of over 8,000 quantitative studies and 8 systematic reviews suggests that stigma-reduction initiatives may be effective in the short to medium term among a range of target groups. The high-profile Time to Change programme led by Mind and Rethink Mental Illness (Time to Change, 2017) had some success in past campaigns to reduce negative discrimination among the general public, but there was no significant reduction among mental health staff (Corker et al, 2013). In fact, some studies indicate that mental health staff have may have greater stigmatising attitudes towards people with mental illness than the general public (Thornicroft et al, 2016).

Haghighat (2001) suggests that educational campaigns aimed at stigma reduction are limited because they only work at the cognitive level, producing short to medium term gains in demonstrating increased understanding of stigma, but have more limited effects at affective and behavioural levels. Limited effectiveness of campaigns may be due in part to a tendency for people to remember and associate rare, negative events with rare objects such as minority groups (low consensus, low distinctiveness), and they are also likely to apply what they learn about one member of a group to other members of that group where there are repeated behaviours (high consistency). This suggests that stigma and prejudice are being actively produced at the same time as efforts are being made to reduce them. To tackle this, Haghighat suggests six types of intervention are necessary to produce longer term stigma reduction effects: educational; affective; legislative; political; linguistic; and intellectual/cultural interventions.

The NHS Mental Health Taskforce (2016) asserts that many people are reluctant to disclose and seek help for mental health conditions in contrast to many common physical health conditions, despite the indication that mental illness is also common, with up to 1 in 4 people having experienced mental illness at some point in their lives (McManus et al, 2007; Singleton et al, 2000). Given this statistic, it is likely that lived-experience exists across the mental health workforce.

To avoid the negative consequences of stigma, people who have experienced mental illness may conceal it and 'pass' as mentally healthy, but they may face stigma when they are 'discredited' by failing to conceal their mental health experiences and may continue to be labelled by their experiences even where they become well again (Goffman, 1963). This presents people with mental illness and other stigmatised attributes with two main options: to conceal their identity; or to manage situations that arise from them being 'out' about their condition. Both of these options are complex, being influenced by individual agency and external pressures and factors including other people and their expectations.

#### ***1.4.4.5 Relationships and self-disclosure***

In mental-health self-disclosure literature, reference is often made to the *therapeutic relationship* (in a wide range of literature) or the *therapeutic alliance* (in counselling and psychotherapy related literature). For this thesis, the therapeutic relationship is any relationship between any mental health practitioner and the service-user, whether this is based on 'therapy' or other forms of support and intervention.

The concept of the therapeutic relationship has a long history (Evans, 2007; McCabe & Priebe, 2004), and approaches to managing therapeutic relationships differ according to therapeutic tradition. These range from the one-way, anti-self-disclosure approach of Freud and traditional psychoanalysts, through relational and intersubjective psychoanalysts who recognise the importance of intratherapy disclosure, to a wide variety of humanistic, feminist, multicultural, group, family, behavioural, and self-help therapeutic approaches that advocate the use of both intra and extra-therapy disclosures (Zur, 2011). At the heart of all of these is the assumption that disclosure has effects on the way in which clients relate to their therapists.

Relationship-centred care is a widely recognised and promoted approach to medical intervention both internationally and in the UK at policy and practice levels (Kitson et al, 2012). It places the relationship between health practitioners and patients as central to successful provision of health care and interventions, emphasising partnership, affiliation, reciprocity, emotional engagement, empathy and authenticity, and rejecting traditional professional detachment (Beach et al, 2006). Silverman et al (2013) suggest that a central component of building relationships is building rapport, citing studies which indicate affiliative patient-doctor relationships create greater patient satisfaction than those based on "power, status, authority

and professional distance” (p.143), and also that social conversation, partnership, warmth, and empathy (among other factors) can variously increase both patient satisfaction and clinical outcomes for physical conditions.

There is little doubt that positive therapeutic relationships with practitioners can have positive clinical and qualitative effects on service-users. Various scales have been used to measure the quality of therapeutic relationships (see McCabe & Priebe, 2004, for examples of measurement tools). Such scales also attempt to ascertain possible links between the strength of the therapeutic alliance; clients’ liking of therapists; perceptions of therapist warmth, expertise, empathy, and congruence; the use of self-disclosure; and the ultimately the impact of these factors on therapeutic success (see Henretty & Levitt, 2010, for an overview). Positive therapeutic relationships have been found to be important between service-users and, among others, nurses (Dziopa & Ahern, 2009), psychotherapists (McCabe & Priebe, 2004), and psychiatrists (Roche et al, 2014), in relation to a range of clinical (for example, symptom relief and medication adherence) and non-clinical (for example, quality of life) outcomes. A poor working alliance has been associated with non-adherence to medication among service-users with schizophrenia and psychosis (Weiss et al, 2002).

Self-disclosure has often been considered in light of its impact on the therapeutic relationship. Various studies indicate that therapist disclosure can have a positive effect on a client’s liking of the therapist, perceptions of therapist warmth, and client willingness to make disclosures of their own, the latter being seen by many as a prerequisite of effective therapeutic intervention (Farber, 2006). A comprehensive review of the literature relating to mental health nursing and therapeutic relationships (Dziopa & Ahern, 2009) suggests a number important elements of good therapeutic relationships, including the use of self-disclosure to avoid a one-sided relationship and encourage openness. Other studies and commentators suggest positive effects of doctor and psychiatrist self-disclosure (Beach et al, 2004b; Howe, 2011).

In contrast, Freud’s psychodynamic theories highlight the importance of the therapeutic relationship (Shattell et al, 2007) while simultaneously warning against self-disclosure lest it deters clients from making their own disclosures (Farber 2006) or interferes with transference and counter-transference (Meissner, 2002; Farber 2006). General nursing (O’Kelly, 1997) and psychiatric nursing (Evans, 2007) draw heavily on psychotherapeutic approaches, language and concepts, including transference and countertransference (O’Kelly, 1997; Jones, 2004),

engagement with psychodynamic theory (Gallop & O'Brien, 2003), and the importance of clear demarcation between practitioners' professional and private selves (O'Kelly, 1997).

Some studies suggest that disclosure by doctors to patients can have negative effects on primary care doctor-patient interactions (McDaniel et al, 2007; Beach et al, 2004b). In Henretty & Levitt's (2010) systematic review of self-disclosure in psychotherapy, one non-analogue (real-situation) study suggested no correlation in working alliance scores as a result of self-disclosure, and one analogue (simulated situation) study suggested a positive correlation. It is difficult to draw conclusions because the evidence base is limited, contradictory, often uses significantly different methodologies, and involves different types of practitioners in different job roles.

#### **1.4.5 Outcomes and effectiveness of peer support**

Leamy et al (2011) and Bird et al (2014) identify the importance of 'meaning' and 'empowerment' in recovery, while peer worker job descriptions in England emphasise a partnership approach between service-users and practitioners to identify and agree goals (Skills for Health, 2010) based on what matters most to them, rather than imposing clinical, practitioner-led aims and outcomes. It is a matter of debate whether effectiveness should be measured in terms of objective, clinical outcomes or self-reported, subjective, quality of life outcomes.

Perkins & Repper (2001) suggest that mental illness interventions often focus on the medical model where the aim is to cure and where goals and activities are defined and pursued because of their therapeutic value. This concentrates the field of vision onto what is abnormal and needs to be corrected rather than helping individuals to pursue everyday activities because they are normal rather than because of their therapeutic value. In this regard, recovery does not mean 'getting better' as in being cured, but living a 'normal' life within a person's individual parameters and limitations. Regarding physical health and disability, goals are not always to restore the person to how they were before an illness, disability or injury, but to assist them in determining their own future aspirations and needs (Mason et al, 2001). A similar approach may be underdeveloped in the provision of mental health services:

“The challenge to mental health professionals is to look beyond clinical recovery and to measure effectiveness of treatments and interventions in terms of the impact of these on the goals and outcomes that matter to the individual service-user and their family.”

(South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust, 2010, p. 3)

Despite the growth of peer support and the positive regard towards it among service-users, peer involvement in mental health service delivery is not without difficulties or concerns. Some practitioners cite concerns about peer worker illness relapse and reliability; peer workers report feeling inferior to other practitioners; practitioners may be defensive and protectionist about their roles and competencies; there may be a lack of clarity regarding peer worker versus other professional role; and concerns may arise about the maintenance of personal and professional boundaries between peer workers and service-users (Gillard et al, 2013).

The research evidence on the effectiveness of peer support programmes is mixed and contradictory. Davidson et al’s (2006) review suggests peer support may “offer cognitive and environmental antidotes to the isolation, despair and demoralization many people experience as a result of their contact with mental health services” (p.448). In addition, Davidson et al’s (2012) review of a small number of experimental studies suggests that peer delivered services can reduce hospitalisation rates and symptoms of mental illness, and that these benefits are associated with peer worker self-disclosure, rather than the provision of general support. Lloyd-Evans et al’s (2014) larger meta-analysis found no evidence of decreased hospital admissions, symptoms or service satisfaction, and some evidence to suggest positive impacts on hope, recovery and empowerment, though these findings were inconsistent across studies and self-disclosure was not identified as a critical ingredient of peer support effectiveness.

It appears that evidence for the effectiveness of peer support is mixed and contended regarding clinical outcomes, but there seems to be some agreement that it has a positive impact on non-clinical outcomes such as recovery, hope, and self-efficacy.

### 1.5 Lived Experience in the Non-Peer Workforce

The nature of the peer support job role requires peer support workers to have mental health lived experience, and they share it not only through their conscious thoughts and actions but automatically by the nature of their job title. Unlike peer workers, non-peer practitioners must decide whether to be explicit about where their mental health knowledge is derived from. While peer workers share their lived experience with service-users in their everyday practice other mental health professionals tend to practice in less reciprocal and more traditional, linear client/professional dichotomies (Repper and Carter, 2010). However, there is some recognition that staff in non-peer roles may also bring their lived experience into the workplace, and in at least one mental health trust lived experience of mental health problems forms a desirable criterion on the person specification for non-peer roles, for example, nursing (see Appendix 2).

Peer support workers may share other types of experience as well as mental health experiences. All practitioners are certain to have lived experience of something, and a proportion may have first-hand experience of mental illness. They may also have experience learned from textbooks and training, or from associating with people who have experienced mental illness. Both peer and non-peer practitioners face choices about which type of knowledge and experience to draw upon in their work. Deciding whether they share an experience may be based on a range of factors, including personal comfort with sharing, whether it is helpful or unhelpful to share, and to whom. Some studies suggest that various subjects of self-disclosure can be helpful to clients (see Henretty & Levitt, 2010, for a review), but they tend to concentrate on certain practitioners (for example, therapists), do not consider disclosure by other types of mental health practitioner, and do not adequately address disclosure of mental health rather than other types of experience. There remains a largely unanswered question as to whether it is helpful for non-peer mental health practitioners to have and share their own mental health lived experience, and in what ways.

There is a further question as to whether justifications for disclosure are needed at all. Perkins & Repper (2001) argue that mental health service delivery is often too focused on illness, interventions, and outcomes, wherein activities must have therapeutic value to be justifiable, rather than being justified because they have other merits or because they are simply part of everyday life for most people. Similarly, disclosing only for defined purposes may abnormally limit conversations between practitioners and service-users.

### 1.5.1 Prevalence

Among the general population, mental illness is estimated to affect up to one in every four people (McManus et al, 2007; Singleton et al, 2000). At a national level it is unclear whether there is greater prevalence of diagnosed and treated mental health conditions in the mental health workforce compared to the general population or other occupations, but some evidence suggests this may be the case. Mental health staff report particularly high levels of depression and stress as a result of work pressures (Reid et al, 1999; Evans et al, 2006). This may be exacerbated by greater demand for services at a time when resources are shrinking due to the UK government's recent austerity measures (Mental Health Taskforce, 2016). Overall, sickness absence in the NHS is higher than for other sectors, and estimates suggest that in 2009 mental ill-health was responsible for over a quarter of absences (Royal College of Physicians, 2015). In 2015 37% of NHS mental health trust staff reported feeling unwell as a result of work-related stress (NHS, 2016). Research among counsellors and psychotherapists indicates that the number who have accessed therapy themselves is unusually high, and is not a result of the requirements of training (Orlinsky et al, 2011). Other studies suggest that psychiatrists may be at higher risk of work-based stress and burnout than the general population, and social workers even higher still (Evans et al, 2006).

At a local level there is some evidence to suggest that the prevalence of mental illness in the workforce of two mental health NHS Trusts is higher than among the general population, and that practitioners are reluctant or fearful to disclose. In Leeds and York Partnership NHS Foundation Trust, staff surveys have indicated that 78% of respondents have experienced a mental health condition or are a carer for someone who has a mental health condition; over 40% would feel uncomfortable disclosing this to colleagues; and 96% would feel comfortable being disclosed to by a colleague (O'Connell, 2014). In a similar staff survey in Dorset HealthCare University NHS Foundation Trust (Dorset Wellbeing and Recovery Partnership, nd), 53% of respondents reported experiencing a mental health condition; 37% had accessed a service or received treatment as a result; and respondents reported significant feelings of stigma and of a 'them and us' culture between staff and service-users. Both studies were methodologically flawed because participation was via self-selection, and not all practitioners who could have taken part did so. It may be the case that practitioners with mental health lived experience were disproportionately attracted to take part, and there may be little or no lived experience among those who did not take part. However, even if this were the case, regarding the Dorset survey

it is straightforward to calculate a minimum level of lived experience across the whole workforce of the Trust using the total number of staff in the Trust, the number who took part in the survey, and number who said they have lived experience. This gives a minimum mental health prevalence rate of 17% (about 1 in 6) and for accessing services of 12% (1 in 8) even if there was no experience at all of mental illness among the 69% of staff who did not respond to the survey.

A high prevalence of mental illness in the workforce may be attributed to several potential causes. As has already been suggested, work pressures may be responsible for stress, depression and burnout among mental health practitioners. It may also be that practitioners with pre-existing mental health lived experience are drawn into mental health because of a desire to use their personal experience and insight to help others. Such practitioners are commonly referred to as 'wounded healers' (Jackson, 2001; Zerubavel & O'Dougherty Wright 2012). It may also be that, among counsellors and psychotherapists in particular, heightened awareness of normative standards primes practitioners to seek their own therapy in order to maintain their professionalism and effectiveness (Orlinsky et al, 2011).

Whatever the causes, it seems clear that experience of mental illness is prevalent across the mental health workforce. If practitioners are not disclosing their mental illness to colleagues and service-users, it is fair to conclude that it is not because they don't have anything to share. Something else must be responsible for the lack of disclosure.

### **1.5.2 Visibility of lived experience**

Mental health problems appear to be relatively common among mental health practitioners, but are reportedly less visible (or articulated) than might be expected given their prevalence (O'Connell, 2014; Dorset Wellbeing and Recovery Partnership, nd). There are several reasons why this perception might arise: anecdotal evidence may be incorrect because of confirmation bias and practitioners may in fact be sharing lived experience regularly without any problems; practitioners may not be sharing lived experience because of benign indifference to its effects; practitioners may feel pressured to adhere to expected norms favouring non-disclosure; and practitioners may actively pursue non-disclosure due to negative beliefs about the effects of disclosing.



### **1.5.2.1 Confirmation bias**

Non-disclosure may be an incorrect assumption perhaps brought about by confirmation bias. Nickerson (1998) describes this as “seeking or interpreting of evidence in ways that are partial to existing beliefs, expectations, or a hypothesis in hand” (p.175). If practitioners and service-users believe that practitioners do not have lived experience and/or do not share it, they may be likely to find and interpret evidence to support that belief by remembering expressions of anti-disclosure sentiments and forgetting examples of pro-disclosure stances or disclosures themselves.

### **1.5.2.2 Benign indifference**

One of the reasons staff may not share their lived experience is they do not see sharing as useful or necessary to their roles. Although the mental health profession may attract ‘wounded healers’ (Jackson, 2001; Zerubavel & O’Dougherty Wright 2012), rather than share their lived experience overtly, practitioners may instead use their insider knowledge to direct and inform their work, with explicit disclosure being viewed as a function of the peer support role rather than of the general workforce. For example, in a mission statement, consultant psychiatrists at South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust (2010) highlight “...the role of people with lived experience of mental health problems *as peer specialists*” (p.9, my emphasis) rather than *as practitioners* in general. This suggests a restrictive view of people with lived experience in terms of their potential job roles. This may be a plausible explanation for some practitioners, but there are other potential explanations for non-disclosure.

### **1.5.2.3 Stigma**

The latest indications from the Time to Change campaign (Time to Change, 2017b) indicate that almost 40% of respondents reported they had experienced stigma because of their mental illness, including losing their job, and the fear of negative consequences may discourage people from discussing their illness with others. Members of the mental health workforce may be reluctant to be open about their mental health experiences for similar reasons, but they may also face professional pressures that discourage disclosure.

#### **1.5.2.4 Conforming to expected norms**

Practitioners may avoid disclosure because they identify with the idea of the ‘well practitioner’ and conform to expected norms which may be enforced either implicitly or explicitly. People tend to define themselves in contrast to other people they are in close proximity to, but they also tend to form alliances and relationships with others who see them as they see themselves (Kernis & Goldman, 2003). Goffman (1963) refers to groups affiliations as in-groups and out-groups, and in mental health settings the largest, simplest and most visible group dichotomy exists between ‘well’ practitioners and ‘ill’ service-user (Richards, 2010). Where practitioners also have mental health lived experience, they may visibly identify with the ‘well practitioner’ group, conceal their actual experiences, and conform to the norms and ideals that are expected of this group. Goffman (1963) refers to this process as the suppression of ‘actual’ identities and the cultivation of ‘virtual’ ones. If practitioners are cultivating virtual identities, it might be expected that there is some innate or external pressure to do so. ‘Norm circles’ (Elder-Vass, 2012) may offer a means to conceptualise and explain such pressures.

#### **1.5.2.5 Norm circles**

Elder-Vass (2012) defines various types of norm circle which overlap with Goffman’s (1963) virtual and actual identities. Norm circles may be described as “social entities with people as their parts [with] causal power to produce a tendency in individuals to follow standardised practices” (Elder-Vass, 2012, p.22). Practitioners may behave as they think practitioners are expected to behave, perhaps presenting themselves as ‘well’ or ‘non-disclosing’. Norm circles offer a potential explanation of the mechanisms of norm enforcement, through the distinction between proximal, actual, and imagined norm circles.

‘Proximal’ norm circles are groups that individuals operate within directly, for example, the people they come into contact with on a daily basis. For practitioners this would include those people in their normal spheres of professional activity, for example, their colleagues, team or department. If practitioners have evidence that disclosure is unacceptable in their team (perhaps because team members express negative views about it, or perhaps because no one talks about doing it) or that their team is comprised of ‘well’ individuals (perhaps because they are unaware of the existence of team members’ lived experiences, or because the team only

comprises of 'well' individuals), they may feel pressured to present themselves visibly as non-disclosing and 'well' too.

Elder-Vass' (2012) concept of 'actual' norm circle has similarities with Goffman's (1963) actual identities, and describes the reality of a situation, which may or may not be different to the imagined situation. It may be that most members of the team (or proximal norm circle) enforce the concealment of lived experience in some way; or it may be that the pressure comes from a minority of individuals; or it may even be the case that no individuals hold these views at all. This raises the question of how the beliefs and customs within norm circles perpetuate themselves. Elder-Vass (2012) suggests this happens through the mental construction of 'imagined' norm circles which, as with Goffman's (1963) virtual identities, represent beliefs about the attributes of particular groups and individuals that might bely reality. For practitioners, encountering one team member with anti-disclosure beliefs may cause them to believe that other team members share such views, which may be extended to the departmental, organisational, or professional levels.

#### ***1.5.2.6 Active pursuance of dogma***

Practitioners may be demarcated from service-users by their professional/provider status; they may have lived experience that they have concealed or that they are open about; and as members of professional networks, teams, and organisations they are both governed by and help perpetuate real and imagined norms, rules, and policies that form expectations of and regulate colleagues' behaviours. What underlies all of this is the perpetuation of assumptions about the positive or negative effects of disclosure, which may or may not be 'correct' or based on evidence:

"Past practice, historical precedent, dogma, belief, and ideology all serve to create a contextual framework that informs action. Professions - most notably nursing and medicine – have long historical attachments to process in the memories, mythologies, fantasies, and stories that create an idealization of practice and a disconnect from fact and reality."

(Malloch & Porter-O'Grady, 2010, p.311 summarising Anderson & Willson, 2008).

Where disclosure is not seen as neutral or value-free, it may be seen as desirable, positive, helpful or beneficial, or conversely as undesirable, negative, unhelpful or damaging (see chapters Two and Three of this thesis for more detail on the evidence base of these positions). Practitioners might actively perpetuate and promote their position regarding disclosure because they believe it to be correct and based on evidence and experience. However, practitioners may also be reticent to change their views and working practices because of a desire to protect an image of personal and professional integrity and competence, wherein changing one's working practices would amount to an admission that previous practice was incorrect, misguided, or damaging (Richards, 2010).

### **1.6 Conclusion**

Lived experience plays an important role in knowledge production, though it may be subservient to scientific, medicalised notions of what counts as evidence. Lived experience includes many types of experience and identity, including mental health. Recognition of the central role of sharing lived experience is embedded in recovery and peer support literature, and both recovery and peer support have become increasingly important and prevalent in statutory mental health provision in recent years.

Peer support may have a range of benefits including promoting recovery, hope for the future, role modelling, stigma reduction, and developing user-defined recovery goals and outcomes. However, the evidence base regarding the role that sharing lived experience plays in this process is sometimes implicit not explicit.

Lived experience is prevalent across the mental health workforce, but there is anecdotal evidence to suggest that practitioners in general are not sharing it with service-users, with this function being restricted to peer support roles. This anecdotal perception may be false, but if it is true then there may be several reasons why practitioners are reluctant to share. Reasons for not sharing might include lack of awareness of benefits of sharing; organisational and team pressure towards non-disclosure; and beliefs that sharing is actively damaging or unhelpful.

If sharing lived experience is beneficial when undertaken by peer support workers, then it may also be beneficial when undertaken by other practitioners, for similar reasons. However,

whether sharing lived experience is helpful from peer workers, and whether it is helpful when undertaken by other practitioners outside of peer support roles is relatively unexplored.

### **1.6.1 Why this research is needed now**

Freud warned against self-disclosure in 1912 and psychoanalytic therapists (among others) have often been reluctant to use it because of its impact on transference (Gelso & Palma, 2011, Hanly, 1998). Jourard (1971) studied self-disclosure in the 1950s and argued the benefits of disclosure among the general population and among nurses, while others such as Pennebaker (1997) and Farber (2006) have extended the field of inquiry more recently. Along the way, the research literature on self-disclosure has grown enormously. Yet despite the plethora of studies that have looked at different types and subjects of self-disclosure across a wide range of social and professional settings, the subject remains controversial and emotive, with little consensus. There is also a lack of training and guidance on the subject to help practitioners make informed decisions about what might be useful to share (or not share), when, how, and with what justification.

The situation is further compounded by the dearth of studies that have looked specifically at the mental health context, or mental health disclosures made by mental health practitioners to mental health service-users within mental health services. What appears to have brought the issue to a head is the increasing employment within statutory mental health agencies of peer support workers, who are both practitioners and people with lived experience. The visibility of this dual status challenges some of the established conventions that may have separated professionals from service-users in the past. It is no longer a neat dichotomy (if ever it was) and new conversations and negotiations are increasingly taking place about how lived experience is manifested and used in the mental health workforce.

This research explored perceptions of the helpfulness of practitioner self-disclosure of mental illness experience from service-users' and practitioners' perspectives. It was instigated by a peer support worker's lived experience of working in mental health services, informed by contemporaneous practice debates, and involved service-users with lived experience of mental illness in its design and analysis. It aimed to explore what individuals thought about self-disclosure of mental illness as well as other identities. Specifically regarding disclosure of mental illness, it explored whether the job role of a disclosing practitioner made sharing more or less

helpful, and in what ways. Although informed by tentative hypotheses, inductive approaches were also used, and additional questions were explored in reaction to the data gained.

The following chapter looks in detail at views of self-disclosure in the literature relating to therapy, social work and mental health.

## Chapter 2: Self-Disclosure and Sharing Lived Experience

### 2.1 Introduction

The previous chapter outlined the main terms and concepts that will be encountered in this thesis, including a brief description of the terms *self-disclosure* and *sharing lived experience* which this chapter explores in more detail.

The body of literature on the subject of self-disclosure is vast. It stretches from Freud's warning in 1912 that the therapists should act as a blank screen, reflecting back only what the patient gives (Freud, 1912; Gelso & Palma, 2011) through to a wide range of more contemporary studies that testify to the positive and negative effects of different types of disclosure made by different people in different settings. Jourard (1971) conducted various studies from the 1950s to the 1970s into self-disclosure, and constructed scales to define and measure it, and more recent studies have been undertaken by Pennebaker (1997) into the (mainly beneficial) physical and mental effects of disclosure. More recently still, Farber (2006) provides extensive coverage of the (also mainly beneficial) uses of self-disclosure in psychotherapy, which will be frequently referenced and summarised in this chapter.

This chapter will explore some of the terminology that is used to describe self-disclosure, the contexts in which this terminology has been used, and some of the associated messages from research. It will outline what self-disclosure is and examine some of its potential benefits. Throughout this chapter, various terms will be used to refer to non-practitioners depending on the context: Farber frequently uses the term *patient*; Jourard (1971) often refers to research *subjects*; while others may refer to *clients*. *Service-user* will also be used in general non-referenced narrative, to reflect the term generally preferred within this thesis, and as a catch-all to include clients and patients.

Research and literature on self-disclosure is vast (Cole & Goettsch, 1981). This chapter will draw extensively on the various overviews, literature reviews, systematic reviews, and meta-analyses offered by Farber (2006), Hill & Knox (2001, 2002) and Knox & Hill (2003), Knox et al (1997), Henretty and Levitt (2010) and Henretty et al (2014), as well as other sources, to explore the issues associated with self-disclosure.

## 2.2 What is Self-Disclosure?

Zur (2011) defines self-disclosure as revealing personal rather than professional information to clients. Although this is a wide enough description to capture the majority of personal disclosures made in professional contexts, there is a good deal of research on disclosure outside of professional contexts among the general population, which suggests disclosure may have positive effects, and non-disclosure may have detrimental effects, on personal wellbeing and inter-personal relationships (Pennebaker, 1997; Jourard, 1971). Some of this is relevant to the self-disclosure debate because practitioners are not only professionals, they are also people.

A wider definition of self-disclosure is provided by Cozby (1973, p.73), that “self-disclosure may be defined as any information about himself which Person A communicates verbally to a Person B.” This is a useful definition in the context of this thesis because verbal disclosures made by some people to other people form the major topic under consideration. However, information may also be revealed non-verbally, either deliberately or unconsciously, through paralanguage, for example gestures, facial expressions, and tone of voice, which may affect the way in which messages are conveyed from one person to another (Pennycook, 1985). Other authors, including Meissner (2002), Goffman (1963), Silverman (2001), and Renik (1995) have variously expanded the list of non-verbal self-revealing actions to include pauses, contemplations, eye contact, the car a person drives, the colour of their skin, or the clothes they wear. These visual clues may be conveyed intentionally or unintentionally, and may cause correct or incorrect assumptions to be made about a person’s background, wealth, culture or other personal and social characteristics (Farber, 2006).

The primary focus of this thesis is the disclosure of mental health lived experience by practitioners to service-users, much of which may be made verbally. This chapter looks at self-disclosure in its widest sense, recognising that there are a wide range of means by which something may be conveyed by one person to another, intentionally or unintentionally, consciously or unconsciously, sometimes with and sometimes without the discloser’s knowledge.



### 2.3 Complexity of Disclosure

The relatively straightforward definition of self-disclosure as any information that someone might convey to someone else (Cozby, 1973) belies the complexity of disclosure, because people are not always fully self-aware (Luft, 1969), aware of what they have conveyed, nor aware of what others discern, assume, or know about them (Goffman, 1963). The Johari Window (Luft, 1969) gives a simplified overview of the ways in which individuals might know about themselves, and make themselves known (or be known) to others:

Figure 2.1: The Johari Window (Luft, 1969)

	Known to self	Not known to self
Known to others	1. Open self	2. Blind self
Not known to others	3. Hidden self	4. Unknown self

The first section of the Johari window deals with the ‘open self’– things people know about themselves that they may make known to others; for example, where they went on holiday, their likes and dislikes etc, or what Goffman refers to as those things that people intentionally ‘give’ when they share information (Goffman, 1959). The fourth section represents information people are not aware of about themselves that others are unaware of too, perhaps that they had an unknown childhood illness or trauma. The blind self (section 2) refers to personal attributes that people are unaware they possess, but that others are nonetheless able to discern about them, for example, that they become unconsciously stressed in some situations and make this visible by the way they act. The hidden self (section 3) refers to attributes that people know they possess which they may or may not choose to share, for example, a fear of heights (though of course, others might guess this without a verbal disclosure being made). Both the blind self and the hidden self have some crossover with what Goffman (1959) refers to as expressions ‘given off’, meaning those signs that people display that they may be unaware they have displayed.

The properties of disclosures are not intrinsic or fixed. Disclosures may impact on either the discloser or the disclosed-to according to context, real and perceived motivations for sharing, what is disclosed, and the nature of and intimacy of the relationship between the parties involved (Chaikin & Derlega, 1974). Disclosures made in the right context, about the right things, at the right time, with the right people, may be beneficial (Knox & Hill, 2003), but disclosing too much, too frequently, or inappropriately may display insensitivity, narcissism or self-absorption on behalf of the practitioner (Farber, 2006).

Disclosure is complex. Disclosers may or may not know they are disclosing; they may convey information about aspects of themselves that they are conscious of and aspects of themselves that they are unaware of; and disclosures may be beneficial or damaging depending on context rather than subject.

#### **2.4 Non-Practitioner Self-Disclosure**

The earliest and perhaps most influential of this research is that of Jourard, beginning in the 1950s with Jourard & Lasakow's (1958) exploration of self-disclosure among American college students indicating that factors such as gender and race may influence disclosure frequency. Further work by Jourard (1971) suggests that self-disclosure is a marker of a healthy personality, and that non-disclosure may be an indicator of two potentially damaging aspects of an individual's personality: (1) that the person does not know their 'real self' and/or (2) that they are unable to communicate it to others, both of which may lead to neurosis. Jourard (1971) further suggests that men disclose less than women, and that this may be responsible for physical and mental ill-health leading to early male mortality.

The potential effects of disclosure and non-disclosure on and by individuals have been regularly explored in the literature since Jourard's early studies. Although Jourard offered little empirical evidence for the connection between disclosure and physical and mental health, more recent evidence suggests that self-disclosure may have both mental and physical effects on those who disclose. Tamir & Mitchell's (2012) research asked participants to make disclosures about themselves, while undergoing neural imaging. Brain activity associated with reward was detected, suggesting that self-disclosure is mentally rewarding and intrinsically valuable. The researchers suggest disclosure may confer social, adaptive and learning benefits that contribute to survival through greater information sharing and cooperation. Self-disclosure speech has

been noted to reduce blood pressure (Tardy & Allen, 1998) while Pennebaker' ( 1997) empirical research and reviews of others' research studies suggest that written and verbal self-disclosure may: improve mental and physical health; improve immune function; reduce blood pressure for long periods; and reduce health centre visits, even where disclosures themselves are traumatic.

## **2.5 Practitioner Self-Disclosure: Origins, Therapeutic Approaches and Prevalence**

Practitioner self-disclosure refers to the sharing of information by practitioners with clients, patients, or service-users. Practitioners might share their experiences, identities, or how they feel about something. Disclosures might include things that practitioners choose to reveal, or things that are apparent about them because of their appearance, behaviour or because they are known outside of the therapeutic environment.

The emergence of the concept of therapist self-disclosure, and the reason for some practitioners' reticence to practice it, may be attributed to the psychoanalytic work of Freud, wherein therapists were directed against disclosure to ensure that the client remained the object of reflection in the therapeutic process, and to avoid interference with transference and countertransference (Freud, 1912; Gelso & Palma, 2011). Freud's advocacy of non-disclosure may influence the practice of some current practitioners, especially those from a traditional psychoanalytic background (Henretty & Levitt, 2010).

The idea that it is possible for practitioners not to disclose altogether has been challenged in recognition of the myriad of ways in which people disclose information about themselves in their everyday interactions (Gibson, 2012). Renik (1995) suggests that such revelations place practitioners in a state of constant disclosure, even if they consciously censor what they give away verbally. Further, disclosure is seen by some as a necessary component of some therapeutic approaches and theoretical standpoints. Relational and intersubjective therapists suggest that human relationships and interactions are central drives necessitating open, mutual dialogue between the therapist and client (Meissner, 2002; Farber, 2006). Humanistic and behavioural therapies advocate the use of self-disclosure to aid the therapeutic relationship and for the purposes of modelling behaviours and normalising experiences (Zur, 2011). Multicultural and feminist therapists cite self-disclosure as an important and central element to the therapeutic process (Henretty & Levitt, 2010), helping to reduce power imbalances between the

therapist and the client, liberate the client, and provide positive role models (Simi & Mahalik, 1997; Lundy, 1993).

Henretty & Levitt (2010) suggest that most practitioners use self-disclosure to some extent, and although practitioners from psychodynamic and psychoanalytic approaches may use disclosure less than other traditions, differences may not be great.

While much of the literature has focused on self-disclosure by therapists, other types of practitioner have been considered in the literature. Some studies have addressed the disclosure of mental illness, for example, Asad & Chreim's (2016) study of peer support workers and Geppert & Taylor's (2014) study of psychiatrists. However, most address general disclosure, rather than disclosure about mental illness, for example, Burnard & Morrison's (1995) and Ashmore & Banks' (2001) studies of nurse disclosure, and Beach et al's (2004a) study of GPs. In professional guidelines, codes of conduct and ethics, self-disclosure is rarely mentioned in relation to any of the major mental health professions, but where it is, it appears to support disclosure management, rather than avoidance (see section 2.10). Peer support workers, however are explicitly expected to reveal their lived experience of mental illness in the course of their work (see Appendix 1, peer worker job description). The impact of professional role on disclosure was investigated through a survey (see Chapters 5, 6 and 7) and through focus groups (see chapter 8). In particular, the second UK focus group focused specifically on the dynamics of disclosure for different types of mental health professional, including peer workers.

## **2.6 Types of Disclosure**

The variety, complexity and context of disclosures impedes the formation of specific, detailed rules governing whether they are beneficial. Further complexities in synthesising messages from research on disclosure include diverse contexts, methodologies and definitions of outcomes.

Since different studies have measured different things in different ways, it is difficult to draw simple conclusions about which types of disclosure are 'better' or 'worse' than others, especially since the appropriateness of a disclosure may vary according to the situation (Chelune, 1975). Outcomes are diverse, and might include clinical outcomes relating to demonstrable, measurable health and wellbeing effects on disclosers, such as reduced blood pressure (Tardy

& Allen, 1998; Pennebaker, 1997), and self-report outcomes for those disclosed to, such as feelings of warmth towards, and liking for, the therapist (Lloyd-Evans et al, 2014; Henretty & Levitt, 2010).

Despite the complexity, some researchers have sought to group disclosures into categories and evaluate their merits according to type, and these are outlined below.

### **2.6.1 Disclosures about feelings and thoughts vs disclosures of experience and identity**

Some researchers have suggested that verbal disclosures may be differentiated by whether disclosures concern the sharing of thoughts and feelings, or whether they concern sharing experiences and identities. This dichotomy is variously described as: self-involving vs. self-revealing disclosures; disclosures of immediacy vs. non-immediacy (or immediate and nonimmediate disclosures); and intratherapy vs. extra-therapy disclosures. Disclosures of thoughts and feelings may also be referred to as disclosures of countertransference. Since there is a great deal of connection between and overlap of these related terms, it is useful to consider them together rather than as discrete concepts.

Self-involving statements (Cherbosque, 1987; Audet, 2011; Watkins, 1990) are those which involve disclosure of the therapist's thoughts and feelings about the client or the therapeutic interaction. Self-involving statements may also be referred to as intratherapy disclosures (Henretty & Levitt, 2010), here and now disclosures (Knox & Hill, 2003; Audet, 2011) and disclosures of countertransference (Farber, 2006) or immediacy (Knox & Hill, 2003).

Self-revealing statements (Zur, 2011) are those which reveal an aspect of a therapist's life, experiences or identities. They may also be referred to as self-disclosing statements (Watkins, 1990), extra-therapy disclosures (Henretty et al, 2014), there and then disclosures (Knight, 2012) and nonimmediate disclosures (Knox & Hill, 2003).

There is mixed evidence about which type of disclosure is more beneficial. Knox & Hill (2003) suggest that self-involving statements can be particularly useful in the therapeutic process because they enable discussion about what is happening at the same time that it is happening, leading to more productive and intense therapeutic interactions. Henretty & Levitt (2010)

suggest that self-involving statements are more effective than self-revealing statements at eliciting positive ratings of therapists by clients. However, Henretty et al's (2014) review (incorporating some of the 2010 findings), cite several studies suggesting that extra-therapy disclosures may be particularly beneficial in counselling contexts and when working with clients who have minority identities such as Lesbian, Gay, Bisexual and Transgender clients, because such disclosures help to create a safe space, reduce stigma, and increase practitioner credibility.

In addition to mixed evidence regarding efficacy, the terms used to describe disclosure are used inconsistently. While Cherbosque (1987) refers to self-involving disclosures as involving the self through intratherapy thoughts and feelings, Knight (2012) defines self-involving disclosures as those which involve the extratherapy experiences and identities of the therapist in the interaction, and describes self-revealing disclosures as those which reveal thoughts and feelings towards the client. Although neither definition is inherently better or worse than the other, in this thesis self-revealing disclosures will refer to revelations regarding extratherapy experiences and identities, while self-involving disclosures will refer to involving the self in the therapeutic relationship by sharing intratherapy thoughts and feelings about the client or the therapeutic relationship.

### **2.6.2 Self-disclosure and levels of intimacy**

Some researchers have described disclosures dichotomously as intimate or nonintimate, and high or low intimacy (McCarthy, 1982), or have described several levels of intimacy, sometimes accompanied by an intimacy measurement scale. McCarthy (1982) defines low intimacy disclosures as those that go no further than concurring with a statement uttered by the client (for example, saying they have experienced something similar). High intimacy statements may be similar to low intimacy statements in terms of their subject matter, but they contain additional expressions of feelings about the experience from the counsellor's perspective (for example, they have experienced something similar *and* it made them feel in particular way).

The published material only refers to broad categories of disclosure (Taylor & Altman, 1966; Ehrlich & Graeven, 1971; Cunningham, 1981; Sedikides et al, 1999), and the detail of what is within each category is not usually specified. However, demographic information forms one type of low or non-intimate disclosure (Watkins, 1990), and numerous studies suggest that it

may be useful for therapists to disclose “education, theoretical orientation and professional and marital status” (Henretty & Levitt, 2010, p.72).

Henretty and Levitt’s (2010) summary of existing research suggests that lower-intimacy disclosures may be better in the initial stages of forming a relationship with clients, and that disclosures of high intimacy are generally received less favourably than those of low intimacy. However, there is no clear or consistent message, and they also warn practitioners against only making disclosures of low intimacy, as they may lack impact.

### **2.6.3 Past vs present disclosures**

Research generally suggests that disclosures might better be made about past struggles that have been overcome, rather than current or unresolved struggles (Henretty & Levitt, 2010; Knox & Hill, 2003). However, caution should be exercised, as indicating that struggles have been resolved could also be disempowering for those clients who have been unable to resolve their issues (Dilts et al, 1997).

### **2.6.4 Positive and negative disclosures**

Watkins’ (1990) review of 16 studies regarding positive and negative disclosures defines positive disclosures as those that are either positive in themselves (i.e. they relate to a positive experience or outcome) or that they agree with the experiences of the client (“I feel that way about that, too”), while negative disclosures either convey negative experiences or they are at odds with the experience of the client (“I do not share those feelings about X”). Based on client ratings of things like disclosure appropriateness, willingness to see the counsellor again, credibility of the counsellor, and ratings of relationship quality, Watkins suggests that positive self-involving statements are preferred by clients to negative self-involving statements; positive self-involving statements are also preferred to any kind of self-revealing statement; and for self-revealing disclosures the results are mixed so that no overall conclusions are able to be drawn.

Henretty et al’s (2014) review of 53 studies relating to counsellor disclosure makes a distinction between positive and negative content valence. Disclosures of positive and negative content valence might be made about intra-therapy thoughts and feelings or extra-therapy experiences. An example of an extra-therapy disclosure of negative content valence might be revealing

information such as a personal struggle, such as addiction. An example of extra-therapy disclosure of positive content valence might include sharing a story of a personal success. Intra-therapy disclosure of negative content valence might include, for example, the practitioner expressing dismay about the client's behaviour or lack of progress. Intra-therapy disclosure of positive content valence might include expressing positive thoughts and feelings about the client's progress or attributes. The review indicates that extratherapy disclosures of negative content valence can lead to more favourable ratings of counsellors compared to non-disclosure, whereas positive disclosure did not seem to have any significant effect.

### **2.6.5 Similar and dissimilar disclosures**

Disclosures of similarity are defined as those which are similar in nature to the experiences of the client, while dissimilar disclosures are not (Watkins, 1990; Henretty et al, 2014). A meta-analytic review of counsellor self-disclosure studies (Henretty et al, 2014) suggests that disclosures of similarity have beneficial effects on client perceptions of therapeutic alliance, rapport with counsellor, and willingness to disclose themselves.

### **2.6.6 Deliberate, intentional disclosures, and unintentional, accidental, unavoidable and client-initiated disclosures**

Disclosures may be deliberate or non-deliberate. Gody (1996) makes a distinction between intentional disclosures and unintentional disclosures. Intentional disclosures are analogous to deliberate disclosures (Zur, 2011). Unintentional disclosures are those that happen without planning or deliberate action, perhaps because a practitioner is seen outside of the therapeutic context, for example with their partner or children, and these are analogous to unavoidable disclosures (Zur, 2011). Unintentional disclosures overlap with accidental disclosures, wherein practitioners may say something that they did not wish to reveal, perhaps as a result of being unexpectedly asked a direct question by a service-user or client (Bottrill et al, 2010).

## **2.7 Benefits of Practitioner Disclosure**

Various benefits have been associated with disclosure. Gorkin (1987, cited in Maroda, 1999) suggests that self-disclosure by practitioners can be beneficial by verifying something that the client believes to be real, establishing the honesty, genuineness and humanness of practitioners,



helping the client to understand how their behaviours impact on other people, and overcoming treatment impasses. Others have suggested that disclosure may help to equalise power between the therapist and the client, normalise clients' experiences (Glessner et al, 2012), be reassuring (Knox & Hill, 2003), and establish authenticity and demonstrate congruence (Burks & Robbins, 2010). Disclosure may also have positive benefits for practitioners, for example being "out" at work regarding sexual orientation can reduce anxiety and increase job satisfaction (Griffith & Hebl, 2002), and the disclosure of mental health conditions by practitioners may reduce the negative effects of non-disclosure (Newheiser & Barreto, 2014).

Practitioner disclosure may increase client disclosure (Henretty and Levitt, 2010). This may be helpful because some level of patient disclosure is a necessity for therapy to work since even non-verbal therapies, such as art and music therapies rely on some form of personal expression (Farber, 2006). Increased self-disclosure by clients may have several other benefits, including offering opportunities for: increased intimacy (the ability to communicate about feelings and thoughts); validation and affirmation (being accepted and reassured); forming a stronger (and positive) personal identity; self-differentiation (understanding different aspects of the self); authenticity (being true to self and others); and catharsis (getting things out in the open and dealt with) (Farber, 2006).

Henretty & Levitt's (2010) review considered the findings from more than 30 quantitative studies and concluded that overall, although the evidence is mixed, practitioner self-disclosure: was more beneficial than non-disclosure; increased clients liking for practitioners; increased client self-disclosure; and that extra-therapy (self-revealing) disclosures were less effective than intra-therapy (self-involving) disclosures. Although this latter conclusion should be treated with caution as Henretty et al's (2014) review suggests that extra-therapy disclosures are more effective than intra-therapy disclosures, nevertheless both reviews suggest that both intra and extra-therapy disclosures are more beneficial than non-disclosure.

## **2.8 Risks of Practitioner Disclosure**

Practitioner disclosure in clinical contexts is often seen as a controversial subject (Audet, 2011), leading to negative consequences for practitioners and service-users:

“Every clinician must grapple with the difficult issue of psychotherapist self-disclosure. Although sharing personal information, reactions, and experiences may at times be therapeutic, it must be done with great caution. More than just a therapeutic technique, therapist self-disclosure may at times be the first step toward boundary violations of increasing magnitude. With each additional disclosure, boundaries may be violated, roles reversed, and patients harmed.” (Barnett, 1998, p.420).

As the above quote illustrates, disclosure may be described as a slippery slope leading to boundary violations (Barnett, 1998; 2011; Bottrill, et al, 2011); or running counter to client preferences for non-disclosure so that the therapist remains anonymous or neutral (Guthrie, 2006; Barnett, 2011).

In contrast the suggestion that it is more useful to disclose successfully resolved, rather than current or negatively resolved past struggles (Gelso & Palma, 2011; Knox & Hill, 2003), self-disclosure of resolved struggles might negatively impact on clients because they fear they will be unable to overcome their difficulties as successfully as they presume the practitioner has (Dilts et al 1997). Where disclosures do concern past struggles or difficulties, particularly around previous conditions or addictions, clients may also worry about the potential for practitioner relapse (Mallow, 1998), perhaps leading clients to censor their own disclosures for fear of negatively impacting on the practitioner (Audet & Everall, 2010).

Farber draws on the work of Kowalski (1999, in Farber, 2006) to consider some of the potential drawbacks of self-disclosure. Disclosure may burden service-users, while for practitioners drawbacks include the risk of rejection; being judged negatively; becoming vulnerable; feeling ashamed of things that have been disclosed; and potentially being judged negatively for not having disclosed at some earlier opportunity.

Disclosure may invalidate the practitioner to service-users, based on the assumption that having lived experience of mental illness is detrimental to their capacity to help:

“The patient must believe at some level that the analyst is healthier than him- or herself. You would have to be crazy to seek help from somebody you believed to be as troubled or more disturbed than yourself.”

(Gody, 1996).

Practitioner self-disclosure may detrimentally move the focus of interactions away from the client towards the problems and issues of practitioners (Dewane, 2006), perhaps causing clients to feel responsible for the welfare of the practitioner, or feel that the practitioner only wants to talk about themselves (Wells, 1994, cited in Audet & Everall, 2010). Disclosures that are poorly executed, with little or no relevance to the client's position or experience, may indicate the practitioner does not understand their situation (Audet & Everall, 2010).

There are some claims that disclosure may interfere with the process of transference within the therapist-client relationship. The exploration of transference is intended to help service-users understand the origins of current issues and difficulties in their external or previous relationships (Dewane, 2006). Self-disclosure might thwart pure exploration of the client's fantasies, assumptions, and beliefs by undermining the therapist's 'blank screen' status and exposing the 'reality' of the situation. Counter-arguments suggest that the therapist is never a 'blank screen', that transference can be explored effectively even when clients have access to real, accurate or disclosed information about the practitioner (Eagle, 2000; Hanly, 1998), and that examining clients' extra-therapy relationships may be as effective as focusing on transference (Hoglund et al, 2006).

Despite potential benefits, with all the potential dangers of disclosure it is understandable that practitioners might seek to avoid making disclosures to protect themselves and service-users from risk.

## **2.9 Practitioner Non-Disclosure**

To avoid the risks and controversies associated with disclosure practitioners might reasonably choose not to disclose. However, there are drawbacks to non-disclosure, which fall into two main categories: the first is that non-disclosure is impossible (and therefore as a strategy, ineffective); the second is that non-disclosure carries its own risks and can result in negative outcomes for both practitioners and service-users.

Under-disclosure (as well as over-disclosure) can be detrimental to clients' perceptions of practitioners (Egan, 1990, cited in Ashmore & Banks, 2001). In addition to preventing verification of a person's attitudes, values and personality (Forgas, 1985, cited in Ashmore & Banks, 2001),

non-disclosure may harm the therapeutic relationship (Gibson, 2012), and cause client distress especially where they have a preference for practitioners of a particular identity (Evans & Barker, 2010) by enabling incorrect assumptions about practitioners' personal characteristics to exist unchallenged (Maroda 1999).

Concealment of personal information might afford benefits such as reducing shame associated with disclosing, or enabling stigmatised individuals to construct and present a desirable self-image (see Kelly, 2000, in Farber, 2006). However, hiding stigmatized identities, including mental health experiences, might also have negative effects such as increased feelings of isolation and inauthenticity, reduced disclosure of non-stigmatized information, and being seen less positively by others (Newheiser & Barreto, 2014). In contrast, being 'out' at work regarding sexual orientation can reduce anxiety and increase job satisfaction (Griffith & Hebl, 2002), while concealment of sexual orientation may render practitioners complicit in their own oppression to the detriment of practitioners and clients alike (Wolfe, 2009).

Successful concealment relies on the possibility that an experience, identity, feeling, thought, or personal characteristic is concealable. Meissner (2002, p. 854) suggests that there is a "false dichotomy between openness and disclosure versus detachment and withdrawal", because concealment is not always possible. People might 'be known' by such means as visible or detectable signs (Goffman, 1963; Silverman, 2001), including: how they dress, or the photos they display in their offices (Raines, 1996); whether they are visibly pregnant (Silverman, 2001; Hjalmarsson, 2005); unintentional body language (Meissner, 2002); the direction in which they steer conversations and interactions which reveals their motivations and intentions (Meissner, 2002; Renik, 1995); their manner of speaking (Meissner, 2002); and the level of detail of their knowledge on particular subjects which might give away real or perceived information about them (Singer, 1977, cited in Renik, 1995). Expressions of empathy give away information about the practitioner's personality and emotions (Meissner, 2002), while silences, omissions and refusals may reveal information that leads to correct or incorrect assumptions about the personality of the therapist (Fischer & Apostol, 1975; Renik, 1995).

One of the intentions of non-disclosure is to foster neutrality to enable the effective examination of transference. However, Stolorow & Atwood (1997, p.433) suggests that consistent non-disclosure may provoke "... hostility and tempestuous conflicts that are more an artefact of the analyst's stance than a genuine manifestation of the patient's primary psychopathology."

Practitioners may therefore be drawn into examining behaviours and attitudes in clients that otherwise might not have been there, on the false assumption that they are created in external or previous relationships with other people:

“...regression transference neuroses, thought by many to be a sine qua non of an analytic process, may actually be iatrogenic reactions to the indiscriminate application of the principle of abstinence.”

(Stolorow & Atwood, 1997, p.433)

Taking all of this together, whether practitioners choose to disclose or not, it is arguable that they are always disclosing something. Like disclosure, non-disclosure may shape service-users' views about practitioners, with potential positive or negative effects.

### **2.10 Guidelines on Self-Disclosure**

The risks and benefits associated with disclosure and non-disclosure are contested. For each assertion of benefit there is typically a counter-argument concerning risk, and vice versa. Planning ahead may help practitioners to make decisions about disclosure to maximise potential benefit, minimise potential risk, and avoid making accidental or inappropriate disclosures “in the moment”, perhaps in response to a client’s question, that they later regret (Bottrill et al, 2010). However, the lack of training and guidance on the subject has been highlighted by several researchers:

“... contradictory empirical findings and theoretical conceptualizations, teamed with ambiguous ethical guidelines (Domenici, 2006) and little to no training as to the nature and use of therapist self-disclosure (Beutler, Crago, & Arizmendi, 1986), may leave therapists feeling vulnerable and anxious about self-disclosing (Hill & Knox, 2002; Knox & Hill, 2003).”

(Henretty & Levitt 2010).

Knox & Hill (2003) and Hill & Knox (2001) offer some pointers on the types of things that practitioners should think about when choosing whether to disclose, including: to whom will disclosures be made; what will be disclosed; when will it be disclosed; why will it be disclosed; how will it be disclosed; how often to disclose; and how does the client respond

to disclosure. However, these guidelines are written in a general way and do not address the disclosure of mental health conditions and experiences in mental health settings. This is not surprising, since mental health disclosure is given scant regard throughout the disclosure literature. It may also be important not to dehumanise practitioner-client interactions by subjecting them to cost-benefit analysis. As Dewane (2006, p. 555) cautions: “sometimes a question is just a question”

### **2.10.1 Disclosure in professional guidelines and ethical standards**

Therapeutic affiliation, as mentioned earlier in this chapter, might account for why trained therapists favour some types of disclosure over others, with those who come from traditional psychoanalytic backgrounds perhaps favouring non-disclosure more than those who do not. However, therapists, and the wider mental health workforce, are diverse. They may be trained in a variety of different medical, psychological, and social approaches, and their practice may be informed not only by their professional training, but also by messages from research and their profession’s guidelines or ethical standards.

Since there is a lack of research on the content of pre-qualifying training regarding self-disclosure across the mental health workforce, it may be useful to look at the professional guidelines and ethical standards relating to the mental health workforce to see if they offer any guidance on self-disclosure, particularly since anecdotal evidence from the NHS Trust involved in this research suggested that practitioners have cited codes of conduct as a reason not to disclose.

Relevant codes of conduct, standards and ethics are included in table 2.1, below (a detailed version can be seen in Appendix 3). Each of these documents was searched for references to disclosure; boundaries, since anecdotal evidence suggests that self-disclosure can be conflated with boundary violations; and maintenance of personal mental health, since a perceived need to project a mentally healthy self-image might result in practitioners feeling the need to conceal mental illness.

Table 2.1: Codes of practice, standards and ethics relevant to mental health practitioners

Practitioner job type	Relevant codes of conduct, standards and ethics	Self-disclosure	Boundaries	Mental health
Nurse, midwife	The Code: Professional standards of practice and behaviour for nurses and midwives (Nursing and Midwifery Council, 2015)	Yes	Yes	Yes
Doctor (Consultant, doctor, psychiatrist)	Good Medical Practice (General Medical Council, 2014); Good Psychiatric Practice Code of Ethics (Royal College of Psychiatrists, 2014); On professional boundaries (Royal College of Psychiatrists, 2013a); Recommendations for psychiatrists on spirituality and religion (Royal College of Psychiatrists, 2013b); Personal beliefs and medical practice (General Medical Council, 2013)	Yes	Yes	Yes
Psychologist	Code of Ethics and Conduct (The British Psychological Society, 2009); Standards of Proficiency – Practitioner Psychologists (Health and Care Professions Council, 2015d); Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	Yes	Yes	Yes
Social worker	Code of Ethics for Social Workers (British Association of Social Workers 2012); Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016); Standards of Proficiency – Social Workers in England (Health and Care Professions Council, 2017a)	No	Yes	Yes
Dietitian	Standards of Proficiency – Dietitians (Health and Care Professions Council, 2013a); Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	No	Yes	Yes
Occupational therapist	Standards of Proficiency – Occupational Therapists (Health and Care Professions Council, 2013b); Code of Ethics and Professional Conduct (College of Occupational Therapists, 2015); Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	No	Yes	Yes
Physio-therapist	Standards of Proficiency - Physiotherapists (Health and Care Professions Council, 2013c); Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	No	Yes	Yes
Psycho-therapist Counsellor	Ethical Framework for Good Practice in Counselling (British Association of Counsellors and Psychotherapists, 2016)	No	Yes	Yes

All of the professional groups listed have guidance or codes issued by registering or regulating bodies. All professions have at least one document that addresses the need to maintain boundaries. Most codes do not mention self-disclosure. Of the few that do mention self-disclosure (in relation to doctors, nurses, and counselling psychologists), none prohibit its use.

There is no suggestion in any document that self-disclosure constitutes a boundary violation of itself.

There is one direct and fairly neutral mention of disclosure contained in the *Standards of Proficiency – Practitioner Psychologists* (Health and Care Professions Council, 2015d), which states that, specifically in relation to counselling psychologists only, they should “be able to critically reflect on the use of self in the therapeutic process” (p. 12). However, there are sections in other codes and guidance that could be interpreted as deterring or warning against disclosure. The Nursing and Midwifery Council warns nurses to:

“make sure you do not express your personal beliefs (including political, religious or moral beliefs) to people in an inappropriate way”

(Nursing and Midwifery Council, 2015, p.15).

Doctors receive similar warnings from their regulatory body the General Medical Council (GMC):

“You must not express your personal beliefs (including political, religious and moral beliefs) to patients in ways that exploit their vulnerability or are likely to cause them distress.”

(General Medical Council, 2013 p.1).

“If you disclose any personal information to a patient, including talking to a patient about personal beliefs, you must be very careful not to breach the professional boundary that exists between you”

(General Medical Council, 2013, p.5)

However, neither of these prohibits disclosure, and simply warn that disclosure should be appropriate and not be accompanied by, or lead to, boundary violations. The GMC make this more explicit when they directly indicate that doctors:

“...may talk about your own personal beliefs only if a patient asks you directly about them, or indicates they would welcome such a discussion. You must not impose your beliefs and values on patients, or cause distress by the inappropriate or insensitive expression of them”



(General Medical Council, 2013, p. 6)

The most explicit consideration of self-disclosure is made in a guidance leaflet produced by the Royal College of Psychiatrists, which states the potential positive uses of disclosure, and that it should be well-managed rather than avoided:

“EXCESSIVE PERSONAL SELF-DISCLOSURE. As in personal relationships, in a professional setting personal disclosure typically has the effect of bringing the two parties closer together, whereas excessive disclosure radically changes the dynamic, so that the focus shifts from the patient to the professional. In almost every case of violations of sexual boundaries there are a series of steps taken on the way, always including a significant increase in self-disclosure by the clinician. Care needs to be given to the how and when of disclosures, and open discussion with colleagues and mentors is essential.”

(Royal College of Psychiatrists, 2013a)

Since all professions have at least one governing document that prohibits boundary violations, this emphasis may encourage over-vigilance regarding boundary enforcement and professional distance. While none of the guidance prohibits disclosure or suggests that it constitutes a boundary violation in its own right, nevertheless guidance may be interpreted as a warning not to use disclosure in case it is used improperly, or is interpreted as a boundary violation. Fear of using disclosure inappropriately and being sanctioned for it may also be understandable given a recent case where a social worker was struck off the Health and Care Professions Council (HCPC) register because of misconduct, in which one of the allegations was that she had shared personal information with a client (Community Care, 2017). However, in this case, the HCPC did not judge that self-disclosure amounted to misconduct, and the registrant was struck off for other reasons (Health and Care Professions Council, 2017b).

### **2.11 Sharing lived experience.**

Service-user perspectives and experiences were strengthened by emergent consumerist approaches in the 1990s, particularly in the field of mental health (Barnes et al, 2000), and service-users have become recognised as experts by experience rather than passive recipients of services delivered by trained experts (Skilton, 2010). This may account for the growing recognition of the importance of lived experience in the delivery of mental health services.

Most of the literature that relates to the sharing of lived experiences uses the term 'self-disclosure'. Where the term 'lived experience' is used, its meaning tends to be implied within considerations of where and how it is used, rather than defining what it is. Bassett et al's (2010) *Lived Experience Leading The Way: Peer Support in Mental Health* makes numerous references to sharing lived experience, such as "peer support is about people with lived experience supporting each other in their wellbeing journey" (p.9), and notes "the expertise of lived experience"(p.3), while Bradstreet's (2006) *Harnessing the 'lived experience': Formalising peer support approaches to promote recovery* refers to service-users "sharing part of their own lived experience to offer hope and practical assistance of recovery to others" (p.3). Stanley and Wise (1993), emphasise that lived experience is peculiar to the individual and multi-faceted. However, none of these sources offer a full definition.

Although definitions are elusive, what appears to be consistent when researchers and practitioners refer to lived experience is that it is subjective, peculiar to the individual, and that it affords expertise that only the individual who has lived that experience might possess. Sharing lived experience appears to be most closely related to self-disclosure of extratherapy experiences, and there is an implicit recognition of individuals having some claim to privileged knowledge and expertise because of their experiences or identities, as opposed to knowledge learned through training.

For the purposes of this thesis, then, sharing lived experience refers to information about the self that one person might share with another. This information is mainly about, but not restricted to, extratherapy experiences and identities. The primary topic of lived experience that might be shared concerns, but is not restricted to, mental health.

## **2.12 Conclusion**

The literature that relates to sharing information by practitioners with service-users primarily refers to self-disclosure rather than sharing lived experience, but aspects of self-disclosure can be roughly equated with sharing lived experience. Evidence is mixed on the efficacy of self-disclosure, and on what parameters efficacy might best be measured. However, overall, there is good evidence to suggest that disclosure, as opposed to non-disclosure, is beneficial on a number of indicators, including how positively the service-user views their relationship with the

practitioner, which may be an important factor contributing to the effectiveness of interventions.

There are three major limitations of the literature:

1. The majority of the studies that Henretty & Levitt (2010) and Henretty et al (2014), as well as other researchers including Newheiser & Barreto (2014), cite used analogue methodology, which means they used a substitute population or a simulated situation for all or part of the study instead of a real practice situation or a clinical population. In fact, only two out of the 53 studies examined in Henretty et al's (2014) review used a clinical population (presumably for ethical or practical reasons). There is a need to conduct studies with clinical populations.
2. Most studies examine self-disclosure in general. Most of them do not specifically examine the disclosure of mental health experiences or identities. Where studies do mention mental health disclosure, it tends to be given little emphasis and limited consideration.
3. Where mental health identities are mentioned (for example, Newheiser & Barreto, 2014) it is not in relation to mental health practitioners and their clients.

The applicability of the findings to self-disclosure by mental health practitioners with mental health service-users is therefore relatively unexplored, and this will form the topic of the scoping review in the following chapter.

### **Chapter 3: A Scoping Review of Sharing Personal Mental Health Lived Experience in Mental Health Settings**

#### **3.1 Introduction**

This chapter comprises a scoping review of the literature to date on self-disclosure by practitioners to service-users regarding their personal mental health lived experiences. It reflects on some of the wider literature on general self-disclosure before focusing specifically on the disclosure of mental illness, conditions and experiences. Section 3.2 outlines the process of searching for relevant studies, inclusion and exclusion criteria, collating and screening of results, data extraction, and quality appraisal. Section 3.3 describes and tabulates the findings from various empirical and non-empirical papers on the subject. Since this review was originally undertaken in 2013-14, a repeat search was undertaken in 2017 to capture and include subsequent publications, and this is also included. Section 3.4 discusses the results and comments on gaps in the current literature, and a summary conclusion is contained in section 3.5.

Involving service-users in the delivery of mental health interventions has a long history, from the work of Harry Stack Sullivan in the 1920s in recruiting men who had experienced mental health conditions to support psychiatric hospital inpatients in America (Davidson et al., 1999), to the involvement of peers in early pilots as “case management aides” in the 1980s (Sherman & Porter, 1991, p.494). More recently, peer support services have established themselves in tandem with the growth of the recovery model (Davidson et al, 2006) beginning in the US and taking hold in the last few years in the UK (Lloyd-Evans et al 2014).

A number of terms have been used to describe peer workers, including consumer-professionals, prosumers (Schiff, 2004), peer providers (Solomon, 2004), and peer consumers and peer support workers (Repper & Carter, 2010). The literature on peer support suggests that peer workers are commonly seen as providing services that are distinct and different to the services offered by other mental health professionals who may or may not have lived experience of mental health conditions. The mental health status of peer workers is generally known by service-users and other practitioners, either through disclosure, or automatically by their job title. However, there is no equivalent expectation for non-peer practitioners to share their lived experience. While a plethora of studies have addressed the general topic of self-disclosure by practitioners with

clients, they rarely focus on the disclosure of mental health conditions by practitioners outside of the peer support role.

Jourard investigated the topic of self-disclosure more than five decades ago (Jourard & Lasakow, 1958), developing a measurement scale that has been repeatedly used, adapted and tested by various investigators since. Burnard & Morrison (1994) used the Jourard Self-Disclosure Questionnaire (JSDQ) with nursing students to measure their level of disclosure to different family members and same and opposite sex friends, and Ashmore & Banks (2001) adapted the questionnaire for use with mental health nursing students, crucially adding *patients* to the list of people that respondents might disclose to. Respondents in Burnard & Morrison's (1994) study tended to disclose more frequently than in Jourard's (1961), suggesting that people may disclose more today than in the past, a possible trend that is also noted (with caution, due to differences in sample sizes and compositions) in Ashmore & Banks' (2001) study. The latter study also suggested that the frequency of self-disclosure might be associated with age, since the mean age of subjects in the 2001 study was higher than in the Jourard's (1961) & Burnard & Morrison's (1994) studies. Ashmore & Banks (2001) found that nurse respondents disclosed less to patients than they did to other target persons, such as friends or family, which they suggest may indicate a lack skills around disclosure, or concerns about with risk, concluding "we do not understand how patients perceive disclosure by nurses and its impact on the therapeutic relationship... educational programmes need to ensure that students are competent in the use of the skill of self-disclosure within the therapeutic process" (Ashmore & Banks, 2001, p. 56). It is unclear why, Ashmore & Banks (2001) assume that practitioners ought to be competent in using disclosure (rather than avoiding it) if they do not know what impact disclosure has on nurse-patient relationships. It may be the case that the potential benefits of general disclosures highlighted in other studies (see, for example, Henretty & Levitt, 2010 for a review of the literature) are assumed to extend to other types of disclosure, such as personal mental health experiences, in all settings including mental health services. However, studies on self-disclosure have rarely taken place in mental health settings, and rarely address self-disclosure of mental health conditions and experiences.

While there is little consideration of the mental health dimension of self-disclosure by practitioners with service-users, research and literature on self-disclosure in general is vast. Henretty and Levitt (2010) offer a systematic review of research on self-disclosure by psychotherapists, identifying and describing a wide range of empirical studies reporting mixed outcomes, with some studies indicating positive, and others indicating negative outcomes on various dimensions. Some general conclusions are paraphrased from this study: self-disclosure has a more positive effect on clients than non-disclosure; it can increase clients' perceptions of a therapist's likeability, attractiveness & warmth; it can increase client self-disclosure; self-involving disclosures are more effective than self-revealing disclosures; and therapists are more reluctant to disclose to clients who have been diagnosed with a personality disorder. The authors identify several issues with current evidence on self-disclosure, mainly that its conflicting nature makes it difficult to draw concrete conclusions from the material available at the present time, but also that much of it relies on 'analogue methodology' whereby studies are undertaken in simulated situations (for example, video enactments and vignettes) calling into question their applicability to real therapy conditions. Key messages, however, suggest non-disclosure is not a viable option, and that there is good reason for practitioners to consider the issue of self-disclosure in some depth, mainly because of the potential benefits it may have (Henretty & Levitt, 2010; Knox & Hill, 2003).

### **3.1.1 Analogue methodology**

Some studies use analogue and others use non-analogue methodology. The distinction between the two is not always neat. At one end of the spectrum, non-analogue studies might examine phenomena that occur within a natural context, such as direct observations in a practice setting, or gather views and observations from practitioners and service-users in practice settings. At the other end of the spectrum, researchers may not be able to undertake research in natural settings for various reasons (for example, ethical considerations, human or financial resources, or time), and may instead use analogue methods, such as simulations and proxies. Simulations could include using vignettes or videos of real or acted practitioners interacting with real or acted service-users, while proxy populations might include gathering the views of students or the general population instead of mental health practitioners or service-users.

Beach et al's (2004a) study of physician self-disclosure to patients offers an example of a non-analogue method, wherein audio recordings were taken of interactions between 124 physicians and 1,265 patients in consultations, then analysed to identify types and frequencies of disclosure. This study was rejected from this scoping review because it did not occur in a mental health setting, nor say anything explicitly about mental health disclosures. However, it provides a useful example of non-analogue methodology because it took place with real physicians and real patients in real practice settings. Another example of a non-analogue study that does make it into this review is Cabral et al's (2014) study, wherein the researchers undertook interviews with peer specialists to gain their views on their role. Although it is not possible within a study such as this to verify the truth of any claims that participants make, the study is non-analogue because it seeks the views of real peer specialist workers, reflecting on their actual role and practice.

Other studies take analogue approaches. An example of an analogue approach (one that does make it into this scoping review) is Armour's (2007) study investigating whether 356 therapy-seekers' views of a potential therapist are affected by knowing about the therapist's personal therapy experiences. It is analogue because it does not use real therapy seekers, but 356 college students, who are (presumably) not actually seeking therapy themselves and have no identified mental health condition, and instead of real therapists, it uses descriptions of fictional therapists who either do or do not disclose their personal therapy experiences.

Some studies contain a mixture of both analogue and non-analogue elements. Abramsky's (2013) study of aviophobic people considers whether practitioners' disclosure of having undertaken aviophobia therapy themselves influences aviophobics' perceptions of them. Abramsky questions the applicability of analogue methodology to real-life situations, and attempts to move away from purely analogue methodology by recruiting people who have a demonstrable fear of flying as measured by a validated measurement scale. However, the study involves university students as a proxy for people who are really seeking therapy; it uses videos of practitioners instead of real interactions with practitioners; and it does not take place in real-life therapy situations. This study, therefore, although relevant, would be described as analogue within this scoping review.

Analogue studies may be methodologically robust, and they may reveal useful information about the investigation subject: after all, mental health service-users and practitioners are people, and as such they may have much in common with other populations of people. However, real practice situations, where real service-users with real mental health conditions interact in real settings with real mental health practitioners, may introduce dynamics which influence the way in which sharing lived experience is viewed, so the applicability of analogue studies to real situations and people is questionable (Hill & Knox, 2001). For the purposes of this scoping review, analogue studies are those that take place using one or more of the following: proxy service-users; proxy practitioners, or proxy (simulated) situations.

### **3.1.2 Guidance**

Guidance, where it exists, is general in nature, rather than mental-health specific. Henretty & Levitt (2010) offer some broad guidelines regarding what may be disclosed, when, why and how. One message is that disclosure may be more useful and beneficial where practitioners have a strong alliance or relationship with service-users and where they are members of the same community, for example LGBT (Lesbian, Gay, Bisexual or Transgender), because this may reduce stigma and increase trust. Knox & Hill (2003) also offer some broad guidelines on self-disclosure, including that infrequent use is more effective than extensive use (and, according to their research, it usually *is* used infrequently); and that consideration should be given to: the appropriateness of disclosures; how intimate disclosures are; the needs of the client; the reason for disclosing; keeping the focus on the client; the type of disclosure (self-involving rather than self-revealing); and disclosing resolved issues rather than ongoing struggles. However, while Henretty & Levitt (2010) suggest that it may not be wise to disclose to clients with personality disorder, neither they, nor Knox & Hill (2003) makes any specific mention of the mental health condition of the therapist except in a general way (for example, warning against the disclosure or unresolved struggles or addictions).

### **3.1.3 Why this research is needed now**

Given the recent increase in support for peer support programmes on a national basis in the UK (Gillard, 2013) the subject of how lived experience might benefit service-users is pertinent at the current time. Societal shifts towards greater openness and an increase in explorations of identity since the 1960s (Farber, 2006) suggest that sharing personal characteristics and



experiences is a contemporary issue that warrants investigation. Although it is widely asserted that disclosure should primarily be for the benefit of service-users, and Henretty & Levitt's (2010) systematic review suggests that indeed there are demonstrable benefits for service-users, researchers from Jourard (1971) to Pennebaker (1997) suggest that being open and transparent may also be beneficial to both the physical and mental health of the discloser.

Davidson et al (1999), in their review of the literature on mental health peer support, identify three forms of peer support: mutual support (for example, support groups); services that are run by consumers; and "the employment of consumers as providers within clinical rehabilitative settings" (p.165). While people with previous or current mental health conditions might be employed in any number of clinical roles and settings, the literature appears to focus on those who are employed in peer support roles, roles that are additional to clinical roles (Davidson et al, 1999; Sherman and Porter, 1991). This review explores the literature relating to a fourth category: the involvement of people who have experienced mental health conditions who are employed in mainstream, rather than peer support, mental health roles.

## **3.2 Method**

### **3.2.1 Database searches**

A literature search was undertaken using the following databases:

- a) ProQuest: including ASSIA (Applied Social Science Index); PILOTS (Published International Literature on Traumatic Stress); and Social Services Abstracts.
  
- b) Social Policy and Practice (Ovid). All resources selected including: AMED (Allied and Complementary Medicine); Econlit; Embase; HMIC (Health Management Information Consortium); Inspec Archive - Science Abstracts; Maternity and Infant Care; Ovid MEDLINE(R); PsycINFO; Social Policy and Practice
  
- c) Social Care Online (Social Care Institute for Excellence).

The following search terms were used:

- a) Self-disclos\* or “self disclos\*” (to include self-disclosure, self-disclose, and self-disclosing)

OR

“shar\* lived experienc\*” or “shar\* lived-experienc\*” (to include share, shared and sharing; and lived-experience and lived-experiences)

AND either

- b) Mental health

OR

- c) Mental health conditions including:

- I. Anxiety
- II. Psychosis
- III. Schizophrenia
- IV. Bipolar
- V. Depression
- VI. PTSD
- VII. Cognitive (to cover illness, impairment etc)
- VIII. Mental (to cover mental illness, impairment, disorder etc)
- IX. Emotional (to cover range of emotional conditions)

OR

- d) Mental health practitioners including:

- I. Doctor
- II. GP
- III. Nurs\* (to include nurse/s or nursing)
- IV. Therap\* (to include therapy or therapist)

- V. Counsel\* (to include counselling, counsel, or counsellor/s)
- VI. “occupational therap\*” (to include occupational therapy or therapist/s)
- VII. “social work\*” (to include social work or social workers)
- VIII. Psycholog\* (to include psychologist, or psychological)
- IX. Psychiatr\* (to include psychiatrist or psychiatry)

A second search, using the same databases, was conducted using the following terms:

- a) “Mental health”

AND

- b) “Peer support\*” (to include peer support and supporter/s)

OR

- c) “Peer mentor\*” (to include peer mentor/s and mentoring)

This search was primarily for wider contextual purposes, though the results were checked to see if any of the articles were relevant for the scoping review.

### 3.2.2 Additional searches:

After searching the databases and sifting and screening the results, the references list for each retained study was checked for further relevant articles that had not previously been identified.

### 3.2.3 Inclusion criteria

Articles were retained if they were wholly or partly about, or made mention of, the following criteria:

- a) ***Practitioner disclosure in mental health/therapy settings.*** The focus of the current research is to investigate how disclosures are viewed within a mental health setting, so review articles should have investigated disclosure within similar settings in order to be comparable. Pietromonaco et al (1992) studied whether recipients’ perceptions of

discloser empathy are affected by whether they both have lived experience of depression, however, articles such as this were rejected because participants were neither mental health practitioners nor service-users, and there was no attempt to draw analogue comparisons with mental health settings. Other studies have examined the impact of self-disclosure by therapeutic group leaders (May & Thompson, 1973; Dies, 1973; Weigel et al, 1972), but they are rejected (apart from pre-dating the post-1990 inclusion criterion) because they focused on disclosure in general (rather than mental health disclosure), the participants were not mental health service-users, and/or disclosure did not take place in mental health settings but in other forums such as university-campus encounter groups. Schools, universities, physical health organisations, and other non-mental health organisations may be very different to mental health settings regarding their approaches, philosophies, cultures, histories, policies, professional standards, and relationship dynamics between service-users and staff. Disclosure between participants in such organisational settings would be a different topic for review.

- b) ***Self-disclosure of the practitioner's mental health.*** Since the current research topic focuses primarily on the disclosure of mental health conditions, this literature review seeks to review research that focuses on this particular subject. For example, Ashmore & Banks (2001; 2002; 2003a; 2003b) undertook research on disclosure in mental health settings with mental health practitioners, but disclosure topics did not include sharing personal experience of mental health conditions, and are therefore irrelevant to this investigation.
- c) ***Self-disclosure to clients.*** This criterion seeks to exclude studies that investigate self-disclosure: to colleagues (for example, Lefley, 1987, which also pre-dates the post 1990 inclusion criterion, or Peters & Brown, 2009); to family members and friends (Jourard, 1971; Pennebaker, 1997); and by clients to practitioners (Pennebaker, 1997) which are numerous but irrelevant to this study.

#### 3.2.4 Exclusion criteria

- a) Articles pre-1990. Although searches were initially conducted without date restriction, the decision was made to restrict the results to 1990 onwards, in line with the emergence of the recovery model and the rise of peer mentor programmes since the 1990s (Davidson, 2006). In addition, Farber (2006) suggests disclosure in psychotherapeutic contexts tends to be post-1990, with pre-1990 research focusing on disclosure in everyday contexts.
- b) Articles about peer support programmes, unless they explicitly focus on, or cover, the sharing of mental health lived experience.
- c) Non-peer reviewed articles (except for dissertations); letters to journals, editorials and opinion pieces, unless highly relevant (though these checked for useful references or perspectives).
- d) Papers that only briefly mention the subject of investigation. For example, articles that briefly mention practitioner disclosure of mental health experience with service-users, but do not investigate the subject, discuss the subject in any depth, or draw relevant conclusions or recommendations about the subject.
- e) Articles about self-involving disclosures, or refer only to counter-transference, which reflect intratherapy disclosures rather than disclosures about the practitioner's identity or experiences.
- f) Articles about working with people under the age of 18, since the present study focused on adult mental health services. However, any articles that appeared in search results were checked in case they contained relevant material.
- g) Articles about non-practitioner disclosure (for example, service-user disclosure, disclosures between partners, friends, or strangers, or disclosure by employees to employers), because the current study focused on disclosures made by mental health practitioners.

### 3.2.5 Collating search results

Results for each of the search terms are presented in the table below. The sifting was undertaken in the following stages:

- A. For each search term, for example, “mental health AND self-disclosure OR sharing lived experience”, results were obtained from the various databases as previously described giving a total of 10,044 results (see column A for breakdown per term).
- B. Results were downloaded to Endnote, amalgamated, and duplicates were removed, leaving 6,164 items (breakdown per term is presented in column B).
- C. Pre-1990 articles were then removed, leaving 4,974 items (see column C for breakdown per term).
- D. When all search terms were later amalgamated into one group, some articles, although only appearing once in each search, appeared in several searches (i.e. up to ten times, once in each of up to ten term searches), so further duplicates were again removed, resulting in a final count of 2,848 results.

Table 3.1: Scoping review search terms and results

Search term 1	Search term 2	A. Total	B. After duplicates removed (within each search)	C. After pre-1990 removed
Mental health	self-disclosure or sharing lived experience	436	293	239
Doctor OR physician OR GP	self-disclosure or sharing lived experience	202	109	105
Nurse/s or nursing	self-disclosure or sharing lived experience	312	194	161
Therapist OR therapy or therapeutic	self-disclosure or sharing lived experience	2,124	1,406	1,078
Social work or worker/s	self-disclosure or sharing lived experience	215	181	167
Psychologist	self-disclosure or sharing lived experience	2,147	1,133	780
Psychiatrist or psychiatry	self-disclosure or sharing lived experience	290	175	127
Occupational therapy or therapist	self-disclosure or sharing lived experience	20	19	18
Mental health	"Peer support*" or "Peer mentor"	1,721	1,062	1,038
"Self-disclos*" OR "Shar* lived-experience*"	Anxiety or Anxious or Psychosis or Psychotic*Schizophreni* or Bipolar or Depress* or PTSD or "post traumatic stress disorder" or Cognitive* or Mental* or Emotional*	2,577	1,592	1,261
Total results, all terms		10,044	6,164	4,974
D. Combined results with duplicates removed again				2,848

### 3.2.6 Screening search results

Screening the results was undertaken in the following way:

- a) **Title:** articles were rejected where the title made it clear that the subject was not related to the topic under review.

- b) **Abstract:** where it could not be ascertained whether articles were relevant based on title, abstracts were reviewed, and articles were eliminated if it was clear they did not cover the review topic.
- c) **Full text skim and scan reading, and text search:** where it was not clear whether an article was relevant from reviewing the title and abstract, the full text was obtained and read in the following way:
1. By skim and scan reading full article to establish relevance.
  2. By using a text search within the software (usually Adobe Reader, sometimes Microsoft Word) to highlight relevant terms and investigate how they have been referred to, including: (i) disclos (for disclosure); (ii) shar (for share, sharing or shared); (iii) lived; (iv) experience; (v) mental; (vi) health. Mentions of the subject would not be overlooked should unexpected synonyms be used because text-searching was combined with skim & scan reading.
- d) **Full-text, thorough reading:** occasionally, skim and scan reading and text searching were not enough to resolve ambiguities and decide whether to include or exclude an article, so articles were read fully, carefully considering whether they met the inclusion criteria.
- e) **Obtaining articles:** most journal papers were easily obtained through the University of York library. Others were obtained through interlending. In a few cases it was difficult to track down papers so authors were contacted who supplied them. In the case of dissertations and theses, educational institutions were contacted, and some supplied copies free of charge. Where charges were payable, a decision was made on whether the cost of obtaining the article was prohibitive given its likely use: low-cost articles (£2.00 GBP per article) were obtained where possible; for higher cost articles (£12.00 GBP per article, usually a thesis or dissertation), it was decided that where an author did not, in the title or the abstract, state explicitly that the publication covered disclosure of mental health conditions by practitioners, then it was unlikely to cover the subject to any extent, and therefore the article was not obtained. Conversely, where it was made



explicit that the thesis or dissertation covered the relevant subject, it was gained where possible.

- f) ***Editorials, opinion pieces, letters to editors etc***: were part of the exclusion criteria. However, since they had not been excluded in the database search itself, they were included in the results. While they were excluded, they were nevertheless skim-read in case they led to any new references or ideas.

Each article was screened individually, moving from one step to the next as described, to retain or reject on the stated criteria. This process resulted in the retention of 20 articles that fit the inclusion/exclusion criteria.

Since this review was carried out in 2014, further papers were identified at later dates (during 2015 and 2016, and up to one month before thesis submission) following the same inclusion and exclusion criteria. Papers were identified in the following ways:

- a) Through discussion of relevant literature with other researchers and colleagues.
- b) Following up citations in related articles.
- c) By repeating original searches to include articles from 2014 onwards.

These activities resulted in an additions 8 articles that were added to this literature review.

### **3.2.7 Data extraction from retained articles**

A data extraction table was constructed to capture the main features of each article, including author, publication type, and study title, and other fields which enabled categorisation, organisation and comparison. These included:

**Country:** UK studies may be more relevant than similar US studies because of their relevance to the UK context.

**Year:** apart from excluding pre-1990 articles, dates may help to draw conclusions regarding contemporaneous proximity to the current research study.

**Study design (empirical only):** enabled labelling of studies by the method that was used, for example, randomised control trials, surveys, focus groups etc. This allowed method suitability appraisal, contributed towards quality appraisal, and enabled comparison of methods between studies.

**Non-analogue or analogue (empirical only):** it was clear during the screening process that some studies had used analogue methodology. Studies conducted with real mental health services users and practitioners might arguably be more relevant than those conducted with a proxy group, such as a student cohort (Hill & Knox, 2001). Identifying analogue and non-analogue studies was therefore adopted to review relevance to the current research study.

**Sample size & characteristics (empirical only):** this contributed to quality appraisal, enabling judgments to be made about potential generalisability of findings, and allowed potential comparison between studies based on the participant attributes.

**Sources (non-empirical only):** allowed consideration of the characteristics of the research subject/s, for example, whether it is written about own or others' experience.

**Study Aims (empirical only):** summary description of what the study set out to achieve and how it relates or compares to other studies.

**Conceptual focus (non-empirical only):** since studies do not set out to undertake an experiment in the way that empirical studies might, this category enabled description & comparison of main concepts and subjects that the author covers.

**Measures used (empirical only):** for description, categorisation, and comparison of different measurement methods.

**Relevant findings and conclusions:** studies may have identified a range of findings and conclusions, some of which were irrelevant to this study, because many studies did not focus

specifically or exclusively on the current research study topic. Therefore, only relevant findings were extracted.

### 3.2.8 Quality appraisal of retained articles

Each article was given a score describing its overall quality, using a process adapted from the TAPUPA framework (Pawson et al, 2003). The process gave low, medium or high-quality scores against each of the following terms, amalgamated into an overall “average” score:

#### *Empirical articles:*

- **Clear aims:** was the aim of the study clear?
- **Transparent:** was the methodology clear? how subjects were chosen; methods and justifications for measurement; the use of statistical tests; and the hypotheses being tested.
- **Accurate:** did the research represent what people/literature said? Bias, reliability, validity (were there any attempts to eliminate bias, or cross-check results?).
- **Purpose:** was the research or approach fit for purpose? Design of research, i.e. focus group, interview etc.
- **Generalisable:** could the results be generalised to a larger population? May not be appropriate to generalise if this was not the purpose.
- **Peer review:** Was the research peer reviewed?
- Impact factor of journal

#### *Non-empirical articles:*

- **Clear focus:** was the focus of the article clear?

- **Arguments evidenced:** did the article present a balanced view?
- **Author credibility, experience, authority:** were they qualified or experienced to express their views?
- **Fit for purpose/audience:** was the article suitable for what it was trying to illustrate or achieve?
- **Generalisable:** although non-empirical, how likely was it that the conclusions might apply to a wider population?
- Impact factor of journal

**Star rating:** Each article was also given a star rating indicating:

- \* The article was not primarily focused on the subject, but made significant, though relatively minor, mention of it.
- \*\* The article was not primarily focused on the subject but included substantial coverage of it.
- \*\*\* The article primarily focused on the subject.

This enabled studies to be grouped into at-a-glance categories regarding their relevance.

### **3.3 Results from first literature review**

Eight empirical and 13 non-empirical studies were identified that made a significant or substantial mention of mental health self-disclosure by practitioners in mental health settings. All of the studies were gained. Matrices were constructed (see table 3.2, 3.3, 3.4, and 3.5 below) to indicate the quality and characteristics of the studies.

### 3.3.1 Empirical results quality appraisal (first literature review)

Seven out of the eight empirical articles were of high or medium quality, with three focusing primarily or substantially on the topic of the current study, and three making significant mention of it. Three of the empirical studies were given medium or high generalisability scores (Cabral et al, 2014; Davidson et al, 1999; Henretty & Levitt, 2010). See table 3.2.

Table 3.2: Empirical studies quality appraisal (first review)

<b>Empirical studies: n = 8</b> (L, M, or H after a reference indicates Low, Medium or High generalisability quality score)			
<b>Quality</b>	<b>High quality</b>	<b>Medium quality</b>	<b>Low quality</b>
<b>*** Primary focus</b>		3 Abramsky (2013) L Armour (2007) L Somers et al (2013) L	
<b>** Substantial focus</b>	1 Cabral et al (2014) M		
<b>* Significant focus</b>	1 Henretty & Levitt (2010) H	2 Bottrill et al (2010) L Davidson et al (1999) M	1 Gough (2011) L

Of the eight empirical papers that were gained, three of the medium-quality studies, Abramsky (2013), Armour (2007) and Somers et al (2013), specifically focused on self-disclosure of mental health conditions by practitioners with service-users in mental health settings. Of the remaining five studies, one high-quality scored study covered the subject substantially, Cabral et al (2014), while the rest only made minor mention of the topic, and these were all afforded a low-quality score using the TAPUPA framework (Pawson et al, 2003). All of the empirical papers primarily focused on psychotherapist or psychologist self-disclosure, except for two (Cabral et al 2014; Davidson et al, 1999) which focused on peer-support.

### 3.3.2 Non empirical results quality appraisal (first literature review)

Five out of thirteen non-empirical articles were assessed as high or medium quality, and four of these focused primarily on the subject. All of the non-empirical studies were given a low-generalisability score. The generalisability scores were based on the range of evidence and the numbers of participants that gave rise to a study's or article's findings. See table 3.3 below.

Table 3.3: Non-empirical papers quality appraisal

<b>Non-empirical papers: n = 13</b> (L, M, or H after a reference indicates Low, Medium, or High generalisability quality score)			
<b>Quality</b>	<b>High quality</b>	<b>Medium quality</b>	<b>Low quality</b>
<b>Relevance</b>			
<b>*** Primary focus</b>	1 Dixon et al (2001) L	3 Costin & Johnson (2002) L Kottsieper (2009) L Mallow (1998) L	1 Miles (1999) L
<b>** Substantial focus</b>		1 Schiff (2004) L	6 Anonymous (2007) L Burnell (2001) L Curtis & Hodge (1994) L Nealy (2011) L Otto et al (2009) L Yarek (2008) L
<b>* Significant focus</b>			1 Jacobs & Nye (2010) L

Of the 13 non-empirical papers, five focused primarily on the topic, three of which were of medium quality (Costin & Johnson, 2002; Kottsieper, 2009; Mallow, 1998), one of low quality (Miles, 1999), and one of high quality (Dixon et al, 2001). Of the remaining eight papers, seven covered the topic substantially, six of which were of low quality (Anonymous, 2007; Burnell, 2001; Curtis & Hodge 1994; Nealy 2011; Otto et al, 2009; Yarek, 2008), and one of medium quality (Schiff, 2004). The remaining paper (Jacobs & Nye, 2010) made brief mention of the topic and was assessed as low quality.

11 out of the 13 studies are based purely on the author's own experience or on a mixture of experience linked to wider literature on self-disclosure. One article (Dixon et al, 2001) is based purely on literature, while the remaining article is a collection of author's views on a practice dilemma (Jacobs & Nye, 2010). Many of the issues that were identified within the empirical literature are also mirrored in the non-empirical literature, with the addition of *conversion*, *contradiction*, and *automatic disclosure*.

### 3.3.3 Empirical studies data extraction (first literature review)

Table 3.4: Extracted data from empirical studies

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Abramsky, L. Therapist Self-disclosure and Motivational Interviewing Statements on Treatment Seeking of Aviophobics	USA Medium 2013 ***	Empirical study; Quantitative; Measurement tools and scales.  Analogue  Dissertation	60 students, who scored a 70 or higher on the FAS (Flight Anxiety Situations Questionnaire).  42 female, 18 male.	Whether therapist self-disclosure of aviophobia, and motivational interviewing statements, affected aviophobics' views of the therapist.	FAS to measure presence of aviophobia. Stages of change questionnaire; counsellor rating form - short; credibility/expectancy questionnaire.	Motivational statements and self-disclosure of therapists' own aviophobia on their own did not make any significant differences to participant ratings. However, when combined, therapists were rated as "more expert and trustworthy". Suggests that it is the therapeutic approach combined with self-disclosure that is key.
Armour, J.D. Effects of therapists' personal therapy experience on perceptions and help-seeking decisions of potential consumers	USA Medium 2007 ***	Empirical study; quantitative; measurement tools and scales;  Analogue  Dissertation	356 male and female college students	Students asked to rate potential therapists based on one of two brief descriptions; including whether the therapist had had therapy themselves	7 point Likert scale; counsellor effectiveness rating scale (CERS); Barrett-Lennard Relationship Inventory-Form OS	No difference between groups; as measured on several factors, including empathy, credibility/effectiveness. No need for therapists to hide they have had own therapy - personal clinical judgment; does not influence credibility; does not influence whether clients will seek therapy from them.

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Somers, A.D. Pomerantz, A.M. Meeks, J.T. Pawlow, L. A.  Should psychotherapists disclose their own psychological problems?	USA  Medium  2013  ***	Quantitative, vignettes & survey measurements tools  Analogue  Journal article	155 undergraduate students	Students split into 2 groups, one read vignettes where therapist disclosed similar psychological issue to client; one where they did not; students asked to rate therapist in disclosure and non-disclosure conditions.	Likert scale adapted from Fox et al (1984) asking for views on various dimensions of feelings towards the therapist (warmth, sincerity, likeability etc.) also therapeutic relationship & likelihood of success.	SD of psychological problems similar to those of client can be positive for therapy outcomes. Results consistent across PTSD, depression and alcohol dependency. Mental health dimension of SD has not been explored to date, only general SD.
Cabral, L., Strother, H., Muhr, K., Sefton, L., Savageau, J.  Clarifying the role of the mental health peer specialist in Massachusetts, USA: insights from peer specialists, supervisors and clients	USA  High  2014  **	Qualitative; interviews and focus groups  Non-analogue  Journal article	Peer specialists (N=44), their supervisors (N=14) and clients (N=10)	Interviews with peer specialists, their supervisors and client	None, interviews etc.	Increasing use of peer specialists in health care settings. Role ambiguity barrier to integration within teams. Lack of knowledge of client perspectives on peer services. Using mental health experience with clients is “critical ingredient” of peer role. Clients report improved mental health from working with peer workers.



Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Bottrill, S., Pistrang, N., Barker, C., Worrell, M.  The use of therapist self-disclosure: clinical psychology trainees' experiences	UK  Medium  2010  *	Qualitative; semi-structured interviews  Non-analogue  Journal article	14 trainee clinical psychologists; mixed orientations: CBT; systemic; psychodynamic therapies	Interviews explored participants' experiences of using SD	Therapeutic orientation and experiences survey, used to measure therapeutic style preferences.	Mental health briefly mentioned, example of SD of OCD, interpreted by practitioner as having improved therapeutic relationship. Practitioner concerns include: difficult to make SD decisions "in the moment"; knowing where to stop, risk/ protecting self, and making best use of disclosures. General report of lack of guidance, training etc. & that SD is taboo.
Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes J.K.  Peer Support Among Individuals With Severe Mental Illness: A Review of the Evidence	USA  Medium  1999  *	Quantitative  Non-analogue  Journal article	Wide range of different quantitative studies	Review the literature on peers support to draw conclusions about the effectiveness of involving people with mental health conditions as providers.	Various.	There is a gap in the research knowledge re. the part that sharing lived experience plays in the peer support role, and further, the impact of self-disclosure by people with mental health conditions in non-peer clinical roles.

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Gough, M.  Looking after your pearls: the dilemmas of mental health self-disclosure in higher education teaching	UK  Low  2011  *	Write up of conference workshop  Non-analogue  Journal article	20 people on conference on MH in Higher Education including service-users and health and social care professionals.	Workshop discussion of dilemmas related to disclosing personal experience of mental health problems by educators to their students in teaching about mental health.	None, write up of workshop discussion	SD can be beneficial in mental health education, but should be for student benefit. Not disclosing can be draining, feel fraudulent, and mentally unhealthy.
Henretty, J. R. Levitt, H. M.  The role of therapist self-disclosure in psychotherapy: A qualitative review	USA  High  2010  *	Systematic review of empirical literature  Non-analogue /analogue mix  Journal article	Wide range of different quantitative studies	Systematic review, many considerations, evaluation of many dependent and independent variables, including gender, ethnicity, sexual orientation etc.	Various	Two studies mentioned related to mental health SD: Mallow 1998, and Dilts et al 1997. On this basis cautions against SD of struggles with disorders or addictions. However, seems supportive of disclosures of illness and grief for various reasons, including explaining absence etc.

## 3.3.4 Non-empirical papers data extraction (first literature review)

Table 3.5: Extracted data from non-empirical papers

Author & Title	Country, Quality Score, Year & Star rating	Conceptual focus & publication type	Sources	Main findings	Relevant findings and conclusions
Costin, C. & Johnson, C.L.  Been There, Done That: Clinicians' Use of Personal Recovery in the Treatment of Eating Disorders	USA  Medium  2002  ***	Reflection of recovered professional on experience and lack of recovery literature  Journal article	Own experience, some literature	Contacted 10 eating disorder programmes, general feeling that there is a lack of training and guidance regarding the employment of people with lived experience of eating disorders to work with other people with eating disorders, despite high interest. High incidence of people in workforce with own or family member's eating disorder experience.	Patients report that having staff with lived experience is a strength. Managers/ colleagues being out about their lived experience encourages other staff members to be out about theirs. Sharing lived experience is useful in author's view as it presents hope and inspiration for patients. SLE also promotes empathy and trust, abates shame, and challenges narcissism, self-pity and grandiosity. Can also place burden on staff of greater responsibility for patient's recovery; staff may be at risk of pushing patients to recover "their way" instead of finding their own recovery route.
Kottsieper, P.  Experiential knowledge of serious mental health problems: One clinician and academic's perspective	USA  Medium  2009  ***	How the author's own experiences of a serious mental health problem influences their practice with clients with serious mental health problems.  Journal article	Own experience; literature	Personal experience of mental health disorder can help in practice to provide hope for recovery and promote open dialogue between practitioner and clients; should be viewed as a competence rather than an impairment or a professional competence issue.	Professionals other than peer mentors can usefully share their mental health lived experience with clients. Reluctance to disclose during training, out of fear of being judged negatively. Reluctance of own therapist to disclose whether they had ever experienced a mental health condition. There is a lack of literature on sharing lived experience of mental health conditions. Training & research needed on this subject.

Author & Title	Country, Quality Score, Year & Star rating	Conceptual focus & publication type	Sources	Main findings	Relevant findings and conclusions
Mallow, A. J.  Self-disclosure: Reconciling psychoanalytic psychotherapy and alcoholics anonymous philosophy	USA  Medium  1998  ***	Reconciliation of AA approach (SD inherent) with psychoanalytic psychotherapy (SD discouraged)  Journal article	Own experience, some literature	Suggests that SD can be used in psychoanalytic approaches as well as therapeutic approaches such as AA	Cautions against using SD in case clients worry about practitioner relapse, but also says client should not have to feel that the practitioners hasn't "been there". Important to strike a balance.
Miles, S.H.  A piece of my mind: A challenge to licensing boards: the stigma of mental illness	USA  Low  1999  ***	Opinion piece on own treatment when came out at work with bipolar  Journal article	Own experience	Author suffered discrimination and fitness to practice investigation when his mental health lived experience became known by the licensing board	Literature suggests that for self-disclosure in general there are competing views about whether to do it and under what circumstances. Stigma of mental illness can affect individuals through discrimination from colleagues and managers.
Anonymous  The Impact That Changed My Life	USA  Low  2007  **	Reflections on impact of car accident on therapy practice  Journal article	Own experience	Greater willingness to use SD after a car crash in which someone was killed.	Author experienced Acute Stress Disorder. SD dealt with specifically by the psychotherapist with clients. SD is useful in therapy; able to better empathise with clients, and of developing better and more fruitful therapeutic relationships; conversion from not using to using more often, though judiciously; no experiences of "boomerang".

Author & Title	Country, Quality Score, Year & Star rating	Conceptual focus & publication type	Sources	Main findings	Relevant findings and conclusions
Burnell, J.  From Life-Threatening Illness to a More Sensitive Therapist: One Woman's Journey	USA  Low  2001  **	How life-threatening illness impacted on practice   Journal article	Own experience	Experience of illness deepened understanding of clients' positions in therapeutic relationship	After illness, SD used more often and to positive effect with clients; sharing experiences of emotional despair and thoughts of suicide, and moving beyond them, noted as helpful for clients; clients cited these disclosures as turning points.
Curtis, L. C. & Hodge, M.  Old standards, new dilemmas: Ethics and boundaries in community support services	USA  Low  1994  **	Changes in mental health services mean traditional boundaries, ethics etc. need to change   Journal article	Personal experience, literature	Ethics and boundaries are difficult to negotiate and there is little concrete guidance - decisions and actions are correct or incorrect according to context and individual situation.	No simple dichotomy between consumers and professionals. Some staff may have lived experience of mental health conditions, may receive services from employing organisation, & may have relationships with other consumers outside of professional role. Contradictory position where staff may feel pressured not to disclose, yet organisations are actively recruiting people who are expected to be open and use their lived experience in their professional role. Advocates openness and congruence. Offers broad decision-making guidelines re. boundaries.
Nealy, E. C.  The man in the mirror: Reflections on authenticity and visibility in the clinical relationship	USA  Low  2011  **	Experiences of the author as a transgender male therapist and issues related to self-disclosure in practice.   Journal article	Own experience	Reactions of clients to self-disclosure and the impact on the therapeutic relationship.	From the perspective of being a transgender therapist, the author advocates bringing the whole self into the therapeutic relationship, highlighting the positive aspects of disclosure, by enabling wider conversations about how clients see themselves, including transgender clients.

Author & Title	Country, Quality Score, Year & Star rating	Conceptual focus & publication type	Sources	Main findings	Relevant findings and conclusions
Otto, R., Goldrick, V., & Helm, S.  Recovery: Three lives, one workplace	USA  Low  2009  **	Three practitioners' reflections who have experienced recovery from a mental health condition  Journal article	Own experiences	Importance of self-disclosure in MH services, not restricted to peer mentors.	Contradiction in mental health services where there is no blame attached to mental health conditions and efforts are made to reduce stigma for clients, yet practitioners hide their own conditions and experiences. SD by practitioners can be useful to reduce stigma. Own experiences suggests reactions to SD can be negative from some colleagues.
Schiff, A.C.  Recovery and mental illness: analysis and personal reflections	USA  Medium  2004  **	Overview of recovery and own experience as consumer-provider  Journal article	Own experience; literature	Outlines recovery model and the unique insights of "prosumers" (those who are both professionals and consumers).	Combination of professional status and consumer status is greater than the sum of the parts. Professionals take the consumer perspective of prosumers more seriously because of their professional status, and likewise, consumers take the professional opinions of prosumers more seriously because of their consumer experience. Being "out" can carry risk of discrimination and being discredited. Author chose not to disclose until training completed.
Yarek, C.  Ethics in peer support work	Canada  Low  2008  **	Own reflections on mental health & peer support  Journal article	Own experience	Experiences of working as a peer, mainly focusing on the dynamics around self-disclosure and boundaries. SD by a practitioners can be positive experience for both clients and colleagues.	Author reflects that hiding illness/experience can be difficult, for example, if recognised accessing a service by someone who knew her, taking medication through the company health plan etc. Being "out" with a positive employer is a positive and supportive experience. Useful to be able to offer client perspective to colleagues, for example, to explain, from personal experience, how some conditions might feel to clients. Disclosure with clients recognised by self and colleagues as useful for "injecting" hope into situation for clients.

Author & Title	Country, Quality Score, Year & Star rating	Conceptual focus & publication type	Sources	Main findings	Relevant findings and conclusions
<p>Jacobs, M. &amp; Nye, S.</p> <p>The therapist's appearance and recovery: Perspectives on treatment, supervision, and ethical implications</p>	<p>USA</p> <p>Low</p> <p>2010</p> <p>*</p>	<p>Eating disorders and whether or how to tackle a dangerously thin colleague</p> <p>Journal article</p>	<p>Responses from therapists towards an on-line discussion about an overly- thin colleague</p>	<p>Reflections by various contributors suggest different ethical considerations need to be made about whether to tackle the colleague about her suspected eating disorder.</p>	<p>Self-disclosure can be positive but risky if client is not to be able to cope as well as the practitioner appears to have done. People with eating disorder may be identifiable without direct disclosure. SD may be inevitable because insider knowledge implies personal experience. Lack of guidance on SD.</p>

### 3.3.5 Repeat Literature Review

The literature review was updated in 2017 to capture any new publications since the review was first undertaken in 2014. Searches were undertaken using the original literature databases and search terms. It was judged that the first scoping review, and wider literature searches for previous thesis chapters, had sufficiently explored the diversity of opinions and non-empirical narratives on sharing lived experience and self-disclosure. Therefore, selection criteria were modified slightly for the second search so that only new, empirical studies were retained. Searches were restricted to articles published from January 2014, overlapping with the date of the previous review.

The second literature search yielded 902 results. After duplicates were removed, 576 articles remained. They were considered for relevance by title and abstract in the first instance, and 28 articles were retained for examination of full text. Of these, 4 were found to be of relevance. Another 4 papers were identified from other sources at various points during the production of this thesis, including citations in published articles, word of mouth, and online searches. These were added to the repeat literature review results. One of these papers, Morgan & Lawson (2015), was not produced as a formal piece of research, but because of its high relevance and collection of data directly from practitioners, it is included in the data extraction table. It is not included in the quality review table because its informal-empirical nature meant that quality scores could not be made with parity to other papers in this review, and it was therefore given a not applicable (N/A) overall quality score.

Quality appraisals are shown in table 3.6, and data extraction is provided in table 3.7, below. These were not amalgamated with previous tables to retain clarity of methods. Emerging themes are integrated with previously identified themes in section 3.3.6.



Table 3.6 Repeated literature search quality appraisal: empirical studies

<b>Empirical studies: n = 8</b> (L, M, or H after a reference indicates Low, Medium or High generalisability quality score)			
<b>Quality</b>	<b>High quality</b>	<b>Medium quality</b>	<b>Low quality</b>
<b>Relevance</b>			
<b>*** Primary focus</b>		2 de Vos et al (2016) L Marino et al (2015) M	1 Gilbert & Stickley (2012) L
<b>** Substantial focus</b>	1 Boyd et al (2016) M	1 Adame (2011) L	
<b>* Significant focus</b>	1 Geppert & Taylor (2014) M	1 Asad & Chreim (2016) L	

Of the 7 empirical papers gained in the second literature search that were quality reviewed, two medium quality studies (de Vos et al, 2016; Marino et al, 2015), and one low quality study, (Gilbert & Stickley, 2012), had a primary focus on the self-disclosure of mental health experiences by practitioners with service-users in mental health settings. Of the remaining four, two were of high quality, with one having substantial focus (Boyd et al, 2016) and the other having significant focus (Geppert & Taylor, 2014) on the subject. The remaining two studies were of medium quality (Adame, 2011; Asad & Chreim, 2016), and neither focused primarily on the subject. Taken together, unlike the studies identified in the first literature search, they variously captured the views of therapists, nurses, mental health professionals in general, peer workers, psychiatrists and service-users. Six of the papers used non-analogue methodology, while one (Giilbert & Stickley, 2012) canvassed the views of students rather than practitioners which was judged to be a mixture of analogue and non-analogue methodology because of the varying degrees to which students might be active or immersed in practice.

Table 3.7 Extracted data from empirical studies (repeat review)

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
de Vos, J.A., Netten, C., & Noordenbos, G.  Recovered eating disorder therapists using their experiential knowledge in therapy: A qualitative examination of the therapists' and the patients' view.	Netherlands  Medium  2016  ***	Empirical, quantitative and qualitative;  Non-analogue  Journal article	205 patient respondents and 24 therapists	Explore the use of lived experience of eating disorders in therapy with eating disorder patients	No scales or measures, mainly yes/no responses to question with qualitative text responses	Patients valued having and using lived experience proportionally similarly to practitioners, but fewer mentioned disadvantages. Can help with, and provide hope for, recovery; and build positive working relationships. Practitioners share with therapeutic goals. Patient responses on advantages/disadvantages are polarised, most practitioners cited both advantages and disadvantages.
Gilbert, P., & Stickley, T.  "Wounded Healers": the role of lived-experience in mental health education and practice.	UK  Low  2012  ***	Empirical, qualitative.  Analogue and non-analogue.  Journal article	Sample size not given. Nursing and social work students in various UK universities.	Explore attitudes to the role of lived experience in education and practice.	None, questionnaires and interviews with nursing and social work students.	Lived experience can equip practitioners with greater understanding of mental health experiences & empathy. Disclosure needs to be managed well and tailored to individuals. Recommends greater recruitment of people with lived experience, and permission to share.

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Marino, C.K., Child, B., & Krasinki, V.C.  Sharing Experience Learned Firsthand (SELF): Self-disclosure of Lived Experience in Mental Health Services and Supports.	USA  Medium  2015  ***	Empirical, quantitative and qualitative;  Non-analogue  Journal article	117 participants with lived experience working in mental health settings	Explore value and use of mental health sharing lived experience in mental health settings.	Likert scales re. purpose and intended benefits of sharing, and qualitative responses	Practitioners with lived experience value sharing experience. Sharing benefits include hope and building relationships. However, need to have a supportive organisational culture. Non-peers disclose less. However, no significant difference in views of disclosure between respondents based on job role. Recommend greater disclosure to combat stigma.
Morgan, P., & Lawson, J.  Developing guidelines for sharing lived experience of staff in health and social care	UK  N/A  2015  ***	Informal/empirical; qualitative discussion;  Non-analogue  Journal article	Mental health practitioners (n=8-10); mental health service-users (n=8-10); representatives of various professional bodies (n=8-10)	To inform discussions about staff sharing lived experience for the benefit of service-users.	None, focus group discussions.	Practitioners disclose to service-users and colleagues. To be effective and safe, disclosure needs to be made within a supportive organisational culture. Benefits included hope, recovery, stigma reduction, increase health and wellbeing of staff, enhance practice. Risks included boundary violations, negative judgement from colleagues. Risks of not sharing, included gossip being invented due to lack of real information, cognitive dissonance/dishonesty. Practical implications explored, and recommendations made re. what, why, how and when to share lived experience. Overall, disclosure may be beneficial but must be well managed.

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Adame, A.L.  Negotiating Discourses: The Dialectical Identities of Survivor-Therapists.	USA  Medium  2011  **	Empirical, qualitative interviews;  Non-analogue  Journal article	Five therapists who had been mental health service-users	Explore management of dual identities	None, interviews with therapists.	Therapists disclose rarely but may share their experiences with service-users where they feel it will be helpful and relevant. May encounter unfit-for-practice assumptions from service-users, even without disclosure because service-users may discover practitioners' histories online. May conceal from colleagues. Other service-users may assume that the practitioner has not faced the same level of difficulty as they have, because they are able to function as practitioners.
Boyd, J.E., Zeiss, A., Reddy, S., & Skinner, S.  Accomplishments of 77 VA Mental Health Professionals With a Lived Experience of Mental Illness	USA  High  2016  **	Empirical, quantitative and qualitative;  Non-analogue  Journal article	77 mental health professionals with lived experience delivering mental health services in an organisation providing mental and physical health services to veterans	Explore the value of lived experience in the workforce and issues related to its utility.	No standardised scales or measures, but various quantitative and qualitative questions asked, including prevalence of mental illness experience and sharing it.	Practitioners feel lived experience is a helpful asset in their jobs, but are cautious about disclosure. Practitioners have disclosed to 16% of colleagues and 14% of patients. Tend to not disclose or discourage disclosure by colleagues due to fears of discrimination.

Author & Title	Country, Quality Score, Year, & focus rating	Study design, Non-analogue or Analogue, Publication type	Sample size & characteristics	Study Aims	Measures used	Relevant findings and conclusions
Asad, S., & Chreim, S.  Peer Support Providers' Role Experiences on Interprofessional Mental Health Care Teams	USA/ Canada  Medium  2016  *	Empirical, qualitative interviews  Non-analogue  Journal article	12 peer support workers	Explore peer workers' experiences in mental health teams	Non, interviews with peer workers	Although identifiable by their lived experience, peer workers still face choices about what to share and to whom. Disclosure to colleagues can provide insider knowledge and increase colleagues' understanding of issues. Peer workers may face discrimination from colleagues and service-users, the latter who may not want someone with mental illness to work with them. Disclosure to client generally beneficial.
Geppert, C., & Taylor, P.J.  What Troubles Psychiatrists: How Psychiatrists View Ethical Dilemmas.	No location detail  High  2014  *	Empirical, quantitative and qualitative;  Non-analogue  Chapter in book	714 psychiatrists	Explore ethical dilemmas for psychiatrists	Various questions asked about ethical dilemmas, including whether respondents would share their diagnosis if it were the same as the person's whom they are treating.	Nearly 70% of practitioners would not disclose, a quarter said it would depend on the context and situation, and 7% said they would disclose.

Analysis of results was based on the data extracted in tables 4, 5 and 7 (above). Four main themes were identified within which findings were clustered: positive aspects of self-disclosure; risks of self-disclosure; pressure against self-disclosure; and lack of research, training, and guidance about self-disclosure in the context of this review.

### **3.3.6 Positive aspects of self-disclosure**

#### ***3.3.6.1 Empirical studies***

All but one (Henretty & Levitt, 2010) of the empirical studies were broadly positive about self-disclosure of mental health conditions by practitioners with service-users, or indicated that it does no harm.

***Enhancing hope for recovery and recovery:*** Several studies suggest that sharing lived experience can increase hope for recovery, and increase the prospect of recovery. De Vos et al's (2016) study involving 205 patient respondents and 24 therapists suggested that practitioners share with therapeutic aims, and that such goals, despite awareness of both advantages and disadvantages of sharing, are generally achieved by providing hope for recovery. De Vos et al (2016) also suggest that a greater proportion of patients value sharing lived experience than practitioners. Marino et al (2015), record similar outcomes related to hope and recovery from the perspective of 117 mental health professionals and Morgan & Lawson (2015) echo this from the multiple perspectives of practitioners, service-users, and professional bodies (nursing, social work etc.)

***Improving or essential to therapeutic relationships:*** Although only one small part of Bottrill's (2010) study specifically cited the disclosure of mental health experiences, as opposed to other types of experience, nevertheless this study of 14 trainee clinical psychologists suggested that self-disclosure can improve the quality of the therapeutic relationship. Other researchers report similar findings from the perspectives of: patients and therapists (De Vos et al, 2016); general mental health professionals (Marino et al, 2015); and service-users, practitioners, and professional bodies (Morgan and Lawson, 2015). Within peer support, Cabral et al (2014) interviewed peer specialists, their supervisors, and their clients and identified that sharing lived experience was a critical ingredient of peer support, rather than other services offered, suggesting that the same services offered by people without lived experience would not be viewed as positively. While these conclusions should be treated with caution due to the

relatively low numbers interviewed, they nevertheless capture a feeling among both service-users and clinicians that self-disclosure can be positive when undertaken in both peer support and other mental health professional roles.

***Impact of self-disclosure & non-disclosure on practitioner:*** Gough's (2011) report on the conclusions of a group discussion among 20 educators, practitioners and service-users during a workshop at a mental health conference, suggested that self-disclosure of personal mental health experiences by mental health educators can be beneficial in mental health education, and that not disclosing can feel draining, fraudulent, and mentally unhealthy. Morgan & Lawson (2015) also report from a focus group of practitioners that non-disclosure can lead to feelings of dishonesty, and may increase the likelihood of gossip being invented about practitioners in the absence of any real information about them.

***Service-user ratings of practitioner attributes:*** Abramsky (2013) investigated whether motivational interviewing and self-disclosure of aviophobia (fear of flying) influenced how participants felt about the therapeutic encounter, including their likelihood to seek future therapy for aviophobia, and their views about the therapist. Neither self-disclosure nor motivational interviewing alone made any significant differences as measured by any of the ratings scales, though when combined participants rated the therapist as more trustworthy and more expert than in non-disclosing, non-motivational conditions. Somers et al (2013), undertook one of the most directly relevant, and the second largest, study into this subject, with 155 undergraduate students being asked to rate therapists in disclosure and non-disclosure conditions, on various dimensions, including warmth, sincerity, likeability, the quality of the therapeutic relationship, and whether therapy is likely to be successful. The results indicate that those therapists who disclosed were rated more highly than those who did not, consistently across a range of conditions including PTSD, depression, and alcohol dependency. However, a similar but larger study (Armour, 2007) found that knowing whether a therapist had previously had therapy themselves made no difference to participants' perceptions of therapist empathy, credibility, or likely effectiveness, or whether they would seek therapy from them. All studies were analogue studies, where proxy (student) participants rated therapists based on vignettes or videos.

**Role-modelling:** Davidson et al (1999) in their review of empirical literature suggest that disclosure can have a positive impact on both clients and colleagues by challenging stereotypes, and providing positive role models.

### 3.3.6.2 Non-empirical papers

**Peer mentors vs. other mental health professionals:** While all of the non-empirical literature came from the perspective of mental health practitioners rather than peer mentors, Kottsieper (2009) explicitly suggests that the benefits of sharing lived experience are not restricted to peer mentor roles, but that sharing lived experience of mental health conditions can be undertaken equally usefully by a wider range of mental health professionals. Similarly, Schiff (2004) suggests that prosumers have unique insights that should be harnessed, and because of their dual status they have credibility on both professional and service-user circles. The positive impact of self-disclosure by practitioners to other professionals is echoed by Yarek (2008), who suggests that the dialogue resulting from a colleague's disclosure can increase a practitioner's understanding of client perspectives.

**Improving therapeutic relationships:** In working on a one-to-one basis with clients, Anonymous (2007) suggests that self-disclosure of a mental health condition (in this case, acute stress disorder) can demonstrate empathy for the client's situation and help to create more productive therapeutic relationships, a view echoed by Costin & Johnson (2002) with the addition that it can also help to build trust, and in the context of eating disorders, challenge narcissism and self-pity. On a more practical note, Dixon et al (2001) suggest that, as with physical conditions, open discussion of the effects of taking medicine, including whether the practitioner has taken those medications themselves, can help clients to work through fears.

**Role-modelling and normalising:** In group therapy contexts, Dixon et al (2001) suggest that self-disclosure is particularly useful to normalise experiences and feelings, reduce the shame that clients might feel about their conditions, instil hope for recovery, and to provide positive role models. As with role modelling in group therapy settings, staff may be more encouraged to be open about their lived experience of mental health conditions if they see managers and colleagues being out about their experiences (Costin & Johnson, 2002), though this can be dependent on the workplace culture and the attitude of the employer (Yarek, 2008).



**Hope and practitioner strength:** In her work with clients with eating disorders, Costin & Johnson (2002) suggest that lived experience is seen by clients as a strength, while Burnell (2001) reports that some clients noted disclosure of emotional despair and suicidal thoughts after her own life-threatening illness as helpful and as turning points for them. Similarly, Yarek (2008) cites that disclosure with clients can provide a useful injection of hope.

**Multiple identities:** Finally, service-users may have multiple identities, and aside from sharing mental health lived experience, it can also be useful to disclose ethnic, religious, sexual or other characteristics where these are relevant and important to the service-user (Dixon et al, 2001), a view echoed by Nealy (2011) in relation to being out about his transgender identity when working with transgender clients, but also when working with other clients as it creates new avenues for discussion about how clients see themselves.

### 3.3.7 Risks of self-disclosure

#### 3.3.7.1 Empirical studies

**Forward planning and disclosure management:** Bottrill et al (2010), while outlining the positive aspects of disclosure, nevertheless highlight potential difficulties reported by study participants, including making decisions in the moment in response to particular situations or questions from service-users; knowing where to stop with disclosure; how to guard against risks when deciding what to disclose; and how to make the best use of disclosures. Other studies suggested a range of potential negative effects of disclosure, but also suggested these could be mitigated by careful disclosure management (de Vos et al, 2016; Gilbert & Stickley, 2012; Morgan & Lawson, 2015).

**Negative Effects for Service-users:** Henretty & Levitt's (2010) systematic review of self-disclosure in psychotherapy, is broadly positive about practitioner self-disclosure concerning a wide range of subjects. It only makes a very brief mention of disclosure concerning mental health, but warns that "therapists may want to practice caution when considering disclosing about their past struggles with addictions or disorders, even if those struggles are similar to those of their client, and even if those struggles are successfully resolved" (Henretty & Levitt, 2010, p. 72). Two studies are cited in support of such concern, indicating briefly that disclosures can be detrimental to treatment, as clients may worry about the mental health of their

practitioner (Mallow, 1998), or may feel disempowered if they feel they cannot cope with their mental health condition as well as their practitioner did with theirs (Dilts et al, 1997).

### **3.3.7.2 Non-empirical papers**

Several dangers of disclosure are identified in the non-empirical literature, danger to clients, danger to practitioners, and the danger of not disclosing.

***Danger to service-users & practitioner relapse:*** Henretty and Levitt's (2010) review cites two non-empirical papers, Dilts et al (1997), not considered here in its own right as it concentrates on substance use, and Mallow (1998). Mallow suggests that self-disclosure of disorders may cause clients to worry about practitioner relapse however, she also suggests that clients should not have to feel that their practitioner does not come from a position of experience, and although appears to encourage caution, this is not at the expense of disclosure per se. When sharing personal experience of eating disorders, Jacobs & Nye (2010) warn that disclosure might be risky where clients feel that they are not able to cope as well as their therapist has, while Costin & Johnson (2002), similarly concerned with disclosure of eating disorders, highlights the potential for practitioners to push clients to recover their way, instead of finding their own route to recovery.

***Danger to practitioners:*** As with clients, disclosure may also have negative effects on practitioners. Costin & Johnson (2002) warns that disclosure may burden staff with extra responsibility for the patient's recovery, while Anonymous (2007, p.568) conversely acknowledges the potential for a "boomerang" effect when sharing personal experiences, though comments that this has not, in fact, happened to date.

***Danger of Non-disclosure:*** Kottsieper (2009) suggests that there are also risks attached to non-disclosure, as this can, stigmatise mental health conditions, convey contradictory and confusing messages, and relegate disclosure to the position of taboo, which are damaging for clients.

### 3.3.8 Pressure against disclosure

#### 3.3.8.1 Empirical studies

***Perceived and overt pressure from colleagues, especially when discloser is pre-qualified:***

Potential negative reactions regarding the disclosure of mental health conditions may pressure practitioners to avoid disclosure. Bottrill et al (2010) suggest that disclosure of mental health conditions can be viewed as a taboo practice by colleagues, and for this reason it may be difficult for practitioners to be open about their experiences in their clinical roles, particularly when they are in pre-qualification training. Several studies suggest that disclosure may be discouraged through pressure from colleagues and/or organisational cultures that do not support disclosure (Marino et al, 2015; Morgan & Lawon, 2015; Adame, 2011; Boyd et al, 2016; and Asad & Chreim, 2016). Geppert & Taylor (2014) suggest that most of the 714 psychiatrists in their survey would be reluctant to disclose a mental health condition, and that this may be due to adherence to non-disclosing psychoanalytic models.

#### 3.3.8.2 Non-empirical papers

***Perceived and overt pressure from colleagues, especially when discloser is pre-qualified:***

Several authors suggest that staff may come under implicit pressure not to disclose, with Schiff (2004) and Kottsieper (2009) choosing not to disclose their own mental health experiences whilst in pre-qualifying training. Curtis & Hodge (1994) cite explicit pressure on staff not to disclose, and Schiff (2004), Miles (1999) and Otto et al (2009) suggest that being open about mental health conditions can create a risk of discrimination and being discredited, encouraging practitioners to hide their experiences from colleagues and managers.

### 3.3.9 Lack of research, training and guidance

#### 3.3.9.1 Empirical studies

Davidson et al (1999) in their literature review, including consideration of a range of quantitative studies, suggest that there is a research gap in the role that having and sharing lived experience plays within peer support roles. Further, the impact of self-disclosure of mental health

conditions by practitioners in other mental health professional (i.e. non-peer) roles is unexplored.

Most of the studies focus on practitioner perspectives regarding how disclosure affects themselves and how they perceive it to affect service-users or the therapeutic relationship. Some, however, also captured the voices of service-users, including de Vos et al (2016), Cabral et al (2014), and Morgan & Lawson (2015). However, except for de Vos et al (2016), the number of service-users included is small.

Somers et al (2013) produced one of the largest studies identified, with 155 participants, and focused specifically on the topic of mental health self-disclosure by practitioners with clients. It nevertheless employed analogue methodology, so it is questionable as to whether their findings are applicable to real practice situations.

Bottrill et al (2010) identify a lack of training and guidance for practitioners in deciding what to disclose, how, and when. This is echoed by de Vos et al (2016) and Morgan & Lawson (2015), the latter of whom make some recommendations for disclosure management based on practitioner, service-user, and professional body feedback and from the existing literature.

### **3.3.9.2 Non-empirical papers**

Kottsieper (2009) concludes that there is a lack of research literature that specifically addresses disclosure of mental health conditions, while three authors (Kottsieper, 2009; Curtis & Hodge, 2001; and Jacobs & Nye, 2010) suggest there is a lack of training and guidance on the subject. Curtis and Hodge (2001) offer some broad decision-making guidelines for practitioners in choosing whether to disclose.

### **3.3.10 Themes confined to non-empirical papers only**

**Conversion:** Two authors (Anonymous, 2007; Burnell, 2001) suggest that they have moved from a position in their practice of rarely or never disclosing, to disclosing more often, in both cases without any negative, and with several positive, effects.

**Contradiction:** Two papers suggest that pressure not to disclose creates confusing and contradictory messages about mental health disclosure. Curtis & Hodge (1994) suggest that staff receive conflicting, contradictory messages, on the one hand being discouraged from self-disclosure, while their organisation actively recruits people on the basis of their mental health lived experience and with the expressed intention that they share it with service-users. This is a reflection shared by Otto et al (2009) who argue that while efforts are made in mental health organisations to reduce stigma for clients, practitioners ironically feel pressured to hide their own experiences, which may inadvertently perpetuate the stigma that practitioners are trying to eliminate.

**Automatic disclosure:** Three papers cite the potential for automatic, unavoidable disclosure, questioning whether non-disclosure is a viable option. Jacobs & Nye (2010) suggest that physical appearance can effectively disclose much about a practitioner's condition, particularly in relation to eating disorders, even where verbal disclosure is not made. Practitioners may also be identifiable because they access services provided by their own organisation or access medicines through a company health plan (Curtis & Hodge, 1994; Yarek, 2008), or because they have relationships with other service-users outside of the professional relationship (Curtis & Hodge, 1994). In addition to being visible because of personal appearance or accessing services, Jacobs & Nye (2010) suggest that people with eating disorders may also be identifiable because the level of their knowledge about conditions betrays them as insiders.

### 3.4 Discussion

This review highlights a relative lack of available research literature on self-disclosure of mental health conditions by practitioners with clients. Only six of the empirical studies focused primarily on the topic in question (Somers et al, 2013; Armour 2007; de Vos et al, 2016; Gilbert & Stickley, 2012; Marino et al, 2015; and Morgan & Lawson, 2015). Although several of these studies were well conducted with a high number of participants, two used analogue methodology which may not relate well to real therapy situations (Farber, 2006). Although utilising similar methodologies on a similar subject, the results of the Somers et al's (2013) and Armour's (2007) studies conflict – with the former finding positive outcomes associated with disclosure, and the latter finding no influence either way. Crucially, both studies were entirely quantitative, relying on ratings alone, so neither study investigated why people answered the way they did, and the voices of genuine practitioners and service-users were not captured.

However, where they asked such questions, other empirical studies indicated positive views and potential benefits of mental health disclosure (de Vos et al, 2016; Gilbert & Stickley, 2012; Marina et al, 2015; Morgan & Lawson, 2015; Boyd et al, 2016), between them captured quantitative and qualitative evidence, and gained the views of real service-users and practitioners rather than proxy groups.

While practitioner perspectives are at the forefront throughout both the empirical and non-empirical literature, several studies are restricted to therapists, as opposed to the wider mental health workforce (doctors, nurses, social workers etc.). The perspective of service-users in relation to self-disclosure of mental health conditions by practitioners is relatively unexplored. Only Cabral et al (2014), Morgan & Lawson (2015), and de Vos (2016) gained the views of non-analogue service-users. Of these, Cabral et al (2014) canvassed the views of only ten, and Morgan & Lawson (2015, p. 80) “eight to ten” service-users, while the latter was not a formal research study. De Vos et al (2016) did gain the views of a substantial number of patients (n=205), which offers the opportunity to extend findings to service-users in general, though respondent were all eating disorder patients, and may not be representative of service-users in general. In addition, Cabral et al’s (2014) study focused primarily on the peer support role, rather than wider mental health professionals, and did not focus primarily on self-disclosure, though it did identify sharing lived experience as the critical element for success in peer programmes. The voice of service-users was also lacking in the non-empirical literature. Although service-users are sometimes reported to have said positive things about their practitioner’s self-disclosure (Burnell, 2001; Costin & Johnson, 2002; Nealy, 2011), their voices are filtered through the subjective reports of the authors, without any internal or external verification as to their accuracy, and most articles focus on the impact that the therapist thinks disclosure had on the therapeutic relationship. The voice of service-users is therefore missing to a large extent within an already limited research base.

Only four of the empirical studies relate directly to the UK. Gilbert & Stickley’s (2012) study was of low quality and restricted to feedback from students. Morgan & Lawson’s (2015) paper was not a formal research study and gained the views of very few service-users and practitioners. In Bottrill et al’s (2010) and Gough’s (2011) studies self-disclosure of mental health conditions was not the focus of the study, and received limited attention, and the studies were not of a high enough quality to be taken as representative of UK attitudes. All of the non-empirical studies related to the USA and Canada.

The evidence regarding the positive effects of self-disclosure in general is fairly sound. From the wider work undertaken by Knox & Hill (2003) through to the systematic review of therapist disclosure undertaken by Henretty & Levitt (2010), potential and real benefits of disclosure are identified and evidenced. Although some studies also evidence negative consequences, they are outweighed by the number of studies that show either neutral or positive effects. Regardless of whether disclosure has positive or negative effects, since there is general agreement that some degree of disclosure is largely unavoidable, the most appropriate question regarding self-disclosure, as Bottrill et al (2010) and Henretty and Levitt (2010) suggest, might well be how to make the best use of disclosure rather than whether it should be done. Not only is disclosure unavoidable, most practitioners, from whatever therapeutic perspective or approach, tend to do it to some extent (Henretty & Levitt, 2010). Given its popularity, the evidence regarding its use, and the unavoidable nature of it, begs the question as to why it is so controversial.

One reason for the controversy might be that practitioners are unsure where to stop – if something is revealed to one service-user, there may be an expectation to reveal without limits, and with a wider range of service-users (Bottrill et al, 2010). However, since some disclosures are inevitable or unavoidable, practitioners already have one foot on the ‘slippery slope’ even if they have taken efforts to avoid direct, verbal disclosures. It may be the case that practitioners’ fears regarding self-disclosure indicate a need to increase practitioner competence in using it, rather than a reason to avoid it. As Bottrill’s clinical psychologists suggest, being able to consider disclosures in advance, rather than being taken off-guard and having to make decisions in the moment, and being able to weigh up risks, know where to stop, and how to use disclosure effectively, are competencies that could be addressed through the availability of guidance and training, which may ameliorate the concerns that practitioners have.

The nature of unavoidable disclosure, whether because of being known in a particular community or accessing specific services, (Henretty & Levitt, 2010; Curtis & Hodge, 1994; Yarek, 2008), or because of a visible characteristic such as being dangerously thin or having a high level of insider knowledge (Jacobs & Nye, 2010) renders non-disclosure impossible or implausible in some cases. This, together with societal shifts towards greater transparency and openness regarding a wide range of identities (Farber, 2006) moves the question on from *whether* to disclose to *what, when, where and how* to disclose (Henretty & Levitt, 2010). Although general guidance is available regarding self-disclosure (for example, Henretty and Levitt, 2010; Knox & Hill, 2003), it is not context specific, does not address the disclosure of mental health conditions

with clients who also have mental health conditions, and does not specifically address the needs and concerns of a wide range of mental health practitioners.

Out of 30 studies in Henretty & Levitt's (2010) systematic review, 20 favoured disclosure as opposed to non-disclosure, from the perspective of clients. Although these studies do not address the disclosure of mental health conditions, they do indicate that clients of therapists tend to value disclosure for a wide range of reasons, while only four studies indicated that disclosure was seen as harmful. The results from the present review agree with these findings. Apart from some potential pitfalls, risks and dangers, none of the papers reviewed here actively discourage disclosure in its entirety, and all contain pro-disclosure messages to some extent. Further, it is suggested that non-disclosure might at best fail to challenge, and at worst buy into and support the stigma that people with mental health conditions face, ultimately to the detriment of service-users.

### **3.5 Limitations and Conclusion**

It is possible that papers were missed in this literature review. This may be due to the databases selected, failure to identify relevant papers during the sifting process, or failing to represent the range of views put forward in papers that were retained. To some extent these limitations were mitigated through undertaking the second literature search which did identify two pre-2014 papers that had been missed in the first review (Gilbert & Stickley, 2012; Adame, 2011). This may be due to reviewer-error, or to changes in the way online databases conduct searches. However, given the large number of results that searches generated, the thoroughness of the sifting process, and the repeated searches, it is likely that most of the relevant literature has been found and considered.

The current review indicates that there is little evidence in the research literature to date to support the view that self-disclosure per se is inherently risky or should be avoided, or to explain the taboo that surrounds it. There is a need for further research to explore attitudes towards self-disclosure of mental health conditions by practitioners with service-users, from a UK perspective. There is also a need for training and guidance on the subject to help practitioners make informed decisions about disclosure that is relevant to their professional role within mental health services. The following chapter outlines how the current study aimed to respond to some of the identified gaps in knowledge.



## Chapter 4: Methodology

### 4.1 Introduction

A survey was administered to practitioners and service-users in an NHS mental health trust in the UK. It asked respondents to give real-life examples of information that practitioners had shared with service-users in the past; to rate the helpfulness of practitioners sharing seven different types of hypothetical disclosure, including personal mental health lived experience; and rate the helpfulness of different types of practitioner sharing information about their own mental health. Respondents were asked to indicate in what ways the real-life examples and hypothetical questions were helpful or unhelpful using free-text. Focus groups were conducted in the UK with practitioners and with service-users to explore some of the survey findings in greater depth, and in a statutory mental health organisation in Australia to provide international comparison.

### 4.2. Methodological Options

The survey method was chosen because it enabled contact with a wide enough range of participants to allow generalisation of results. Ratings scales enabled quantitative statistical analysis of attitudes towards disclosure, and the inclusion of qualitative free-text response options allowed participants to define what aspects of disclosure were important to them. Various other methods of undertaking the research were considered, and some of these options are explored below.

#### 4.2.1 Measuring outcomes

Different researchers have justified and explored both objective, clinical outcomes and subjective, quality of life outcomes as valid areas of research. Beach et al's (2004a) study investigated whether self-disclosure in physical health settings by physicians (GPs) affected patient experiences. They used self-report methods to gain patients' qualitative assessments of the doctors' warmth, friendliness, comfort, reassurance, and satisfaction, rather than clinical outcomes such as whether they got better treatment, recovered more quickly, or were more likely to take advice or medication. Lloyd-Evans et al (2014) considered both self-report outcomes (for example, hope, recovery, and symptom reports) and clinical outcomes (for

example, hospitalisation and employment) as important in the evaluation of mental health peer mentor programmes, with the latter being considered as objective outcomes.

These studies raised several questions for the current study regarding the legitimacy of different approaches, and whether to measure 'objective' clinical outcomes, 'subjective' self-report outcomes, or both. Concentrating exclusively on either of these positions might thwart respondents' ability to decide for themselves what counts as an outcome, or may value some types of outcome more highly than others: for example, while professionals and funders may be more interested in clinical outcomes, service-users may value quality of life outcomes. It was felt to be outside the scope of this investigation to answer questions about which outcomes count before attempting to find out what people think about the subject.

The impetus for this research was to find out what practitioners and service-users think about sharing lived experience, rather than to measure its clinical impact, because there had been relatively little exploration of attitudes towards the subject in the literature thus far. For this reason, respondents' feelings about sharing lived experience were felt to be valid and legitimate objects of analysis for an exploratory study.

#### **4.2.2 Self-report vs. observation of real practice situations**

There are several drawbacks associated with self-report measures of past experience: respondents' views gathered through self-report methods may not accurately reflect what happens in in real-world practice situations (Bryman, 2012); subjective evaluations of interventions may be contradicted by independent, objective measures (Sheldon & Macdonald, 2009); and the recollection, interpretation and evaluation of events may change over time (ibid).

Jourard developed a 60-question self-disclosure scale (Jourard & Lasakow, 1958) and a 25-question scale (Jourard, 1961a), which have since been adapted by others (for example, Ashmore & Banks, 2001) to measure the frequency of various disclosure subjects. While this has been verified as internally valid, it does not appear to predict whether practitioners disclose in real situations (Cozby, 1973), and several studies suggest that self-reports of past disclosures contradict observed disclosure behaviour (Chelune, 1975). This may be due to social desirability bias (also referred to as response bias), wherein practitioners report disclosing less of the things that they feel are inappropriate, and more of the things that they think are more appropriate

(Burnard and Morrison, 1994). It may also be because disclosers are not always aware of the ways in which they give away information about themselves (Gibson, 2012; Luft, 1969). Similarly, disclosure recipients may not recognise they have been disclosed to because sharing every-day information forms a normal part of general reciprocal conversations, which Abramsky (2013) describes as disclosures of low-intimacy. Haghghat (2001) suggests that people tend to remember and associate rare, negative events with rare objects such as minority groups. Hence, they may be more likely to remember negative practitioner behaviours and characteristics if they know the practitioner has experienced mental illness than when they think the practitioners is part of the majority 'well' population. Further, two respondents reporting the same situation may have different perspectives of its merits, for example, disclosures may cause discomfort to a service-user, but be seen as helpful by a practitioner where they have used it for therapeutic purposes (Bishop & Lane, 2001) or to help service-users cope with uncomfortable information (Bram, 1995). These factors may cause biased reporting of disclosure prevalence, or conflicting reports of disclosure effects.

Direct observations of practice situations, for example, Beach et al's (2004a) study which analysed audio recordings of physician-to-patient disclosures made in real practice situations, may offer a method of minimising concerns associated with recall and subjectivity, but they also have drawbacks. The problem of reactivity (Bryman, 2012), also referred to as the Hawthorne effect (McDaniel et al, 2007), may occur where participants know they are being observed and alter their behaviour as a result. This could cause practitioners to avoid disclosure when being observed if they think it may be viewed as unprofessional, even if they disclose in their non-observed practice.

There were also two practical reasons for rejecting direct observation methods: ethical approval for covert observation would have been unlikely for a study such as this because potential benefits would not justify the means; and unlike Beach et al's (2004a) study, which analysed 1,265 physician/patient interactions, resources for the current study were not sufficient to undertake enough direct observations to draw any generalisable conclusions.

### 4.2.3 Measuring complexity

Efforts to measure disclosure may be limited because they fail to recognise and capture its complexity, with common methods of enquiry, such as surveys and measurement scales, reducing enquiry to pre-defined, researcher-devised questions that offer limited perspectives (Antaki et al, 2005). Quantifying and identifying types of disclosure is likely only to be partial and superficial, concentrating on the surface signs of disclosure rather than their deeper meaning to the participants (Burnard and Morrison, 1994), and non-verbal disclosures may be missed by this type of approach. Counselee recall of the extent of counsellor disclosure may be affected by non-verbal cues, such as the manipulation of deliberate counsellor pauses, even where there is no material change in actual disclosure (Fischer & Apostol's, 1975), and disclosures accompanied by non-verbal indicators that convey underlying attitudes, beliefs and idiosyncrasies may result in greater self-revelation than simply increasing disclosure frequency (Burnard and Morrison, 1994). Further, disclosure may be more powerful when it is used less frequently (Knox & Hill, 2003). Measuring disclosure is not simply a matter of quantifying its occurrence and correlating this with outcome measures.

### 4.2.4 Methodological options conclusion

While there may be an objective reality regarding whether an intervention achieves a particular outcome, socially constructed realities are nevertheless real to those who experience them (Elder-Vass, 2012), and are a legitimate target of study.

Surveys focused on perceptions of the helpfulness of disclosure, as defined through consultation with service-users in the development of the research. Helpfulness was a sufficiently personal concept to allow respondents to define what they felt to be helpful to them, and in what ways, rather than researchers restricting investigation more narrowly defined clinical or quality of life outcomes.

Direct observations (for example, Beach et al, 2004a) were rejected because they were assessed to be too time consuming for available resources, subject to bias through observation, and potential knowledge gains were felt to be unlikely to justify covert observation.

Measuring clinical outcomes (for example, Lloyd Evans et al, 2014) were considered but rejected because they were felt to undermine the ability of practitioners and service-users alike to define what counts as an outcome, and what types of outcome they valued.

Although there were methodological drawbacks to using self-report measures (such as those used by Jourard & Lasakow 1958; Ashmore & Banks, 2001), meaning that what happens in real life may be remembered incorrectly (Sheldon & Macdonald, 2009), they were adopted because they were resource-effective and because triangulation of results would enable analysis of any contradictions between recall of past disclosures, and feelings towards potential future disclosures, as well as comparison between service-user and practitioner reports of disclosure types and helpfulness.

As indicated there are methodological and practical difficulties associated with studying 'real world' disclosures. In the current study, although recall and revisionism might have affected individual accounts of disclosure, it was felt that data from a broad range of respondents would be sufficient to gain an understanding of competing attitudes towards disclosure, grounded in practice situations. Bias was minimised by triangulating results, checking whether service-user reports agreed with practitioner reports of disclosure, and whether qualitative enquiry agreed with quantitative results. Exploring attitudes towards future hypothetical disclosures as well as real-life historical disclosures limited the effect of recall bias because participants were asked about their current views as well as their subjective recollections of past events. Exploration of survey data in focus groups also enabled researcher interpretations to be discussed, clarified, validated, or rejected. Service-users were also recruited to take part in the research process, from design through to analysis, for a variety of reasons (see section 4.5) including the mitigation of potential researcher bias.

### **4.3 Survey**

A survey was undertaken with practitioners, and another with service-users, in a UK NHS Foundation Trust to ask for participants' views on how helpful or unhelpful it is for practitioners to share their lived experience with service-users.

### 4.3.1 Method used

The surveys for the practitioners and service-users were almost identical, so that they could be compared later. A comparison of both sets of questions is included in Appendix 4. Surveys consisted of:

- i. Demographic questions asking for age, ethnicity, disability, gender and other relevant information. A full list can be seen in Appendix 5 (service-user survey, and demographic section of practitioner survey), and these along with the rationale for each item can be viewed in Section 4.3.6 of this chapter. Practitioners were additionally given a list of job roles, for example nurse, doctor, social worker, and they were asked to indicate which was closest to theirs (see Appendix 5).
- ii. A question asking practitioners if they had ever shared anything with a service-user, and asking service-users if a practitioner had ever shared anything with them.

Practitioners who had shared were directed to the next question, which asked for examples of disclosure. Those who had not shared were asked to give reasons for choosing not to disclose. The latter question was added after considering a study by Ashmore & Banks (2003) which asked nursing students not only why they disclose but also gave them the opportunity to express freely why they chose not to share information about themselves.

Since service-users may have experienced practitioners who had disclosed and others who had not, they were all asked to indicate why they thought practitioners choose not to share personal information with service-users.

- iii. A section asking participants to give up to three examples of where a practitioner had shared something with a service-user, in what ways it was helpful or unhelpful, and why. Service-users and practitioners who had not experienced or used disclosure did not complete this section.

iv. A section asking participants to rate the perceived helpfulness of seven types of disclosure on a 1 to 5 scale, with 1 being unhelpful, and 5 being helpful. Types of disclosure included:

- Personal mental health experiences
- The mental health experience of a close family member or friend
- Religion
- Physical Health
- Difficult or traumatic life experiences
- Hobbies and out of work interests
- Sexual Orientation

Each question in this section included a free-text box for participants to say why they answered the way they did.

v. A section on the practitioner survey asking practitioners if they would feel differently about disclosing if they had a different role or job in their organisation.

vi. A section asking participants to rate, on a 1 to 5 scale, how helpful or unhelpful it is for different types of practitioner to share their mental health lived experience with service-users, with 1 being unhelpful and 5 being helpful. Examples of job roles included nurse, doctor, and social worker, and a full list can be seen in the survey in Appendix 5.

Participants were given one free-text box to indicate, if relevant, why they gave different ratings to different types of practitioner.

vii. An opportunity to make comments about the survey or sharing lived experience via a free-text box.

viii. An opportunity to leave contact details to be kept informed of results and to get involved in further activities such as focus groups and working groups.

### 4.3.2 Survey method justifications

A cross-sectional survey was used because they may allow generalisations to be made about wider populations, especially where participants are randomly selected, and the incorporation of both quantitative and qualitative questions allows for triangulation of findings to check validity (Bryman, 2012). Surveys were also chosen because they offer a means of contacting a large number of potential participants in a cost-effective way (Greener, 2011), which was relevant to the limitations of researcher capacity and financial resources in the current study.

### 4.3.3 Existing disclosure tools and intimacy scales

The existing literature was searched to investigate whether suitable disclosure measurement scales already existed that might be adopted or adapted for the current study. Citations were followed to locate original sources wherever possible.

Some studies investigated whether the intimacy of a disclosure (how personal it is) affects its utility, so additional searches were undertaken to identify any suitable disclosure-intimacy measurement scales that might determine whether disclosure helpfulness is influenced by disclosure intimacy in the current study.

No tools were found that were suitable for the current study. Self-disclosure questionnaires either did not address the disclosure topics of interest in the current study, or had been developed to measure disclosure in the general population rather than by professionals within mental health settings. Studies and papers either mentioned the existence of intimacy tools or scales without publishing them, or published them without sufficient detail of disclosure topics they related to.

However, developmental research discussions were informed by the general messages these papers contained, and some of these are outlined below.

The frequency with which different types of information are shared may be connected to how personal or intimate they are. Ashmore and Banks' (2001) study indicated that nursing students shared less revealing information such as favourite sports, music, and social activities most



often, while details of personal sex lives were disclosed least often with religious beliefs falling somewhere in between.

Taylor & Altman (1966, p.730) devised and validated a scale to categorise different types of information according to their perceived level of intimacy, organising them into “13 topical categories: religion, love and sex, own family, parental family, hobbies and interests, physical appearance, money and property, current events, emotions and feelings, relationships with others, attitudes and values, school and work, biography.” However, they did not include a breakdown of what the disclosures were within those headings. This pattern was repeated with other studies, for example, Ehrlich & Graeven (1971) adapted Taylor & Altman’s (1966) categorisation, but did not specify the detail of the disclosure statements categorised as low or high intimacy, other than giving general category headings similar to those of Taylor and Altman (1966), described. Cunningham (1981) gives another adaptation of the Taylor & Altman (1966) scale, but again no detail is provided of what was contained within the broad category headings. Sedikides (1999) describes the categorisation of various statements according to how personal they are, but contact with the author (email, 12.05.14) revealed the items were categorised by colleague consensus, and had not been formally validated. Strassberg & Anchor (1975) mentioned the development of an intimacy scale but did not publish it, and contact with Professor Strassberg (05.02.14) indicated this information is no longer accessible.

Dies (1973) presents a mixture of questions aimed at attitudes towards self-disclosure by therapists in group therapy situations. The disclosure questions are generally concerned with whether the therapist should disclose information about very broad areas, such as their past experiences, as well as function, boundary and conduct issues between therapists and clients. Its connection to the current study is limited.

Cunningham (1981) did not provide a list of individual disclosures used in his study, but did provide broad category headings, and also provided some of the original validated Taylor & Altman (1966) intimacy ratings which suggested that:

- Disclosures deemed to be of the highest intimacy were: love dating and sex; parental family; emotions and feelings; and own marriage and family.

- Disclosures deemed to be of lowest intimacy were: biographical characteristics; interests, hobbies and habits; and politics and government.
- Disclosures of medium intimacy included: religion; physical condition and appearance; money; relationships with 46 others; attitudes and values'; and school and work.

While this provides some insight into the types of disclosures that have been measured in previous studies, and which disclosure subjects are seen as more or less intimate, they did not correlate sufficiently with the disclosure items that would be explored in the current study, and it was unclear how questions about disclosure were worded.

No previously validated self-disclosure or disclosure-intimacy tools were identified that could be adopted for use in the current study. It was therefore decided to construct a self-disclosure questionnaire and to pre-test it for reliability. It was also decided to construct an intimacy measurement scale to help analyse whether the intimacy of a disclosure is connected to its helpfulness.

The final version of the self-disclosure survey can be viewed in Appendix 5. The intimacy measurement scale is described in section 4.6 and can be seen in Appendix 6.

#### **4.3.4 Terminology**

##### ***4.3.4.1. Sharing lived experience vs self-disclosure***

Although the term 'self-disclosure' tends to be used in much of the literature, the term 'sharing lived experience' tended to be preferred when consultations took place with service-users (Sharing Lived Experience Conference, 2013; the investigation site's service-user research panel, 2013; and the University of York's service-user research panel, 2014). For the purposes of this study, 'sharing lived experience' was used where possible.

##### ***4.3.4.2 Helpful vs acceptable***

The survey asked respondents about the helpfulness of disclosure. Initially several other terms were considered instead of 'helpful', including 'useful', 'beneficial', and 'acceptable'. However,

discussions suggested that these terms might carry implicit suggestions that clinical outcomes (for example, remission rates) might be of higher importance than qualitative outcomes defined by service-users themselves. 'Useful' might suggest utility, implying that the merits of disclosure are to be judged on whether they lead to a pre-defined outcome, and, implicitly, one decided by the practitioner rather than the client. 'Beneficial', likewise, suggested that that judgements might be made according to whether there is any tangible, measurable benefit to service-users, rather than less tangible quality of relationship outcomes that service-users might define as important for themselves. 'Acceptability' and 'unacceptability' were considered but rejected because they suggested judgment about whether different types of disclosure should or should not be made, rather than asking about their effect on those who make and receive those disclosures. It was felt that a helpful/unhelpful dichotomy would encourage respondents to think about their own subjective perceptions of why disclosures might be made and what effect they might have on both the discloser and those disclosed to.

#### **4.3.5 Question content**

##### ***4.3.5.1 Disclosure categories vs scenarios***

Initially, discussions with the Trust indicated that the survey might best follow the format of the previous (unpublished) study into self-disclosure by social workers with clients (Lovell, 2013), as this study had led to contact between the researcher and the Trust. The social worker survey had contained scenarios outlining different disclosure subjects (religion/ethnicity, sexual orientation, family circumstances, and mental health), and asked participants to rate them according to acceptability. This method had been deliberately chosen to identify whether practitioners felt that disclosure of Lesbian and Gay sexual orientation was less acceptable than other types of disclosure, in particular heterosexual disclosure.

Since the current study was aimed a variety of professionals (doctors, nurses, social workers, psychologists etc.), working in a variety of mental health settings (forensic, adults, older people, gender services, personality disorder, eating disorder etc), and aimed to incorporate a range of disclosure subjects (rather than mental health only), designing a range of scenarios that were neutral and avoided bias towards certain services or professionals was problematic. It was apparent that some scenarios might have more resonance with some professionals, service-users, and areas of service delivery than others, and this might influence responses. Balancing

these issues across scenarios was judged to be impractical. To overcome this, questions were constructed that concentrated on sharing types of lived experience, and which avoided steering participants to consider professional roles and service contexts. However, it was practical and feasible to include a single question regarding the helpfulness of one type of disclosure (personal mental health) when made by a range of different practitioners.

#### **4.3.5.2 Disclosure topics**

The current study was primarily focused on mental health lived experience, but it was decided to ask questions about other types of personal attributes, identities and experiences that might also be shared, partly to avoid incorrect assumptions about which aspects of a person's identity might be most or least important to a service-user, and also to act as comparators to the sharing of mental health lived experience. In deciding what types of self-disclosure to include, several previous studies were explored to see whether existing self-disclosure scales might be used or adapted. These included:

- (i) Jourard & Lasakow's (1958) 60 question survey which he used among female nursing students to explore the extent to which (i.e. how often) they shared personal information with different friends and family members.
- (ii) Ashmore & Banks (2001) slightly adapted version of Jourard's subsequent (1961a) 25 question survey (based on the previous 60 question survey) on similar types of disclosure (again among nursing students, this time female), to include disclosure with patients (as well as family and friends). The survey asked people how often they shared information about: attitudes and opinions, including politics, religion, race, sexual morality, gender roles, alcohol consumption, child rearing, physical attractiveness; tastes and interests, including food, drink, clothes, films, music, home furnishings, social gatherings, hobbies, receiving gifts; work (or studies), including feelings about work or studies, such as stress, enjoyment, boredom, satisfaction, aspirations, abilities, barriers, salary, career choice, and relationship with employers; money and personal situation, including salary, debts, savings, loans, property, budgeting etc.; personality, including likes and dislikes about self, sex life, feelings, attractiveness to others, anxieties, fears, worries, things to be proud of, self-esteem, and vulnerabilities; body, including likes and dislikes, and

statistics regarding appearance, height, weight, health problems, fitness/exercise, illnesses (implicitly physical), and sexual function.

- (iii) Hendrick's (1988) counsellor self-disclosure scale, aimed at discovering what types of information clients might want to know about their counsellor. The underlying content of the scale is similar to Jourard's (1961a) scale, and includes items such as family structure, beliefs, professional affiliation/approach, etc. It differs from Jourard's checklist in that it refers to disclosure of the practitioner's personal religious beliefs, rather than to their attitudes about others' religious beliefs and religion in general, and it refers to the practitioner's sexual orientation as well as sexual practices.

These were discussed and a shortlist was devised for discussion between the Chief Investigator and the Lead Practitioner at the Trust. After consultation with the Trust's service-user research panel (2013) and the University of York's service-user group (2014) a final list of 7 hypothetical disclosure items was chosen. These were: personal mental health lived experience; the mental health of a close family member or friend; difficult or traumatic experiences; disability including long term physical health conditions; religion; sexual orientation; and hobbies and out of work experiences.

It was recognised in these discussions that asking only about these 7 disclosures restricted the field of enquiry and presented categories that were researcher-defined rather than allowing participants to decide freely what is important to them. Therefore, an open ended question was included in the survey allowing respondents to indicate what kinds of things practitioners had disclosed, and their thoughts in relation to these. The number of examples respondents could give was restricted to 3 to ensure the survey was not too onerous to complete or analyse.

#### ***4.3.5.3 Wording of ratings questions for hypothetical disclosure topics***

For each of the seven questions which asked participants to rate the helpfulness of different disclosure topics, service-users were asked to rate how helpful or unhelpful it would be for practitioners to share the disclosure topic, and practitioners were asked to rate how helpful or unhelpful it would be for them to share information about themselves with a service-user. This meant that service-users were asked to answer in a generalised sense, while practitioners were

asked to speak about themselves sharing, rather than practitioners in general sharing information. This presented a disparity, but it was felt to be preferable to other options. For example, asking practitioners to respond about practitioners in general might cause them to make assumptions about other practitioners' motivations, knowledge, or skills that could influence the response, rather than ratings being influenced primarily by the disclosure topic.

This also meant that practitioner responses might be influenced by whether they had the relevant identity or experience to share, for example personal mental health lived experience. However, this was discussed and the wording of the question was felt to be sufficient to indicate its hypothetical nature, by the inclusion of "how helpful or unhelpful do you think *it would be* to share" rather than "how helpful or unhelpful *is it* to share..."

#### **4.3.6 Demographic data**

Demographic data on research participants was gathered to enable analysis of results based on various criteria. The rationale for the inclusion of the various demographic items are listed below. The size of the survey was limited in order to reduce respondent burden and to reduce printing and postage costs, and subsequently the amount of demographic data gathered was restricted.

##### **4.3.6.1 Professional job roles**

Jourard's 1964 seminal and influential study (see Jourard 1971 for updated reprinted publication) suggested that people either seek to convey accurate information about their selves (which is seen as healthy), or the selves that they would like people to see (which involves deception and avoidance, and is unhealthy). Similarly, it was considered that views about the helpfulness of practitioner disclosure may be influenced by desires to maintain an image of what a person ought to be like or how they should behave in a given professional role. This study therefore gathered job role information to explore the impact (if any) of job role on responses.

A list of job roles (doctor, nurse, social worker etc.) were discussed and compiled with the Informatics team at the Trust. As a result, practitioners were asked to indicate in the survey the job type most like their own. This item was not included in the service-user survey.

#### 4.3.6.2 Mapping service-user diagnosis and practitioner specialism

In the initial stages of research planning, it was decided to match service-users who received particular services with practitioners who delivered those services, to see if there were differences in how disclosure is viewed within and across individual services. The reason for this was because there was anecdotal evidence from within the Trust that practitioners were less likely to disclose personal information to a service-user if they had a diagnosis of personality disorder, due to fears they may misuse such information to the detriment of the practitioner. This has some resonance with the literature, with Henretty & Levitt's (2010) systematic review which identified three studies suggesting practitioner disclosure is influenced by 'client diagnosis' (Simone et al, 1998) 'symptomatology' (Kelly & Rodriguez, 2007), or 'personality disorder' (Mathews, 1989). Discussions took place regarding how the survey might identify and record the diagnosis of individuals, and the service delivery area of practitioners. The following actions were considered and rejected for indicated reasons:

- (i) **Identifying service-user diagnosis.** Practitioner experience within the Trust suggested that in many cases service-users are unaware of the name for their condition, so there was too much scope for different people to describe the same conditions in different ways, making it difficult to analyse responses by diagnosis. Checklists to get around this would be unacceptably long and, because of service-user uncertainty with their diagnosis, likely to be completed inaccurately. This question was therefore rejected.
- (ii) **Identifying service received.** Asking service-users which service they receive was considered carefully. This was rejected because, as with identifying diagnosis, service-users may not be aware of which service area they receive services from. Instead, work was undertaken to stratify samples taken by service area, as described below.
- (iii) **Identifying service area by sample stratification.** Work was undertaken to develop the means to draw samples from each service area (for example, personality disorder, eating disorder, gender services etc.), sending out coded surveys so that returns from each service area, could be identified and compared. A great deal of work was undertaken to enable this to happen and, although this looked promising,

it was eventually rejected for purely unavoidable reasons. It was eventually identified that the Trust's informatics system, while it could generate suitable stratified samples for service-users, could not generate comparable stratification for practitioners, so it would not be possible to compare responses by service area. In addition, many practitioners may work across several service areas and with service-users with a variety of diagnosed conditions, drawing into question whether any data generated in this way would have been useful. Therefore, a decision was made to generate random samples of both practitioners and service-users. In the latter case, it was stratified to ensure that service areas with small numbers of service-users were not missed out by chance.

These actions meant that, should there be an issue with, for example, practitioners sharing lived experience more or less with service-users who have certain types of diagnoses, it would have to emerge from the qualitative data, and be identified proactively by participants.

#### **4.3.6.3 Other demographic data**

The rationale for asking questions about other identifying, demographic data, is outlined below:

- (i) **Age:** Henretty & Levitt (2010) indicate in their meta-analytic review of therapist self-disclosure that studies show no difference in disclosure by age. However, they do indicate that there may be some differences by the number of years that practitioners have practiced, with early career therapists disclosing less than more experienced therapists, and although no effect of age was found in these studies, it might be expected that those practitioners who have worked for longer tend to be older than those at the beginning of their career. The effects of age on disclosure may be useful to explore in more depth should age effects be observed in the current study. Participants were therefore asked to state their age in years, with an option of 'prefer not to say.'
- (ii) **Gender:** Dindia & Allen (1992) conducted a meta-analysis of previous studies to ascertain whether there are differences between genders regarding self-disclosure. It concluded that women disclose slightly more than men, and that



the gender of the person to whom the disclosure is being made may affect disclosure rates. Hardin & Yanico (1983) suggest that men, more than women, expect therapist disclosure. Further consideration of gender differences may be useful if gender differences were indicated in the results of the current study. Tick box gender options included male and female, but also transgender and intersex to ensure inclusivity and avoid imposing binary gender identities onto participants. There were further options of 'other' and 'prefer not to say.'

- (iii) **Sexual orientation:** There is much in the literature to suggest that sexual orientation disclosure is an important topic, particularly for Lesbian and Gay therapists (Galgut, 2005; Moore & Jenkins, 2012) and Lesbian and Gay clients (Evans & Barker, 2010; Galgut, 2005). Atkinson et al (1981) suggest that disclosure of a minority sexual orientation (being Gay) to someone else with the same sexual orientation may increase clients' ratings of the therapists as more trustworthy, expert, and attractive, while Moore & Jenkins (2012) suggest coming out by Lesbian and Gay practitioners to heterosexual clients is potentially problematic. Asking for the sexual orientation of respondents may assist in further investigation of any differences in responses between different sexual orientations, particularly with regard to the specific sexual orientation disclosure question in the survey. Participants were therefore asked to indicate whether they identified as Straight, Gay, Lesbian, Bisexual, Other, or preferred not to say.
- (iv) **Ethnicity:** Differences in disclosure may be associated with ethnicity. Plasky & Lorion (1984) suggest that BME respondents on a self-disclosure inventory may be less likely to disclose to a psychiatrist than white respondents, while Jourard (1961a) suggests that British people are more reserved and disclose less than American counterparts. Gathering ethnicity data may help to identify any effects on attitudes towards disclosure in the current study. Ethnic monitoring categories were adapted from Census ethnicity categories, though sub-categories were amalgamated into broad categories for reasons of space. The tick box options were:

- White (English, Welsh, Scottish, Northern Irish, Irish, British, Gypsy or Irish Traveller, other white background)
  - Mixed / Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed / Multiple ethnic background)
  - Asian / Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)
  - Black / African / Caribbean / Black British (African, Caribbean, Any other Black / African / Caribbean background)
  - Other ethnic group
- (v) **Physical disability** (including long-term physical health conditions): The effect of practitioner disclosure of physical health conditions on colleagues and clients is explored in the literature (Edwards, 2004; Gignac & Cao, 2009; McDaniel, 2007). Disclosure of physical health conditions might be affected by whether the practitioner and service-user share health concerns. Participants were asked under a section titled 'Physical disability (including long-term physical health conditions)' to indicate whether they 'have a disability', 'do not have a disability' or 'prefer not to say.'
- (vi) **Religion**: Jourard (1961b) suggests that religious denomination does not affect disclosure (except among Jewish males), with similar results being reported by Hargie et al (1995) in their study of Catholic and Protestant disclosure in Northern Ireland. However, while religion may not, in itself, affect disclosure rates in general, it may be that case that the ratings of the helpfulness of religious disclosure are affected by whether the practitioner and service-user share similar or different religious beliefs. Asking participants for their religious affiliation (religious vs non-religious) therefore, may allow some examination of this issue. It was not possible, because of space limitations, to provide an

extensive list of different religious categories, so the responses were restricted to 'I am religious', 'I am not religious' and 'prefer not to say.'

(vii) ***Whether the practitioner has direct contact with service-users in their role:***

This question arose from discussions with the Trust where it was suggested that disclosure might be viewed differently by those staff who have direct contact with service-users to those who do not, due to their relative proximity to service-users and opportunities for disclosure. Asking this question would help to investigate whether such differences exist. Practitioners were asked to indicate they had direct contact with service-users defined as 'in a clinical role, rather than an administrative role.' Options included 'yes', 'no' and 'prefer not to say.'

(viii) ***Whether the practitioner provides clinical supervision for staff who have direct contact with service-users:***

Disclosure is a topic that may be discussed in supervision, or that may take place in supervision between the supervisor and supervisee (Banks, 2013; Davidson, 2011). As with direct contact (above) the extent to which respondents are linked with service-users, either directly, or in the case of this question, via staff that they manage, may affect how disclosure is seen. In addition, it may give insight regarding the origins or policing of pro- or anti-disclosure attitudes. The question asked practitioners whether they 'provide clinical supervision for staff who have direct contact with service-users' defined as defined as 'in a clinical role, rather than an administrative role.' Options included 'yes', 'no' and 'prefer not to say.'

(ix) ***Whether the practitioner has personally experienced a mental health issue:***

The mental health lived experience of practitioners is the central area of focus for this study, and therefore it was felt essential that the lived-experience status of practitioner respondents was ascertained. There was no directional hypothesis about the difference, if any, that lived experience might make. The question asked 'have you personally experienced a previous or current mental health issue or condition that is significant or problematic for you?' Options included 'yes', 'no' and 'prefer not to say.'

- (x) ***Whether the practitioner has a partner or close family member who has experienced a significant or problematic mental health issue or condition:*** As with personal mental health lived experience, close proximity to a family member who has mental health lived experience may affect views regarding the sharing of lived experience. The question asked ‘do you have a partner or close family member who has experienced a significant or problematic mental health issue or condition? Options included ‘yes’, ‘no’ and ‘prefer not to say.’
- (xi) ***Pay scale or managerial level:*** Various discussions were held with the Trust to look at incorporating a question about pay scale or managerial level. Discussions with the Trust suggested that practitioners in managerial positions might either be reluctant to share their own lived experience with service-users or colleagues, or they may influence others against disclosure. However, it was felt that gaining this information in a meaningful way would not be possible because it might be seen to be intrusive or potentially identify individuals, and would be too difficult to incorporate because of the varied pay structures and managerial levels across the Trust. Participants would be likely to use different terms that could not be categorised easily if they were given free-text options, and providing tick boxes would mean extensive lists that might put participants off completing the survey altogether. Instead, asking whether participants had direct contact with service-users, and whether they had supervisory responsibility for people with direct contact with service-users, might enable some tentative exploration in this area.

#### **4.3.7 Pretesting: Cognitive appraisal**

Cognitive appraisal for questionnaires typically involves undertaking a pilot of the research activity with proxy participants who are close in their characteristics to the participants that the research will eventually involve, to gauge whether people understand the questions that are being asked, identify and amend any ambiguities, and make any necessary changes to improve or remove unforeseen problems and barriers (Drennan, 2003). In the case of the current study, there were two target populations for the survey who would receive two slightly different surveys: service-users and practitioners.

In light of this, six people took part in the cognitive appraisal: 3 who had used mental health services, drawn from a service-user group, were recruited to test the service-user survey, and 3 social work students at the University of York were recruited to act as proxy mental health practitioners. Participants were paid £10 each for their time, and the activity took about an hour for each cognitive appraisal. Each participant was asked to read the participant information sheet, verbalising their understanding of it as they proceeded, then complete the survey, reading the question out loud, explaining their understanding of it, and indicating how they would answer. This enabled the principal investigator to assess whether questions were understood in the intended way, and whether changes were necessary as a result of any feedback. Based on this feedback, the changes were either made, did not need to be made for a given reason, or were rejected for a given reason.

#### ***4.3.7.1 Summary of changes accepted***

Various typographical and punctuation errors were identified and corrected. Below is a list of the major changes that were made or rejected.

##### *4.3.7.1.1 On the demographic section:*

The term “disability” was deemed to be vague, since it did not specify whether this included only registered disabilities, or physical health conditions that are disabling. It was clarified to include “or long term physical health conditions.”

On the practitioner survey, it was felt that “*Have you personally experienced a significant or problematic mental health issue or condition?*” did not clarify what “significant or problematic” meant, and for whom. It was also not felt to be clear whether participants should include previous or only current conditions or experiences. It was therefore re-worded to read: “*Have you personally experienced a previous or current mental health issue or condition that is significant or problematic for you?*”

##### *4.3.7.1.2 On the questions:*

Question 1a: when asking participants to give examples of things that practitioners have shared with service-users, the question was re-worded to include “*please give a specific example from your own experience*” as it was felt that participants might either give generalised examples, or

examples they had heard from other people. A subsequent part of this question was also reworded to ask *“in what ways was sharing this information helpful or unhelpful in this specific example”* to ensure that participants were not giving answers that related to two different experiences.

Question 1b: the words *“about themselves”* were added to the question *“Why do you think practitioners choose not to share information about themselves when working with service-users?”* since ‘information’ might refer to any kind of information about anything.

Question 2: The words *“Tick or circle your choice”* were added to this question on the service-user hard copy survey, to clarify how service-users should indicate their answers on the ratings scale.

Question 2 order of questions: It was clear that one participant did not distinguish between item (b) personal mental health and item (g) the mental health of a family member or friend, instead feeling they had been asked the same question twice. It was decided to put the questions next to each other so that it would be easier to see how they differed.

Question 2 (practitioner survey): The question was reworded from *“how helpful or unhelpful do you think it would be to share the following kinds of experience or information with a service-user”* to *“how helpful or unhelpful do you think it would be to share the following kinds of experience or information **about yourself** with a service-user”* as it was not clear that practitioners should be answering from their own perspective, rather than thinking about colleagues or the workforce in general.

Question 3: The original wording of this question was *“How helpful or unhelpful do you think it would be for the following practitioners to share information about themselves with service-users?”* because although it had been intended that this question referred to sharing mental health, this had not been made explicit: *“How helpful or unhelpful do you think it would be for the following practitioners to share information about their own mental health experiences or conditions with service-users?”*

Any other comments box: this was reworded so it was clear participants could make comments about any aspect of the survey, as it could be interpreted as only relating to the previous question. The new wording included *“about this survey or sharing lived experience”*.

#### **4.3.7.2 Summary of changes rejected**

##### *4.3.7.2.1 On the demographic section:*

It was noted that the term “religion” only had optional answers listed as: ‘I am religious’, ‘I am not religious’ and ‘Prefer not to say.’ It was questioned whether clarification was needed on what ‘religious’ meant, and the difference between practising and non-practising. It was judged that such clarification might raise further questions about what practising and non-practising mean to different people, and that this could cause greater confusion. It was decided to leave the question so that people might answer in terms of whether they felt they were religious, which seemed to be accurate enough for the purposes and relative importance of the question.

##### *4.3.7.2.2 On the questions sections:*

Question 2 Ratings: these were considered to be difficult to complete because answers about helpfulness were deemed to be so context specific, depending on the exact nature of the potential disclosure, who was making it, why etc. No solution was suggested by participants, and the researcher was unable to identify a suitable alternative. It was decided to see how people answered in the test-retest conditions – if participants continually chose the middle, neutral rating choice, rather than a broad range of different choices, then it might be deemed that people did indeed find it too difficult to express an opinion on the ratings scales. This did not emerge, and the question was kept as it is.

Question 3: It was suggested to add a free-choice “other” category to the list of job roles that could be rated for self-disclosure helpfulness. This was rejected in light of the expanded lists of job roles supplied by the Trust which were felt to cover all major roles.

#### *4.3.7.2.3 Information sheet (practitioner survey):*

It was suggested that a definition of mental health lived experience should be included. It was felt, however, that a suitable definition had been included, and that this would be sufficient for the target audience, who would be likely to understand what the term meant. Re-wording was considered, but a simple alternative definition could not be identified.

### **4.3.8 Pretesting: Test-retest reliability**

Test-retest involves participants completing the same activity twice some time apart, and comparing the responses to see whether they are similar (Bryman, 2012). If they are then it is likely that the survey is capturing what respondents really think, rather than reflecting merely how they feel that day. In the case of the current study, it involved completing the survey twice, a week or two apart, to check whether participants answered it similarly each time.

#### **4.3.8.1 Test-retest procedure**

28 students took part in the test-retest activity. They were drawn from the BA and MA in Social Work at the University of York, and used as a proxy for practitioners because sufficient numbers could be approached quickly and easily, and because there were insufficient time and resources to pre-test in the NHS. The strength of using social work students was that they were close to practice. The limitations were that they were not drawn from the same population that would take part in the study, and no service-users were involved in this activity.

Efforts were made to conduct the second test two weeks after the first test, to lessen the chance that participants would remember the previous answers they gave. In the main, this was possible, though for a few participants it was necessary to repeat the test only one week apart because they had other commitments. Completing a survey took approximately 30 minutes, and students were paid £5 for each completion, being paid for both at the end of the second completion.

A paired samples t-test was used (using SPSS) to assess agreement between the ratings for each question on survey completions 1 and 2. It was decided that reliability would be established if participants gave similar scores on each completion, but scores would not have to be equal.



For this reason, the paired samples test was chosen over Cohen's kappa. There were two additional yes/no questions, and agreement was tested using Cohen's kappa.

#### 4.3.8.2 Test-retest results

As there were no significant differences between time 1 and time 2, it may be concluded that the survey has test-retest reliability. See table 4.1.

Table 4.1: Paired samples t-test results for pretesting survey (ratings)

Rating of the helpfulness of sharing	Mean difference (Standard Deviation)	95% confidence interval	t (p)	df
Personal Mental health lived experience	0.29 (0.81)	-0.03 to 0.60	1.87 (0.07)	27
Sexual orientation	0.15 (0.82)	-0.18 to 0.47	0.94 (0.36)	26
Religion	.000 (0.67)	-0.26 to 0.26	0.00 (1.00)	27
Physical health	-0.07 (0.55)	-0.29 to 0.14	-0.70 (0.49)	26
Difficult or traumatic experiences	0.43 (1.26)	-0.06 to 0.92	1.80 (0.08)	27
Hobbies	-0.22 (0.80)	-0.54 to 0.10	-1.44 (0.16)	26
Mental health of a family member or friend	-0.07 (0.92)	-0.44 to 0.29	-0.42 (0.68)	26
Mental health by nurse	0.11 (0.83)	-0.22 to 0.43	0.68 (0.50)	27
Mental health by social worker	0.21 (0.69)	-0.05 to 0.48	1.65 (0.11)	27
Mental health by counsellor	0.14 (0.59)	-0.09 to 0.37	1.28 (0.21)	27
Mental health by psychiatrist	0.07 (0.47)	-0.11 to 0.25	0.81 (0.42)	27
Mental health by occupational therapist	-0.07 (0.77)	-0.37 to 0.23	-0.49 (0.63)	27
Mental health by doctor	0.11 (0.83)	-0.22 to 0.43	0.68 (0.50)	27
Mental health by peer support worker	0.00 (0.98)	-0.38 to 0.38	0.00 (1.00)	27
Mental health by non-clinical staff	0.04 (1.04)	-0.37 to 0.44	0.18 (0.86)	27

Using Altman's (1991) classification of kappa values, there was good and very good agreement between the first and second completions of the two yes/no questions asked in the survey, see table 4.2.

Table 4.2: Cohen's kappa results for pretesting survey (yes/no answers)

Question	k
Have you ever shared something about yourself or your experiences with a service-user?	1.00***
If you had a different clinical role/job in your organisation, would you feel differently about sharing information about yourself with service-users?	0.62***
***p<0.001	

Text responses were not tested for reliability. Giving different text responses on the second survey were judged not to invalidate responses given on the first.

### 4.3.9 Survey sampling and recruitment

#### 4.3.9.1 Sampling

In the planning stages it was believed, based on discussions with the Informatics team, that there were approximately 4,000 staff in the NHS Trust, and 12,000 service-users (after excluding under 18s and learning disability services), and initially samples would have been stratified for both service-users and practitioners, so that comparisons could be made between groups. An online sample size calculator (<https://www.dsrresearch.com/>) indicated a minimum sample size of 49 respondents in each sample to enable comparison between samples to give a 95% confidence interval, and 20% probability of Type II error, which are the minimum suggested levels established by convention (Field, 2013).

It seemed reasonable to assume that the current survey might attract a response rate of about 11%, because the Time to Change evaluation study (Corker et al, 2013) had achieved this response level from mental health service-users in 2011. To get a minimum sample size of 49 respondents would have meant sending surveys to at least 490 service-users. It was also assumed that practitioners would respond at higher rates than service-users since, although there may be additional demands on their time, they would also be more likely to be 'well' when they received the survey, and hence more likely to complete it.

#### ***4.3.9.2 Practitioner inclusion and exclusion criteria***

There were no inclusion or exclusion criteria for practitioners and, since there was no cost attached to sending out electronic invites, all were targeted to receive surveys.

Anecdotal evidence from discussions with the NHS Trust suggested that some practitioners felt that disclosure ought to be avoided more when working with people with personality disorder, as they may be more likely than other service-users to use information against the practitioner. The current study initially aimed to explore whether service-user diagnosis (or type of service received) affected how practitioners felt about sharing lived experience with them. Such views might have emerged from a mixture of qualitative responses in the general sample, and from looking at targeted sub-group samples of practitioners who delivered particular services compared to practitioners working with different service-user groups.

To this end, discussions were held between the Chief Investigator and the NHS Trust to develop a means of stratifying the sample according to the type of service received by service-users. It later transpired that it was not possible to generate a sample of practitioners by service area, so this sampling strategy was abandoned. All staff were invited to take part, and a proportionate stratified sample was used for service-users to encourage participation from all service areas, but without anticipation of achieving any minimum sub-group sample sizes.

#### ***4.3.9.3 Service-user inclusion and exclusion criteria***

The research aimed to contact current service-users rather than ex-service-users, to ensure that responses came from those with contemporaneous rather than historical experiences. To ensure this, service-users must have had 2 direct contacts within the previous six months, and an open referral (i.e. the referral had not been closed). Of the services that were included in the study, some were felt to be generic in nature, providing services to a wide range of service-users with various diagnoses. It was decided to deal with these as one group and take a general sample, and these are outlined in table 4.3. Other services were felt to be more specific, and they were sampled individually. See table 4.4 for a breakdown of specific services targeted.

It was decided to exclude service-users in several services, for a variety of reasons. These are outlined in table 4.5.

Table 4.3: Service-user inclusion criteria: general sample

Service	Reason to include in general sample
Care homes	Mix of diagnoses among service-users, and staff provide a range of services to several or all diagnoses.
CMHT	
Liaison psychiatry	
Assertive outreach	
Medication/treatment	

Table 4.4: Service-user inclusion criteria: specific samples

Service	Reason to include
Addiction Services	Practical to identify and constitutes a specific service.
Bipolar	
Eating Disorders	
Gender Identity	
Memory services including young people with dementia	
ADHD	
Perinatal	
Early Intervention & detection.	
Forensic services	
Personality Disorder	
Psychological Therapies	

Table 4.5: Service-user exclusion criteria

Service	Reason to exclude
Carers services	Excluded after discussion because it may not have been clear from whose perspective carers responded to questions, and giving extra instructions would have complicated the wording of questions which may have caused confusion to respondents. Also questions about future of service within the Trust.
Crisis resolution	Service-users may be particularly unwell at this point and it may be an insensitive and unwelcome intrusion.
Inpatient services	
Recovery and rehabilitation	
Intensive community services	
Day services	Service-users will be receiving another service, so contact them via main service received.
Dietetics	
Healthy Living Service	
Occupational therapy	
Physiotherapy	
Psychosocial interventions	This service comprises one nurse with no caseload.

#### ***4.3.9.4 Sampling frame and administering the survey***

Practitioners received a link to an online version of the survey by email. Service-users received a hard copy by post with a reply-paid envelope, and they were also given a link to complete an online version of the survey if they wished. All participants received a participant information sheet, and all respondents completed a consent form.

##### *4.3.9.4.1 Practitioners*

The informatics team at the Trust identified a total of 2,856 clinical staff within the Trust. However, because 311 email addresses could not be located, a total of 2,545 surveys were emailed to practitioners 04.09.14. Automated “undelivered” responses were received for 149 practitioners. Of these, 134 practitioners had left the Trust; 11 were on maternity leave and due back after closure of survey; and 4 were on sick leave, due back after closure of survey. 2,396 practitioner emails were therefore presumed to have been delivered.

##### *4.3.9.4.2 Service-users*

It was decided to generate a proportionate stratified random sample of 2,000 service-users from a possible total of 13,933 service-users within the included service areas. 2,000 was the maximum number that could be contacted within the available budget.

The sample size within each service was calculated by dividing the required sample (2,000) by the total population (13,933) then multiplying by the population of each service. Numbers were rounded up. It was also decided with the lower numbers not to drop to less than a sample of 3 people if possible. See Appendix 7 for a breakdown of the number of survey invites generated for each service area.

This resulted in a total sample of 2,029 for whom postal addresses were generated. For reasons of confidentiality, addresses were kept within the Trust and were not seen or accessed at any point by the Chief Investigator. Reminder letters were sent to participants approximately 2 weeks after the initial mail out. For reasons of cost they did not contain further copies of the survey, but the reminder letter did contain a link to the on-line version of the survey.

#### **4.3.9.5 Publicity**

A flyer containing information about the research was produced and distributed in various locations across the Trust where potential service-user participants would be likely to see it (see Appendix 8). The purpose of the flyer was to improve response rates by letting potential participants know in advance that they may receive a survey, explaining what the survey was about, and informing service-users how to request help to complete it if they needed it.

Publicity was also produced for staff, and would have been directed at staff through 'Desktop', a page that staff see when they log on to their work computers, and 'Communications' a bulletin distributed electronically to staff. Desktop and Communications articles were written in advance and approved by the ethics committee, and can be viewed in Appendix 9. Only the Communications article was distributed, because of logistical problems with posting the Desktop article within the required timeframe.

### **4.4 Focus Groups**

#### **4.4.1 Focus group rationale**

Three focus groups and a semi-structure interview were held in the UK, and three focus groups took place in Australia. Focus Groups were held to enable interrogation of survey responses, clarify possible meanings, and provide a wider range of insider-perspectives. Focus groups also enabled the generation of concepts and ideas that informed further analysis of survey responses. They were held separately with practitioners and service-users to ensure that participants were able to discuss their perspectives openly without prejudice.

Initially, there was an intention to replicate the UK study in its entirety in Australia to provide international comparison and explore a wider range of perspectives. Australia was chosen because its mental health system, interventions, and research base are similar to those in the UK, and it was possible to identify a mental health organisation that dealt with a broadly similar client-group to the UK Trust. A university PhD candidate was identified to take this forward but they were not able to continue and a replacement was not found. Due to timescales and capacity, the Chief Investigator took responsibility for completing the Australian activities,

including ethical approval, fieldwork, and analysis. This involved a two-week visit by the Chief Investigator to the Australian organisation in July 2015.

Greener (2011) suggests that focus groups can reduce power imbalances between participants and the researcher, provided that the researcher adopts a secondary role in discussions and participants are able to construct meaning through natural interaction and exchange. To this end, service-users were involved as co-facilitators in the UK to increase their control over the process, reduce power inequalities that might occur if all participants were service-users and all facilitators were practitioners or researchers, and to gain insights and perspectives underpinned by lived experience, rather than professional concerns. Employees of the UK Trust who were involved in and familiar with the research co-facilitated the UK focus groups with the service-user, to provide support, share responsibilities and use their insider knowledge to inform discussions. Discussions were held about involving service-users as facilitators in Australia but there was insufficient time and capacity to enable this to happen. Since one of the dangers of focus groups is that they might lose focus, given the lesser role of the researcher (Greener, 2011), meetings were held with facilitators to agree topics, discuss potential pitfalls such as loss of focus and how to deal with them, and it was agreed that the researcher would also take part as necessary to clarify, request further information, and refocus where necessary.

#### **4.4.2 Focus group method**

Focus groups followed an iterative process whereby UK survey responses informed discussion in the first two UK focus groups (one with practitioners and one with service-users); survey responses and UK focus group feedback informed discussion in the Australian focus groups (two with practitioners and one with service-users); and all data collected in the UK and Australia informed discussion in the final UK practitioner focus group and a semi-structured interview with a UK service-user. Focus group feedback also informed further survey data analysis. Focus groups explored and clarified themes that emerged from the surveys, and asked whether findings in each country were relevant and applicable to the other. All focus groups were audio recorded and transcribed for analysis.

#### 4.4.1.1 UK focus group round 1

At the focus groups, a presentation was made by the Chief Investigator about the background, methods, and main findings of the study at that point. The focus groups were semi-structured, and planned discussion topics are given in Table 4.6, below.

Table 4.6: UK focus group 1 discussion topics

UK Practitioner Focus Group 1: Discussion Topics	UK Service-user Focus Group 1: Discussion Topics
Discussions focused on whether practitioners had received training and guidance on disclosure in their roles; whether there was a need for training and guidance; what training and guidance might contain; whether disclosure could offer hope for recovery when made by practitioners other than peer workers; what types of lived experience might be helpful to share; why practitioners find sharing hobbies so helpful; how practitioners can decline disclosure sensitively, without causing offence; and differences between helpfulness of real-life examples of sharing lived experience compared to hypothetical examples.	Whether disclosure can offer hope for recovery when made by practitioners other than peer workers; what types of lived experience might be helpful to share; the helpfulness of practitioners sharing hobbies; differences between helpfulness of real-life examples of sharing lived experience compared to hypothetical examples; how practitioners can decline disclosure sensitively, without causing offence; and what should be contained in training and guidance for practitioners, if it were to be produced.

#### 4.4.1.2 Australian focus groups

Australian focus groups were facilitated by an employee of the Australian organisation who was familiar with the research and able to use their insider knowledge to inform discussion. The Chief Investigator audio recorded the discussions, took notes and took part in the discussion where clarification or further information was required.

A presentation was made by the Chief Investigator about the background and methods of the study, the main findings from the survey, and feedback from the first two UK focus groups. These focus groups were recorded, and transcribed for analysis. The focus groups were semi-structured, and discussion topics were devised based on the survey findings and previous discussions in the UK focus groups, and included:



- The Australian perspective on sharing lived experience, and whether feedback from the UK resonates with the Australian experience.
- Whether there is there a need for training and guidance on disclosure.
- How peer support is viewed in Australia regarding their status as professionals or consumers.
- Why risk of disclosure might be attached to some types of practitioner more than others.
- How practitioners can decline disclosure sensitively, without causing offence.

#### **4.4.1.3 UK focus group 2 discussion topics**

A semi-structured interview was undertaken with one service-user, as they had been unable to attend the first UK focus group. The interview was facilitated by an employee of the NHS Trust, and the Chief Investigator took notes and took part in the discussion. The practitioner focus group was facilitated by the Chief Investigator, and mutually agreed notes were recorded during the session on flipchart paper. Topics for discussion are illustrated in Table 4.7, below.

Table 4.7: UK focus group 2 and interview discussion topics

<b>UK Practitioner Focus Group 2: Discussion Topics</b>	<b>UK Service-user Interview: Discussion Topics</b>
The focus group was run as a co-productive workshop, exploring how risk of disclosure differs for different practitioners. Participants were asked to identify the risks and benefits of disclosure. These were displayed around the room. Blank flipcharts were displayed around the room and labelled with different practitioner job roles, including doctor, peer support worker, nurse, health care support worker, occupational therapist and psychological practitioners. Risks and benefits were considered in turn regarding their applicability to each of the job role types. Consensus among the group was sought, and recorded notes agreed as reflecting the general view. This built a hierarchy and topography of risk and benefit according to job role.	General views about practitioners sharing their lived experience. Whether training and guidance would be useful, and if so, what key messages it should contain. How practitioners can decline disclosure sensitively, without causing offence.

### **4.4.3 Focus groups sampling and recruitment**

#### ***4.4.3.1 UK focus group round 1***

Participants were chosen from survey respondents who had indicated they would like to take part in a focus group. They were selected to offer a balance of views on the helpfulness of sharing personal mental health lived experience, with some rating it unhelpful (1 or 2 on the scale) and others rating it helpful (4 or 5 on the scale). They were also invited to take part because they had given substantial or detailed qualitative justifications for their ratings, indicating an interest in the subject.

A range of different types of practitioner were sought for the practitioner focus group. In an effort to achieve attendance of 6 to 8 participants, which Finch & Lewis (2003) suggest is the optimum size for focus groups, invites were sent initially to 12 service-users, and 24 practitioners by email. Further invites were sent where there was no response or where respondents declined, until sufficient confirmations were gained for the groups to run with 6 to 8 attendees, taking into account previous Trust experience of 50% attendance.

#### ***4.4.3.2 Australian focus groups***

Open invites to focus groups were distributed to service-users across the Australian organisation via flyers, and to practitioners via flyers, word of mouth, email invites across the organisation, and inclusion in an internal newsletter.

#### ***4.4.3.3 UK focus group 2 discussion topics***

The single service-user who took part in a semi-structured interview had been invited to the first UK focus group, using the method described in section 4.4.3.1 above. There was insufficient time and capacity to invite other service-users to attend a second UK group. 32 practitioners were invited to take part in the second UK focus group, using the same method described in section 4.4.3.1, above.

## 4.5 Analysis

### 4.5.1 Quantitative analysis: Comparison of means

Appropriate parametric and non-parametric tests were chosen according to the normality distribution of the data, to indicate whether differences were significant and ascertain effect sizes.

There is some controversy about whether parametric or non-parametric tests should be used with non-normal data. There is further controversy about whether Likert-type scales can be treated as scale data and subjected to parametric testing, because the intervals between points on the scale cannot be assumed to be equal (Jamieson, 2004). However, some statistical experts suggest parametric tests are more robust than non-parametric tests, even where the assumption of normality is violated, and that parametric tests are suitable for use with Likert scales because they are robust and do not lead to erroneous conclusions (Sullivan & Artino, 2013; Norman, 2010). Further arguments suggest that where the sample size is greater than 30, normality may be assumed even where the data is not normal and parametric tests may be used (Ghasemi & Zahediasl, 2012). Based on these arguments, in the analysis of quantitative data, where all groups being compared were of a size greater than 30, parametric tests were used. To further counteract the potential effect of unequal intervals, in the current research, respondents were asked to indicate whether sharing information was unhelpful (1 on the scale) or helpful (5 on the scale), but there were no further qualitative descriptions of the points on the scale between these two positions, and only numbers were used. It was felt that this indicated equal numerical intervals between points, and removed the potential influence of subjective interpretation of labels.

Normality may not be assumed where the sample size of any group within a comparison is less than or equal to 30. In this case, the data may or may not follow a normal distribution, and a test of normality is required to be able to choose between parametric and non-parametric tests. The Shapiro-Wilks tests was used to ascertain normality (Field, 2013; Ghasemi & Zahediasl, 2012). Using this test, the p value of all tested samples has to be greater than 0.05 to be assessed as normal, enabling the use of parametric tests. Where any single sample has a p value of less than 0.05, it may be assumed to be not normal, and a non-parametric test should be used.

Therefore, in the following presentations, parametric and non-parametric tests are used based on assessments of sample size and/or the Shapiro-Wilks test.

For parametric tests, the Independent Samples t-test was used where only two variables were being compared; and where more than two variables were being compared, one-way analysis of variance was used, with Bonferroni adjustments to p-values to reduce the chance of making a Type 1 error.

It was not necessary to perform any parametric tests on pairs of variables, and the Kruskal-Wallis test was used where more than two variables were being compared, checking pair-wise comparisons and adjusted p-values to identify which variables differ and to control for Type 1 errors.

Where there are significant differences in means, it is useful to consider how large those differences are, and the process for determining effect sizes differs according to the test used (Field, 2013). Pearson's  $r$  was used to report effect sizes so that they were consistent, standardised and directly comparable to each other. This posed a problem for calculation because SPSS outputs do not always give the necessary statistics to calculate  $r$ .

For parametric tests the following calculation was used to determine Pearson's  $r$  effect size (Field, 2013):

$$r = \sqrt{\frac{t^2}{t^2 + df}}$$

These statistics are generated by SPSS when performing a t-test, but not for ANOVA. To obtain the same statistics for ANOVA, it was re-run using planned contrasts.

The following calculation may be used to calculate Pearson's  $r$  from the Mann-Whitney test (Field, 2013):

$$r = \frac{Z}{\sqrt{N}}$$

The Kruskal-Wallis test does not generate these values directly, so they are obtained by calculating the post-hoc comparison effect sized, using the Mann-Whitney test (Hannah & Dempster, 2012).

Effect sizes are described as small, moderate, or large, according to the value of  $r$ , with  $r=0.10$  being a small effect,  $r=0.30$  a medium effect, and  $r=0.50$  a large effect.

It was hypothesised that there may be differences between practitioners' and service-users' ratings of helpfulness of disclosure, and such comparisons were made across all ratings questions. However, there were additional variables that might be combined with practitioner/service-user status for some types of disclosure, and these are outlined individually in Table 4.8 below.

Table 4.8: Grouping variables used for comparison on ratings questions

<b>Disclosure subject</b>	<b>Grouping variables</b>	<b>Justification</b>
Personal mental health lived experience (1)	Service-users.  Practitioners with mental health lived experience.  Practitioners without mental health lived experience.	Service-users have lived experience by default.  The presence or absence of lived experience among practitioners may affect response ratings.
Mental health (2)	Service-users.  Practitioners with lived experience & with a family member or friend with lived experience.  Practitioners with lived experience & without a family member or friend with lived experience.  Practitioners without lived experience & with a family member or friend with lived experience.  Practitioners without lived experience & without a family member or friend with lived experience.	Service-users have lived experience by default.  The presence or absence of lived experience among practitioner may affect response ratings.  Having a close family member or friend with lived experience may affect practitioner response ratings, and may interact with the presence or absence of personal mental health lived experience.
Mental health of family member or friend	Service-users.	Service-users were not asked if they have a family member or friend with mental health lived experience. There was no need to consider 'proxy'

Disclosure subject	Grouping variables	Justification
	<p>Practitioner with a family member or friend with lived experience.</p> <p>Practitioner without a family member or friend with lived experience.</p>	<p>experience because they have direct personal lived experience of.</p> <p>Practitioners were asked if they had a family member or friend with lived experience, to see if it acts as a 'proxy' in the absence personal lived experience</p> <p>Having a family member or friend with lived experience might affect how helpful practitioners rate sharing this type of information.</p>
Religion	<p>Service-users who are religious.</p> <p>Service-users who are not religious.</p> <p>Practitioners who are religious.</p> <p>Practitioners who are not religious.</p>	<p>Both practitioners and service-users were asked whether they were religious or non-religious.</p> <p>Whether they are religious might affect how helpful they view the sharing of information about religion.</p>
Sexual orientation	<p>LGB service-users.</p> <p>Straight service-users.</p> <p>LGB practitioners.</p> <p>Straight practitioners.</p>	<p>Both service-users and practitioners were asked whether they identified as Lesbian, Gay, Bisexual (LGB) or Straight. Due to low numbers of LGB respondents, these were amalgamated into binary LGB/straight categories for analysis.</p> <p>A respondent's sexual orientation might affect how they view the helpfulness of sharing sexual orientation.</p>
Difficult or traumatic experiences	<p>Service-users.</p> <p>Practitioners with mental health lived experience.</p> <p>Practitioners without mental health lived experience.</p>	<p>Having mental health lived experience was used as a proxy for having experienced something difficult or traumatic.</p> <p>Having lived through difficult or traumatic experiences might affect how helpful sharing such experiences is seen to be.</p>
Hobbies and out of work activities	<p>Service-users.</p> <p>Practitioners.</p>	<p>There were no demographic categories that were hypothesised to affect ratings of sharing information about hobbies and out of work activities.</p>

#### **4.5.2 Quantitative analysis: regression analysis of practitioner ratings of sharing personal mental health lived experience**

In addition to testing individual questions in the manner described, backward linear regression was performed to investigate which factors predicted practitioner ratings of sharing personal mental health lived experience. The demographic variables and grouping variables entered into the model were recoded into binary variables wherever necessary, and included whether practitioners: had ever shared anything with a service-user; had personal experience of mental illness; had a family member or friend with mental health lived experience; had a physical disability; were religious; were LGB or straight; were white or non-white; were male or female; and were a doctor or not a doctor. Age (in years) was also entered as a continuous variable.

The doctor/non-doctor binary was chosen to reduce practitioner job categories to a reasonable number. Two options were considered: amalgamating nurses and doctors into one category because of their medicalised training and practice, and comparing them to all other staff members as a single group; and comparing doctors with all other types of staff (as a single group) because of doctors' unique status at the top of the medical hierarchy and elevated risk aversion compared to other practitioners. The latter was chosen as it was hypothesis-driven and based on qualitative findings from within this study.

#### **4.5.3 Qualitative analysis**

Qualitative data was gathered and analysed using elements of grounded theory (Strauss & Corbin, 1998) and content analysis (Richards, 2009). Elements of grounded theory included the use of open coding to allow themes to emerge from the data rather than from the researcher's a priori theories and assumptions; and the use of iterative processes whereby issues emerging from surveys were taken for discussion with focus groups, and focus group feedback enabled further, more targeted analysis of the survey data. This iterative process was also used between the UK and Australia, taking UK survey and focus group findings for discussion with Australian focus groups, and bringing messages back from Australia to discuss with further UK focus groups. Content analysis enabled coded data to be quantified to explore which concerns and issues arose most frequently in relation to different types of disclosure. Content analysis was used to inform investigation of text responses by theme frequency, though less frequent themes were

also explored based on emerging hypotheses and are reported in this thesis. Content analysis was also used to illustrate proportions of positive, negative and mediating factors.

Qualitative survey text responses were coded according to emerging themes (see Appendix 13 for an overview of NVivo node categories and sub-categories), and as positive or negative (and to both positive and negative, or neither, where applicable (see appendix 14 for a table of positive and negative code frequencies). Retrospectively, some codes were identified as 'mediating factors' for example, that the helpfulness of disclosure depends on how it is done, when it is done, or who is disclosed to (see Appendix 14 for a list of mediating factors and their frequencies). The frequencies of positive, negative and mediating factors were illustrated visually for the seven hypothetical disclosure questions, using proportionally-sized circles to reveal similarities and differences between service-user and practitioner responses. Each circle's area in  $\text{mm}^2$  corresponds to the percentage of respondents who mentioned either a positive, negative or mediating factor in their response to that question. This was then combined with the three-category helpfulness ratings (described below) to enable comparisons of positive, negative and mediating factors across unhelpful, middle, and helpful ratings of the seven hypothetical disclosure types, and between practitioners and service-users. Selected examples of this process can be seen in Chapter 7 and a full visual representation of the circles can be seen in Appendix 10.

Qualitative analysis was also combined with quantitative analysis. In the qualitative analysis, the five-point rating scale was reduced to three ratings categories: unhelpful (1 or 2 on the scale) middle (3 on the scale), and helpful (4 or 5 on the scale). This allowed comparison of differences in qualitative data between unhelpful ratings, middle ratings, and helpful ratings of hypothetical disclosures.

#### **4.6 Measuring the Intimacy of Disclosures**

As mentioned previously, it was not possible to identify a suitable existing scale that could be used to categorise the intimacy of the disclosure questions that would be used in the current study, so it was necessary to develop one.



### 4.6.1 Method

Participants were asked to “rate the following potential disclosures according to how *personal* you think they would be if a practitioner shared them with a service-user in a work setting” (emphasis as original). They were then presented with the self-disclosure items that were used in the surveys, and asked people to rate them on a 1 to 5 scale, with 1 being ‘not personal’ and 5 being ‘highly personal’ (see Appendix 6 for copy of questionnaire).

### 4.6.2 Participants and demographics

A total of 58 participants completed a questionnaire.

Social work students at the University of York were approached in person during lectures. A link to an on-line version of the questionnaire was advertised on flyers at the University of York, and the questionnaire was promoted via the blog ([jonnylovellblog.wordpress.com](http://jonnylovellblog.wordpress.com)) and via the blog of Martin Webber ([www.martinwebber.net](http://www.martinwebber.net)).

20 students from the University of York completed a hard copy of the questionnaire. 38 people completed the on-line copy. Payments of £5 were made to students completing the hard copies, and those who completed on-line were entered into a prize draw for £20 of Amazon vouchers. The demographic characteristics of participants are given in Table 4.9, below.

Table 4.9: Personal characteristics of respondents

Variable	N=58 (%)	Variable	N= 58 (%)
<b>Employment status</b>		<b>Sexual orientation</b>	
Employed (health and social care role)	29 (50.0)	Straight	54 (93.1)
Student (health and social care role)	27 (46.6)	Gay or bisexual	4 (6.9)
Prefer not to say	2 (3.4)	<b>Ethnicity</b>	
<b>Type of employment</b>		White	54 (89.7)
Mental health	35 (60.3)	Mixed	4 (6.9)
Not mental health	20 (34.5)	Asian	2 (3.4)
Prefer not to say	3 (5.2)	<b>Disability</b>	
<b>Job role</b>		No disability	43 (75.4)
Social work (student)	20 (35.1)	Disability	8 (14.0)
Social worker	16 (28.1)	Prefer not to say	6 (10.5)
Peer support worker	6 (10.5)	<b>Religion</b>	
Nurse	4 (7.0)	Not religious	40 (70.2)
Others (single digits)	10 (17.8)	Religious	14 (24.6)
Prefer not to say	1 (1.8)	Prefer not to say	3 (5.3)
Age	Mean=37.0, age range = 20-62 years		

Demographic data were collected so that analysis could be undertaken regarding the impact that identity has on perception of intimacy of disclosure in the event that ratings of intimacy were found to correlate with ratings of helpfulness.

### 4.6.3 Results

Difficult or traumatic experiences were rated as the most personal type of disclosure, followed by personal mental health lived experience. Hobbies were rated least personal. See Table 4.10, below, for a full list of mean ratings. It was not necessary to perform any statistical analysis on these results, since this exercise only required mean ratings for each type of disclosure.

Table 4.10: Mean ratings of intimacy of disclosures

Type of Practitioner Disclosure	Intimacy scale mean Rating (1=not personal, 5=highly personal) n=58
Difficult or traumatic life experiences	4.28
Personal mental health lived experience	3.86
Sexual orientation	3.28
Physical health	3.21
Religion	2.84
The mental health lived experience of the practitioner's close family member or a friend	2.83
Hobbies and out of work experiences	2.19

## 4.7 Service-User Involvement

### 4.7.1 Background

Involving members of the public, including recipients of services, in research activities is considered to be good practice by The National Institute for Health research (2013) who suggest that that service-users value involvement in research because it offers opportunities for inclusion, enables them to set the agenda, and can help to bring about positive change in their communities of interest or identity.

There is some evidence that service-user involvement in mental health research can have positive effects on the way research is undertaken and the knowledge that it generates, including strengthening the validity or responses gained from other service-users (Telford & Faulkner, 2004), and reflexivity (Veseth et al, 2017).

Involving service-users in all stages of research may increase the credibility of findings among service-users, increase research accuracy by ensuring the right questions are addressed, and ensure that appropriate language is used to describe service-users' experiences (Shaw, 2012). It can increase the relevance of research, reflecting the expressed views of service-users rather than researchers' potentially incorrect assumptions about what matters to them, through involvement in all stages of research including planning, design, data collection, analysis, and interpretation of findings (Rickinson, 2011). This may help to produce research that is carried out 'with' rather than 'on' populations who are being studied (Involve, 2013), break down the "power divisions...between researchers and researched" (Stanley & Wise, 1993, p.177), and ensure that research agendas are not distorted by professional, academic interests (Oliver, 1997).

Although the current research involved service-users, the idea for it emerged from a practitioner, albeit one with lived experience working in peer support, and it remained researcher and practitioner-led. Efforts were made to balance power inequalities by involving service-users in all stages of the research, achieving a partnership approach but falling short of fully delegated power or citizen control as identified on Arnstein's (1969) ladder of participation.

#### **4.7.2 Types of involvement**

Service-users influenced the development of the research in the following ways:

*(i) Initiation of research:* Although the research was initiated by a practitioner, they had personal mental health lived experience, worked as a peer support worker in a mental health organisation, and identified the research topic from their work with mental health service-users and practitioners. The topic was therefore rooted in the lived experience of both practitioners and service-users.

*(ii) Consultation:* Consultation with service-users was undertaken through discussion with Leeds Researchers, the Trust's service-user research group (18.12.13); and through discussion with the University of York's Service-user and Carer Participation Advisory Group (06.05.14).

Service-users' and practitioners' views and suggestions on the focus of the research were also gathered in other ways. The Chief Investigator attended the NHS Trust's *Lived Experience in the Workforce* conference (08.11.13), distributing leaflets which outlined the research topic and requested feedback, either via filling in a blank space on the leaflet and handing it back, or by contacting the Chief Investigator by email. A project blog was set up, promoting the research and inviting communication from service-users and practitioners ([www.jonnylovellblog.wordpress.com](http://www.jonnylovellblog.wordpress.com)). Feedback was also invited from the NHS Trust's *Lived Experience Network*, a support and communication forum for staff with lived experience.

Feedback was uniformly positive. There were no suggestions regarding choice of methodology. Discussions suggested that it was not useful to limit the types of disclosure to mental health lived experience, since this implies that the prevailing concern for mental health service-users in their relationship towards others is mental health status and experience, rather than other aspects of identity such as ethnicity, religion, sexual orientation, or disability. Therefore, it was decided to include questions on a variety of types of lived experience. This approach would also enable analysis of whether there are different attitudes towards different types of lived experience, though this was not the primary purpose of the study.

There were some suggestions that 'sharing lived experience' should be used rather than 'self-disclosure' because disclosure sounded inherently more 'dramatic' than sharing and this might prime participants to see disclosures as more serious than they might otherwise be, affecting responses. This issue was considered carefully, but it was decided to retain 'disclosure' because of its long-standing and substantial connection to the research subject in the published literature, because it would be likely to be familiar to practitioners, and because, if it did provoke strong reactions, this would be important to the research. Using the term 'sharing lived experience' might bias responses in the opposite direction, perhaps making the subject appear less controversial than it otherwise does. To strike a balance, both terms were used alongside one another.

Suggestions regarding the wording of the survey were made through pre-testing activities, which are covered in section 4.3.7 of this chapter.

As part of this initial consultation, service-users were invited to put themselves forward for other research and post-research activities, which are outlined below.

*(iii) Service-users as researchers and facilitators: Service-users were involved in research analysis and as co-facilitators of focus groups.*

Involvement in analysis provided wider perspectives and possible interpretations of data. A meeting was held with two mental health service-users and the Lead Practitioner from the NHS Trust, to generate initial qualitative codes on a small sample of anonymised survey responses. Each attendee took 10 completed, but redacted, surveys home to code, and the group met a week later to compare the codes generated. An initial coding frame was then developed by consensus, which the Chief Investigator used to inform further coding using NVivo. A further meeting was held several weeks later to examine a sample of codes within NVivo and consider whether they had been applied accurately. The list of codes was supplied to participants, who identified which codes they wished to examine further to assess accuracy of coding. Each identified code was then examined in NVivo by extracting all quotes associated with that code, and assessing as a group whether the code had been suitably applied to the data. This provided a validity check for coding of responses. Formal statistical tests were not used to assess reliability of coding, but discussions indicated a high level of agreement among participants with the way in which data had been coded.

#### **4.7.3 Recruiting service-users**

Role descriptions were devised and circulated to service-users through Leeds Researchers and the University of York's SUPA Group, inviting service-users to put themselves forwards for one or more roles. Six service-users were recruited in this way.

#### **4.7.4 Service-user payment**

Payment for service-users involved as researchers was encouraged by the NHS Trust and is considered to be good practice (Involve, 2010). The NHS Trust did not have an established policy on payment for service-user involvement, so a policy was produced based on good practice guidance, taking into account examples of payment rates (Involve, 2010) and the potential effects of payment on people who receive government benefits (Involve, 2010; DWP 2009a; DWP 2009b; Scott 2013; Scott 2014). Payment for service-users was included in the project budget, see table 4.11 below.

Table 4.11: Service-user payment

Activity	Rate
Research meetings and research analysis	£10 per hour
Focus group facilitation	£15 per hour
Travel expenses	£5 per session attended
Attendance of focus group	£20 per session attended

Payment for attendees of the Australian research activities was made at the same rate, but there were no Australian co-facilitators.

## 4.8 Ethics

Three separate ethical approvals were required: one for pre-testing the research materials at the University of York; one for undertaking research activities in the NHS in the UK; and the third for undertaking research activities in NothWestern Mental Health in Australia.

### 4.8.1 University of York ethical approval

The ethics application to pre-test the surveys with students, as outlined in section 4.3.7 and 4.3.8 was submitted to the Social Policy and Social Work Ethics Committee on 02.04.14. Since the pre-testing methodology had been submitted as part of the NHS submission, and had been approved, the University ethics committee accepted the NHS ethical approval in place of its own. Permission was therefore granted on 02.05.14.

### 4.8.2 National Health Service Integrated Research Application System (NHS IRAS).

All research that takes place in the NHS must have national ethical approval and local research governance approval, and researchers are required to have a letter of access, known as a research passport. The Letter of Access was applied for on 07.04.15 and gained on 06.05.14. The NHS Research Ethics Committee Application was submitted on 07.04.14 and approved on 08.04.14. Research and Development (local governance) application was submitted on 07.04.14 and approved on 09.05.14. No substantial changes were required to documents, other than correcting document file names or typographical errors.

### **4.8.3 Substantial amendment submission**

Several changes were made to the surveys in response to the pre-testing activities, so it was necessary to submit an application for approval of substantial amendments to the NHS Research Ethics Committee and to the local research site. The details of those changes are outlined in section 4.3.7 of this chapter. The NHS Research Ethics Committee substantial amendment application was submitted on 07.08.14 and approved on 18.08.14. The local Research and Development substantial amendment application was submitted on 18.08.14 and approved on 21.08.14.

### **4.8.4 Australian ethical approval**

It was agreed on 20.01.15 that the Chief Investigator should pursue the ethics application for the Australian research, and the research ethics process was begun shortly afterwards. Contact was made with Melbourne Health Research Office and it was confirmed that a Low/Negligible Risk form should be completed. This process was very similar to the UK. Human Research Ethics Committee approval was gained on 21.04.15, and local Site Specific Approval was gained on 17.06.15.

## **4.9 Communication and Dissemination**

A project blog was set up to post: updates to service-users who were involved in the project; publicise activities and progress to service-user participants, service-users in general, and the general public; and post any relevant publications and news items as they become available. The blog went live on January 18<sup>th</sup> 2014. Since then updates were posted in March, May, August and September 2014, and January 2015. The blog enabled posting of moderated comments on updates, and contained the contact details for the Chief Investigator.

## **4.10 Presentation of Results**

The following four chapters present the results of the study. Chapter 5 focuses on quantitative survey results. Chapter 6 analyses the qualitative data from the survey relating to real-life examples respondents gave of practitioners sharing their lived experience. Chapter 7 considers the qualitative data from the survey related to questions about the 7 types of hypothetical

disclosure practitioners might make, and how the job role of the disclosing practitioner affects the helpfulness of personal mental health disclosure. Finally, chapter 8 examines feedback from the UK and Australian focus groups.



## Chapter 5: Quantitative Results

### 5.1 Introduction

This chapter presents the quantitative results of the survey that was conducted among service-users and practitioner of the UK NHS Trust. It covers response rates and demographic information about respondents, examines whether there were differences between the helpfulness ratings of different questions, and investigates whether there were differences within and between groups of respondents based on various demographic criteria and grouping variables.

Table 5.1: Survey distribution and response rates

Type of Respondent	Number of surveys distributed	Number Returned	% Response Rate
Practitioner	2,396	200	8.3%
Service-user	2,029	111	5.5%

The service-user response rate fell short of achieving the anticipated 11% response rate that the Time to Change evaluation study (Corker et al, 2013) achieved in 2011, but was similar to the 6% response rate achieved by the same study in 2008, the first year that it was run.

Although service-users were sent a reminder letter, it was not possible to surmise what effect this had, because technical issues regarding the way mail was handled by Royal Mail meant that over sixty responses were held back for a considerable period of time, and since they were not date stamped it was impossible to tell whether they had been returned before or after the reminder letter was sent.

The practitioner response rate also fell short of the expected return rate based on surveys undertaken in similar ways in organisations such as Leeds and York Partnership NHS Foundation Trust (LYPFT) (2015), and Dorset Wellbeing and Recovery Partnership (nd). This may be due to several factors. Since the original email distribution of the survey had generated controversy among a small number of practitioner recipients, in order to avoid further issues a reminder email was not sent. The lack of a reminder may have contributed to the lower response rate. The survey was not promoted on the Trust's 'desktop' news pages, as originally planned, due to organisational constraints, whereas other surveys did use such methods. The LYPFT and Dorset surveys may have achieved greater response rates because they did not comprise formal

research and did not require ethical approval, so survey promotion could evolve more creatively and was not constrained by time or method. The LYPFT and Dorset surveys were also carried out and promoted by the organisations in which they took place, whereas the current research may have been associated more with the University of York than the local Trust, which may have resonated less with potential participants who may have felt less compulsion to complete it. Some participants may have been deterred from completing the current research survey because it was more comprehensive than previous surveys, took longer to complete, and asked for in-depth responses.

## 5.2 Respondent demographics

### 5.2.1 Mental health lived experience

All service-users (n=111) were presumed to have mental health lived experience because of their status as users of mental health services. Of the 200 practitioner respondents, exactly half of those who gave an indicative response said they had experienced a mental health condition or illness that was significant or problematic to them (see table 5.2). This is significantly higher than the rate for the general population where mental illness is estimated to affect up to one in every four people at some point in their lives (McManus et al, 2007; Singleton et al, 2000).

Table 5.2: Prevalence of mental health lived experience among practitioners

<b>Personal Mental Health Lived Experience</b>	<b>Practitioner Sample n=200 (%)</b>
No	94 (47.0)
Yes	94 (47.0)
Prefer not to say	11 (5.5)
Missing	1 (0.5)

## 5.2.2 Other demographic information

Table 5.3: Demographic information

Variable	Practitioner Sample n=200 (%)	Service-user Sample n=111 (%)
<b>Gender</b>		
Male	64 (32.0)	32 (28.8)
Female	135 (67.5)	74 (66.7)
Transgender	0 (0.0)	3 (2.7)
Intersex	0 (0.0)	2 (1.8)
Other	0 (0.0)	0 (0.0)
Prefer not to say	0 (0.0)	0 (0.0)
Missing	1 (0.5)	0 (0.0)
<b>Sexual Orientation</b>		
Straight	167 (83.5)	85 (76.6)
Gay	10 (5.0)	6 (5.4)
Lesbian	5 (2.5)	1 (0.9)
Bisexual	4 (2.0)	7 (6.3)
Other	1 (0.5)	2 (1.8)
Prefer not to say	12 (6.0)	5 (4.5)
Missing	1 (0.5)	5 (4.5)
<b>Ethnicity</b>		
White	177 (88.5)	103 (92.8)
Asian	8 (4.0)	2 (1.8)
Black	9 (4.5)	0 (0.0)
Mixed	2 (1.0)	5 (4.5)
Other	2 (1.0)	0 (0.0)
Missing	2 (1.0)	1 (0.9)
<b>Physical Disability</b>		
No disability	172 (86.0)	65 (58.6)
Disability	19 (9.5)	40 (36.0)
Prefer not to say	7 (3.5)	5 (4.5)
Missing	2 (1.0)	1 (0.9)
<b>Religion</b>		
Religious	55 (27.5)	40 (36.0)
Not Religious	122 (61.0)	51 (45.9)
Prefer not to say	22 (11.0)	12 (10.8)
Missing	1 (0.5)	8 (7.2)
<b>Age</b>	(Mean =43, range 22-66)	(Mean=49, range 18-88)
18-19	0 (0.0)	3 (2.7)
20-29	20 (10.0)	9 (8.1)
30-39	56 (28.0)	23 (20.7)
40-49	53 (26.5)	20 (18.0)
50-59	55 (27.5)	22 (19.8)
60-69	8 (4.0)	13 (11.7)
70-79	0 (0.0)	5 (4.5)
80-89	0 (0.0)	9 (8.1)
Missing	8 (4.0)	7 (6.3)

### **5.2.2.1 Gender**

The gender split was almost identical for both practitioners and service-users, with about one third male and two thirds female (see table 5.3). 5 service-user respondents (4.5%) identified as transgender or intersex, and none of the practitioner respondents did.

Female service-user respondents were over-represented compared to national and local comparators. Nationally, Money (2015) suggests 55% of service-users are female, and locally 60% of respondents to a survey of the local Trust's users of community services were female (Quality Health 2015).

The gender of practitioner respondents mirrored national and local comparators. Nationally, the make-up of NHS employees was 72% female and 28% male in 2014 (NHS England, 2015), and the NHS Trust's own recent survey of practitioners (Leeds and York Partnership NHS Foundation Trust, 2015), attracted 70% female and 30% male respondents.

### **5.2.2.2 Sexual orientation**

The expressed sexual orientation identities of respondents can be seen in table 5.3.

It is difficult to accurately estimate the size of the national Lesbian, Gay, and Bisexual (LGB) population. There are multiple reasons for this, including a general lack of reliable data; different studies use different methodologies; people may be reluctant to divulge their sexual identity or behaviours; and some studies measure sexual identity while others measure sexual behaviour. Government estimates suggest LGB people make up 5-7% of the UK population, but this figure includes LGB identities, behaviours and desires (Betts, 2008). One review of several national UK studies (Betts, 2008) report that estimates of the UK LGB identity vary from 0.3% to 3% of the UK population. More recent research, which also included a review of previous research, suggests estimates of the LGB-identifying population range from 1.1% to 2.4% (Hayes et al, 2012), and concludes that people with Lesbian, Gay and Bisexual identities may make up roughly 1.75% of the UK population.

The current research asked people about their sexual identity rather than behaviour, and whatever the true national figure, this survey received a higher response rate from LGB service-

users (12.6%) than would be expected from current national prevalence estimates. The survey also received a higher LGB response rate than the Trust's 2015 survey of service-users (Quality Health, 2015) in which 2% of respondents identified as LGB.

The survey also received a higher response rate from LGB practitioners (9.5%) than might be expected from both the 2014 national prevalence rates and from national NHS data (NHS England, 2015) in which 2% of survey respondents identified as LGB.

### **5.2.2.3 Ethnicity**

Most respondents were white (roughly 90% for both service-users and practitioners), and mostly the remainder were of Asian, Black and Mixed ethnicities, in small numbers, with few missing data (see table 5.3). National NHS workforce statistics in 2014 (NHS England, 2015) indicate lower numbers of White practitioners (71%), but similar numbers of Asian, Black and Mixed staff members, and a greater percentage of those who state "other" or who do not answer the question.

There were no Black service-user respondents, in contrast to 5% of practitioner respondents, and there were a few more service-users who identified as Mixed (5%) than practitioners (1%). This was broadly similar to the Trust's 2015 local service-user survey (Quality Health, 2015), wherein 89% of service-users identified as White, 1% as mixed, 3% as Asian, and 3% as Black.

The ethnicity of survey respondents was broadly similar across all ethnic categories to local census data, when the separately published census data for Leeds and York (Office for National Statistics, 2011) are manually combined.

### **5.2.2.4 Physical disability**

A greater proportion of service-users (36%) than practitioners (10%) said they had a long term physical health condition or physical disability, while 86% of practitioners and 59% of service-users identified as non-disabled (see table 5.3). For practitioners, this follows a similar pattern as for the wider NHS workforce, of which 76% say they do not have a disability, 6% say they do, and the remainder do not indicate (NHS England, 2015). Locally, there were no figures available regarding disability for service-users.

### **5.2.2.5 Religion**

The current study included a simple dichotomous question asking respondents to state whether they were “religious” or “non-religious”. These labels might resonate with how people feel about their personal practice and belief regarding spirituality and faith. In contrast, the national NHS practitioner study (NHS England, 2015) and the local LYPFT service-user survey (Quality Health, 2015) stated specific faiths (such as Christianity, Hinduism etc.) which might encourage participants to think more in terms of their identity, family, background, or birth religion. Any differences between lived experience survey respondents and respondents of other surveys might be indicative of different methodologies.

In the current research (see table 5.3) service-users were more likely (36%) to identify as religious compared to practitioners (28%).

77% of service-user respondents to the Trust’s own survey (Quality Health, 2015) identified as religious, compared to 36% in the current study. Religious service-users may therefore be under-represented in this study.

Nationally, the NHS workforce survey (NHS England, 2015) suggests that roughly 55% of practitioners stated a religion compared to 28% in the current study, and 10% stated atheism, compared to 61% in the current study stating non-religion. Religious practitioners, therefore, may be under-represented in the current study, while there appear to be far greater numbers of non-religious practitioner respondents.

### **5.2.2.6 Age**

The age of respondents can be seen in table 5.3. The mean age of practitioners was 43 years, while for service-users it was 49 years. There may be a higher mean age for service-users than practitioners because there is no upper age limit for using services, while practitioners are likely to retire at or before retirement age. There is a greater age range among service-users (18-88 years) than practitioners (22-66 years). Differences in the lower age ranges may be due to practitioners needing to undertake practice qualifications or, if unqualified, needing to gain relevant experience before they can secure a position, hence practitioners are likely to join the

Trust at a later age than service-users. Differences in upper age ranges are likely to be due, as with differences in mean ages, to practitioner retirement.

The Trust's own survey report (Quality Health, 2015) collected data on service-users' ages by age groups which differ to those in the current survey, and the report does not indicate mean age nor age range. It is, however, possible to make some very rough comparisons. These suggest that the Trust's Quality Health (2015) survey received fewer younger respondents and more older respondents than the current survey. 13% of Quality Health (2015) survey respondents were in the 18-35 age range, compared to 31.5% of respondents to the current survey in the 18-39 age range. 43% of Quality Health (2015) respondents were aged 66 or over, compared to 24.3% aged 60 or over in the current survey. In between these ages, other groups are broadly similar between the Quality Health (2015) and the current survey.

Nationally, estimates suggest the mean age of practitioners in the NHS is 42 years old (NHS Employers, 2015) with an age range of 20 to over-65 (NHS, 2015), compared to a mean age of 43 years and a range of 22-66 in the current survey.

### **5.2.3 Practitioner job roles**

Practitioners were asked to indicate their job role, either by ticking a box to indicate the job title closest to theirs, or as a free-text response. Tick box options included: nurse, doctor, consultant, social worker, health care support worker, health care assistant, clinical psychologist, psychotherapist, counsellor, physiotherapist, occupational therapist, and peer support worker or mentor. With additional free-text responses, respondents indicated 32 different job titles. To summarise the data, responses have been grouped into six categories based on an assessment of job functions and affiliations, and are presented in table 5.4 below.

Table 5.4: Practitioner job types

<b>Practitioner Job type (self-description)</b>	<b>Practitioner n=200 (%)</b>
Nurses & nursing assistants (Nurse, bank nursing assistant, drug liaison midwife)	75 (37.5)
Support workers various types (Carers support worker, wealth care assistant, health care support worker, outreach worker, senior support worker, therapy support worker, user involvement worker, peer support worker or mentor)	40 (20)
Allied professionals (social worker, dietitian, occupational therapist , physiotherapist)	29 (14.5)
Doctors (Consultant, doctor, psychiatrist)	23 (11.5)
Therapist, psychologist, counsellor (CBT therapist, clinical psychologist, counsellor, forensic psychologist, psychological wellbeing practitioner, psychotherapist)	22 (11)
Various uncategorised (Adult safeguarding lead, associate practitioner, deputy support manager, manager, mandatory trainer/advisor, operational manager, specialist practitioner, trade union rep)	9 (4.5)
Missing or prefer not to say	2 (1.0)
<b>Total</b>	<b>200 (100)</b>

#### **5.2.4 Whether practitioners have ever shared anything about themselves with a service-user**

Practitioners were asked if they had ever shared any information about themselves with service-users. Of the 200 practitioners who responded, 49 (24.5%) said they had not, and 151 (75.5%) said they had.

94 practitioners said they had personal mental health lived experience. Of those, 81 (86.20%) said they had shared something about themselves with a service-user, and 13 (13.8%) said they had not.

94 practitioners said they did not have mental health lived experience. Of those, 66 (70.20%) said they had shared something about themselves with a service-user, and 28 (29.8%) said they had not.



Service-users were asked if practitioners had ever shared any information about themselves with them. Of the 110 service-users who gave a response, 62 (56.4%) said they had not, and 48 (43.6%) said they had.

45 of the 49 non-disclosing practitioners gave their age, which had a mean of 45.22 years. 147 of the 151 disclosing practitioner gave their age, which had a mean of 42.61 years. The difference was not significant.

### **5.2.5 Whether practitioners would share if they had a different job role**

Practitioners were asked if they would feel differently about sharing if they had a different job role. Overall, of the 195 who gave a response to this question, 58 (29.7%) said they would feel differently, and 137 (70.3%) said they would not feel differently.

41 (83.7%) of the 49 practitioners who said they had not disclosed anything to a service-user said they would not disclose if they were in a different job role. 8 (16.3%) said they would feel differently if they were in a different job role.

151 practitioners indicated they had disclosed some information about themselves to service-users. 146 of these gave a response to the question of whether they would feel differently in a different job role (5 did not respond). Of these 146 respondents, 50 (34.2%) said they would feel differently about disclosing if they were in a different job role, and 96 (65.8%) said they would not.

### **5.3 Ratings of the helpfulness of sharing different types of lived experience**

It was hypothesised that the personal identity of respondents might affect how they rate particular questions, due to the potential added insight that certain experiences, conditions or identities might afford, and the belief that sharing such information could be helpful to others. For example, personal experience of a health condition might affect helpfulness ratings of sharing information about health conditions; being religious or non-religious might affect helpfulness ratings of sharing religion; and whether practitioners have mental health lived experience might affect how they view the helpfulness of sharing that information with service-users. These variables were entered into statistical tests as grouping variables, and responses

to each question were analysed according to whether there was a relevant, associated demographic trait that might affect ratings. A list of grouping variables and their justifications is given in Chapter 4, Methodology.

In the following analyses, higher mean ratings indicate that sharing information is more helpful and lower mean ratings indicate sharing information is less helpful.

### 5.3.1 The helpfulness of sharing personal mental health lived experience

Participants were asked to rate the helpfulness of practitioners sharing their mental health lived experience with service-users.

#### 5.3.1.1 The influence of lived experience on ratings of sharing lived experience

Practitioners with and without personal mental health lived experience were compared to each other and to service-users.

Table 5.5: Mean ratings of sharing personal mental health lived experience: grouping variable personal mental health lived experience

Respondent type	N	Mean rating	Standard Deviation
Service-user	107	3.29***	1.56
Practitioner with Lived Experience	94	2.97**	1.29
Practitioner without Lived Experience	93	2.47	1.21
Total	294	2.93	1.41
F (2,291) = 8.865, p<0.001			
Difference from comparator (practitioner without lived experience)			
*p<0.05, ** p<0.01, *** p<0.001			

Having lived experience, whether among practitioners or service-users, was associated with a higher mean helpfulness rating of sharing mental health lived experience, compared to not having lived experience. Service-users rated sharing lived experience highest, and practitioners without lived experience rated it lowest (see table 5.5).

Service-users rated sharing mental health lived experience higher than practitioners without mental health lived experience (mean difference=0.82, 95% Confidence Interval=0.35 to 1.29, p<0.001, r=0.29).

Practitioners with mental health lived experience rated sharing mental health lived experience higher than practitioners without mental health lived experience (mean difference=0.50, 95% Confidence Interval=0.01 to 0.98,  $p<0.05$ ,  $r=0.20$ ).

**5.3.1.2 The influence of lived experience combined with having a family member or friend with lived experience on ratings of sharing personal mental health lived experience**

The presence or absence of mental health lived experience among practitioners was combined with the presence or absence of having a family member or friend with mental health lived experience, to investigate whether having such relationships is sufficient alone to affect ratings of helpfulness.

Table 5.6: Mean ratings of sharing personal mental health lived experience: grouping variables personal mental health lived experience and family or friend with lived experience

Respondent type	N	Mean rating	Standard Deviation
Service-users	107	3.29***	1.56
Practitioners with lived experience & with a family member or friend with lived experience	60	3.00*	1.33
Practitioners with lived experience & without a family member or friend with lived experience	33	2.91	1.26
Practitioners without lived experience & with a family member or friend with lived experience	45	2.78	1.20
Practitioners without lived experience & without a family member or friend with lived experience	47	2.17	1.17
F (4,287) = 5.633, $p<0.001$			
Difference from comparator (practitioner without lived experience and without family member or friend with lived experience) * $p<0.05$ , ** $p<0.01$ , *** $p<0.001$			

Service-users gave the highest mean rating of helpfulness, while practitioners without personal mental health lived experience and without a family member or friend with lived experience gave the lowest rating of helpfulness (see table 5.6).

Service-users rated sharing mental health lived experience higher than practitioners without lived experience and without a family member or friend with lived experience (mean difference=-1.12, 95% Confidence Interval=-1.80 to -0.44,  $p<0.001$ ,  $r=0.42$ ).

Practitioners with mental health lived experience and with a family member or friend with lived experience rated sharing mental health lived experience as more helpful than practitioners with neither (mean difference=-0.83, 95% Confidence Interval = -1.59 to -0.75,  $p<0.05$ ,  $r=0.32$ ).

There was no significant difference between ratings of helpfulness between service-users and practitioners who had both personal lived experience and a family member or friend with lived experience.

### 5.3.2 The helpfulness of sharing information about the mental health of a family member or friend

Participants were asked to rate the helpfulness of practitioners sharing information about the lived experience of a family member or friend with service-users.

Table 5.7: Mean ratings of sharing information about the mental health of a family member or friend: grouping variable family member or friend with lived experience

Respondent type	N	Mean rating	Standard Deviation
Service-user	103	3.02*	1.48
Practitioner with a family member or friend with lived experience	112	2.88*	1.36
Practitioner without a family member or friend with lived experience	78	2.39	1.26
F (2,290) = 5.064, $p<0.05$			
Difference from comparator (practitioner without family member or friend with lived experience) * $p<0.05$ , ** $p<0.01$ , *** $p<0.001$			

Service-users rate the helpfulness of sharing this information highest, and practitioners without a family member or friend with lived experience rate helpfulness lowest (see table 5.7).

Service-users rate sharing the mental health lived experience of a family member or friend as more helpful than practitioners without a family member or friend with mental health lived experience (mean difference=0.63, 95% Confidence Interval=0.14 to 1.13,  $p<0.05$ ,  $r=0.22$ ).

Practitioners with a family member or friend with mental health lived experience rate sharing mental health lived experience as more helpful than practitioners without (mean difference=-0.50, 95% Confidence Interval= -0.99 to -0.01,  $p<0.05$ ,  $r=0.18$ ).

### 5.3.3 The helpfulness of sharing information about religion

Participants were asked to rate the helpfulness of practitioners sharing information about their religion with service-users.

Table 5.8: Mean ratings of sharing information about religion: grouping variable religion

Respondent type	N	Mean rating	Standard Deviation
Service-users who are religious	36	2.42*	1.48
Practitioners who are religious	52	2.31*	1.23
Practitioners who are not religious	118	1.98	1.17
Service-users who are not religious	47	1.62	0.87
F (3,249) = 4.210, p<0.05			
Difference from comparator (service-users who are not religious)			
*p<0.05, ** p<0.01, *** p<0.001			

Religious service-users rated the helpfulness of sharing religion highest, and non-religious service-users rate it lowest (see table 5.8).

Religious service-users rate sharing of religion higher than non-religious service-users (mean difference=0.80, 95% Confidence Interval=0.10 to 1.50, p<0.05, r=0.37).

Religious practitioners rate sharing of religion higher than non-religious service-users (mean difference=0.69, 95% Confidence Interval=0.56 to 1.33, p<0.05, r=0.32).

### 5.3.4 The helpfulness of sharing information about sexual orientation

Participants were asked to rate the helpfulness of practitioners sharing information about their sexual orientation with service-users.

Table 5.9: Mean rankings of sharing information about sexual orientation: grouping variable sexual orientation

Respondent type	N	Mean rank (p)
LGB service-users	13	185.15 (1*,2*)
LGB practitioners	16	171.75 (1*)
Straight practitioners	158	126.10
Straight service-users	71	117.36
(chi-square=17.546, df=3, p<0.001)		
1 Difference from comparator (straight service-users)		
2 Difference from comparator (straight practitioners)		
*p<0.05, ** p<0.01, *** p<0.001		

LGB service-users rate the helpfulness of sharing sexual orientation highest, and straight service-users rate it lowest (see table 5.9).

LGB service-users rate the helpfulness of sharing sexual orientation higher than straight service-users (test statistic=-3.31,  $p<0.05$ ,  $r=0.34$ ).

LGB service-users rate sharing of sexual orientation higher than straight practitioners (test statistic=-3.01,  $p<0.05$ ,  $r=0.24$ ).

LGB practitioners rate sharing of sexual orientation higher than straight service-users (test statistic=2.89,  $p<0.05$ ,  $r=0.30$ ).

There was no significant difference between ratings by straight service-users and straight practitioners, nor between LGB service-users and LGB practitioners.

### 5.3.5 The helpfulness of sharing information about physical health

Participants were asked to rate the helpfulness of practitioners sharing information about their physical health (including any health conditions or physical disabilities) with service-users.

Table 5.10: Mean rankings of sharing information about physical health: grouping variable physical health condition

<b>Respondent type</b>	<b>N</b>	<b>Mean rank</b>
Service-users with physical health condition	39	163.46
Practitioners with physical health condition	18	159.39
Practitioners without physical health condition	165	137.79
Service-users without physical health condition	59	129.52

Service-users with a physical health condition rated sharing information about physical health conditions highest, and service-users without a physical health condition rated it lowest (see table 5.10).

There were no significant differences between service-users and practitioner ratings of the helpfulness of sharing information about physical health, nor within groups based on the whether respondents had a physical health condition.

### 5.3.6 The helpfulness of sharing difficult or traumatic experiences

Participants were asked to rate the helpfulness of practitioners sharing information about their own difficult or traumatic experiences with service-users.

Table 5.11: Mean ratings of sharing information about difficult or traumatic experiences: grouping variable (proxy) personal mental health lived experience

<b>Respondent type</b>	<b>N</b>	<b>Mean rating</b>	<b>Standard Deviation</b>
Service-users	98	2.84*	1.43
Practitioners with lived experience	90	2.58	1.25
Practitioners without lived experience	93	2.33	1.30
F (2,278) = 3.420 , p<0.05			
Difference from comparator (practitioners without lived experience)			
*p<0.05, ** p<0.01, *** p<0.001			

Service-users rate the sharing of difficult or traumatic experiences highest, and practitioners without lived experience rated it lowest (see table 5.11).

Service-users rate the sharing of difficult or traumatic experiences higher than practitioners without lived experience (mean difference=0.50, 95% Confidence Interval=0.04 to 0.97, p<0.05, r=0.15).

### 5.3.7 The helpfulness of sharing hobbies and out of work experiences

Participants were asked to rate the helpfulness of practitioners sharing information about their hobbies and out of work experiences with service-users.

Table 5.12: Mean ratings of sharing information about hobbies and out of work experiences: no grouping variable

<b>Respondent type</b>	<b>N</b>	<b>Mean</b>	<b>Standard Deviation</b>
Service-users	100	2.94*	1.41
Practitioners	194	3.40	1.18
t =2.805, df=171.579, r=0.21			
Difference from comparator (practitioners) *p<0.05, ** p<0.01, *** p<0.001			

See table 5.12. Service-users rate the sharing of hobbies and out of work experiences as less helpful than practitioners do (t=2.81, df=171.58, p<0.05, r=0.21).

#### 5.4 Variables associated with practitioner ratings of the helpfulness of sharing mental health lived experience

Backward linear regression was used to investigate which variables were associated with practitioners' helpfulness ratings regarding sharing personal mental health lived experience with service-users. Backward regression was chosen as there were no hypotheses regarding which factors might be more relevant than others and how they might affect each other, except that having personal mental health lived experience might affect helpfulness ratings, and this variable was included in the model. The full list of demographic and grouping variables entered into the model were: personal experience of mental illness; family member or friend with mental health lived experience; physical disability; religion; sexual orientation; ethnicity; gender; age; whether they had ever shared anything with a service-users; and job role (binary doctor/non-doctor).

Table 5.13: Variables associated with practitioner ratings of the helpfulness of sharing lived experience

Grouping variables	Unstandardised Coefficients		Standardised coefficients	t	p
	B	Std. Error	Beta		
Constant	2.77	.35		7.89	.000
Family member or friend with lived experience (no, yes)	.42	.19	.168	2.23	.028
Not religious/religious	-.37	.21	-.137	-1.77	.079
Has ever shared anything with a service-user (no, yes)	.96	.23	.314	4.14	.000
Ethnicity (not white/ white)	-1.04	.31	-.269	-3.40	.001
Sexual orientation (Straight/not straight)	.78	.31	.185	2.48	.014
Job role (Non-doctor/doctor)	-.65	.29	-.167	-2.22	.028
R <sup>2</sup> = 0.24, R <sup>2</sup> (adj.) = 0.21					



Six variables were associated with increased ratings of the helpfulness of sharing mental health lived experience, but only five are significant (see table 5.13). Together they explain 24% of the sample variance (21% of the population variance). Practitioners rated sharing mental health lived experience higher if: they had a family member or friend with lived experience; if they had ever shared anything with a service-user; if their ethnicity was non-white; if they were Lesbian, Gay or Bisexual as opposed to straight; and if their job role was not that of doctor ( $r^2$  adj.=0.21,  $F(6,147)=7.83$ ,  $p<0.001$ ). Practitioners being non-religious was retained in the model but was not significant. Excluded factors that do not appear to influence ratings included gender, age, physical health conditions, and whether the practitioner has personal mental health lived experience.

It was expected that the presence or absence of personal mental health lived experience among practitioners might affect practitioner ratings of sharing mental health lived experience but this was not a factor retained in the regression model. A Pearson correlation was run to investigate correlations between factors that might explain this (see table 5.14). Ratings of sharing lived experience correlate highest with the presence or absence of lived experience, sexual orientation, whether practitioners have ever shared anything, whether they are a doctor or not, and whether they have a family member or friend with lived experience.

Although the correlations are not high, it is possible that the presence or absence of lived experience is interacting with these 5 factors in some way so that having lived experience appears not to make a difference to ratings on this question. The demographic factor that has the largest effect on whether a practitioner has ever shared anything, after whether they are a doctor, is whether they have mental health lived experience. If practitioners have lived experience they are more likely to have shared something, and if they have shared something, they are more likely to rate sharing mental health higher. It may be the case that having mental health lived experience is not enough on its own to be included in the model, due to being affected by one of the five correlation factors highlighted in table 5.14.

Table 5.14 Correlations between ratings of sharing personal mental health lived experience and demographic characteristics.

Ratings of sharing personal mental health lived experience	Pearson Correlation
Female vs. male	-0.03
Not white vs. white	-0.04
Age	-0.01
No lived experience vs. lived experience	0.20**
Straight vs. not straight	0.17*
Whether ever shared anything	.34**
Non-doctor vs. doctor	-0.20**
No disability vs. disability	0.09
Not religious vs. religious	-0.12
No family member vs. family member with lived experience	0.18*

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001

## 5.5 The helpfulness of different types of practitioner sharing personal mental health lived experience

### 5.5.1 Service-users compared to practitioners: the sharing of personal mental health lived experience when undertaken by different types of practitioner

Table 5.15: Helpfulness of sharing personal mental health lived experience when shared by practitioners in different job roles

Independent Samples t-test	Respondent Job role	N	Mean	Standard Deviation
<b>Mental Health Discloser Job Role</b>				
	Nurse			
	Practitioner	197	2.82*	1.33
	Service-user	98	3.19	1.56
Social worker	Practitioner	197	2.59**	1.31
	Service-user	96	3.12	1.60
Counsellor	Practitioner	196	2.45***	1.33
	Service-user	98	3.33	1.55
Psychologist or psychotherapist	Practitioner	193	2.36***	1.31
	Service-user	99	3.32	1.59
Occupational therapist or physiotherapist	Practitioner	197	2.79**	1.31
	Service-user	94	3.25	1.48
Doctor	Practitioner	197	2.44***	1.29
	Service-user	100	3.28	1.62
Peer support worker	Practitioner	194	3.56	1.33
	Service-user	97	3.56	1.47
Health care support worker or assistant	Practitioner	197	2.96	1.34
	Service-user	98	3.29	1.60
Non-clinical staff	Practitioner	198	2.30	1.30
	Service-user	98	2.38	1.52

Difference from comparator (service-user) \*p<0.05, \*\* p<0.01, \*\*\* p<0.001

See table 5.15. Service-users rated helpfulness higher than practitioners when asked to rate the sharing of mental health lived experience by: nurses ( $t=-2.05$ ,  $df=169.26$ ,  $p<0.05$ ,  $r=0.16$ ); social workers ( $t=-2.79$ ,  $df=159.09$ ,  $p<0.01$ ,  $r=0.22$ ); counsellors ( $t=-4.76$ ,  $df=170.28$ ,  $p<0.001$ ,  $r=0.34$ ); psychologists or psychotherapists ( $t=-5.21$ ,  $df=167.54$ ,  $p<0.001$ ,  $r=0.37$ ); occupational therapists or physiotherapists ( $t=-2.64$ ,  $df=289$ ,  $p<0.01$ ,  $r=0.15$ ); doctors ( $t=-4.53$ ,  $df=163.97$ ,  $p<0.001$ ,  $r=0.38$ ).

The same pattern held for sharing by health care support workers or assistants, and for sharing by non-clinical staff, but the results were not significant. Practitioners and service-users scored sharing by peer support workers identically.

### 5.5.2 Doctors compared to other practitioners: the sharing of personal mental health lived experience when undertaken by different types of practitioner

Table 5.16: Helpfulness of sharing personal mental health lived experience when shared by practitioners in different job roles: doctors compared to non-doctors

Independent Samples t-test Mental Health Discloser Job Role	Respondent Job role	N	Mean	Standard Deviation
Nurse	Non-doctor	173	2.94***	1.33
	Doctor	23	1.96	0.98
Social worker	Non-doctor	173	2.68*	1.32
	Doctor	23	1.96	1.02
Counsellor	Non-doctor	172	2.56***	1.3471
	Doctor	23	1.61	0.89
Psychologist or psychotherapist	Non-doctor	170	2.45**	1.32
	Doctor	22	1.64	0.95
Occupational therapist or physiotherapist	Non-doctor	174	2.87*	1.32
	Doctor	22	2.27	1.08
Doctor	Non-doctor	173	2.54***	1.30
	Doctor	23	1.65	0.88
Peer support worker	Non-doctor	170	3.66*	1.26
	Doctor	23	2.78	1.59
Health care support worker or Assistant	Non-doctor	173	3.04*	1.34
	Doctor	23	2.39	1.27
Non-clinical staff	Non-doctor	174	2.34	1.31
	Doctor	23	2.00	1.24
Difference from comparator (doctor) * $p<0.05$ , ** $p<0.01$ , *** $p<0.001$				

Practitioners who are not employed as doctors rated helpfulness higher than doctors when asked to rate the sharing of mental health lived experience by: nurses ( $t=3.44$ ,  $df=194$ ,  $p<0.001$ ,  $r=0.24$ ); social workers ( $t=2.53$ ,  $df=194$ ,  $p<0.05$ ,  $r=0.18$ ); counsellors ( $t=4.50$ ,  $df=37.05$ ,  $p<0.001$ ,  $r=0.59$ ); psychologists or psychotherapists ( $t=3.59$ ,  $df=32.53$ ,  $p<0.001$ ,  $r=0.53$ ); occupational therapists or physiotherapists ( $t=2.03$ ,  $df=194$ ,  $p<0.05$ ,  $r=0.14$ ); doctors ( $t=4.26$ ,  $df=36.08$ ,  $p<0.001$ ,  $r=0.58$ ); peer support workers ( $t=2.53$ ,  $df=25.85$ ,  $p<0.05$ ,  $r=0.45$ ); and health care support workers or assistants ( $t=2.18$ ,  $df=194$ ,  $p<0.05$ ,  $r=0.15$ ). The same pattern held for sharing by non-clinical staff, but the result was not significant.

### **5.6 Demographic factors influencing whether a practitioner has ever shared anything with a service-user**

Demographic factors were entered into a binary logistic regression to see which, if any, factors predict practitioners' yes/no responses to the question asking if they had ever shared anything with service-users. Factors included: age; gender; whether they have personal mental health lived experience; whether they are a doctor or non-doctor; whether they have a disability; whether they are religious; sexual orientation (LGB vs straight); and ethnicity (white vs not-white). No models were generated that increased prediction based on these factors.

### **5.7 Correlation between perceived intimacy and helpfulness of disclosure subjects**

The perceived intimacy of each hypothetical disclosure subject had been ascertained prior to the investigation, in order to evaluate whether the level of intimacy of a disclosure affected ratings of helpfulness. A Pearson Correlation test was performed on the data. There was no correlation between intimacy and helpfulness rating on any of the disclosure subjects.

### **5.8 Conclusion**

Compared to local and national comparators, demographic characteristics that were over-represented among service-users included being female, being lesbian, gay or bisexual, and being in the 18-39 age range. Under-represented characteristics of service-users included being religious, and being aged 60 or over. For practitioners, the over-represented characteristic was being lesbian, gay or bisexual, and the under-represented characteristic was religion. Other

service-user and practitioner characteristics were broadly similar to local and national comparators (see table 5.17, below, for a summary).

Table 5.17: Demographic characteristics summary: current survey compared to national and/or local comparators

<b>Characteristic</b>	<b>Service-users</b>	<b>Practitioners</b>
<b>Gender</b>	Female over represented	Similar to comparators
<b>Sexual orientation</b>	LGB over-represented	LGB over-represented
<b>Ethnicity</b>	Similar to comparators	Similar to comparators
<b>Religion</b>	Religious people may be under-represented	Religious people may be under-represented
<b>Age</b>	Younger people over represented; Older people under-represented; middle age groups similar	Similar to comparators
<b>Physical disability or long term health condition</b>	No suitable local or national comparator	Similar to comparators

It was possible to match a relevant demographic characteristic (or grouping variable) with most types of hypothetical disclosure.

Table 5.18 shows a summary of the between-group effects that grouping variables had on ratings of different types of disclosure. In some cases it was not possible to apply a grouping variable to both practitioners and service-users and these have been omitted from the table for clarity, for example, service-users have lived experience by default so service-users without lived experience cannot be compared to service-users with lived experience nor to practitioners, and there was no grouping variable for hobbies and out of work experiences.

Where both practitioners and service-users shared a question's related characteristic, there was a consistent non-significant trend where service-users always rated disclosure as more helpful than practitioners did across all types of disclosure (see Chapter 4 for a list of grouping variables and proxies). The only question where there was no grouping variable was hobbies and out of work experiences, where practitioners rated helpfulness higher than service-users, and where the difference was significant.

Where neither practitioners nor service-users shared a question's related characteristic, there was a non-significant trend where practitioners consistently rated disclosure as more helpful

than service-users. However, this only applied to non-mental health related questions, because it was not possible for lived experience to be absent among service-users.

Where service-users had a characteristic related to the question, but practitioners did not have that characteristic, there was a consistent trend for service-users to rate disclosure higher than practitioners. The differences were significant across all mental health questions, and sexual orientation, but not for religion and physical health.

Where practitioners had a question's related characteristic, but service-users did not, there was a consistent trend for practitioners to rate disclosure as more helpful than service-users, and the differences were significant for religion and sexual orientation, but not for physical health.

Table 5.18: Between groups summary of grouping variables and question ratings

Disclosure	Highest rater (service-users or practitioners)	Significant (yes/no)
<b>Both service-user and practitioner share the question's related characteristic</b>		
Personal mental health lived experience	Service-user	No
The mental health of a family member or friend	Service-user	No
Difficult or traumatic experiences	Service-user	No
Religion (Religious)	Service-user	No
Sexual orientation (LGB)	Service-user	No
Physical health (condition or disability)	Service-user	No
Hobbies (no grouping variable)	Practitioner	Yes*
<b>Neither service-user nor practitioner have the question's related characteristic</b>		
Religion (Religious)	Practitioner	No
Sexual orientation (LGB)	Practitioner	No
Physical health (condition or disability)	Practitioner	No
<b>Service-user has the question's related characteristic, practitioner does not</b>		
Personal mental health lived experience	Service-user	Yes***
The mental health of a family member or friend	Service-user	Yes *
Difficult or traumatic experiences	Service-user	Yes*
Religion (Religious)	Service-user	No
Sexual orientation (LGB)	Service-user	Yes*
Physical health (condition or disability)	Service-user	No
<b>Service-user does not have the question's related characteristic, practitioner does</b>		
Religion (Religious)	Practitioner	Yes*
Sexual orientation (LGB)	Practitioner	Yes*
Physical health (condition or disability)	Practitioner	No (p>0.05)
*p<0.05, ** p<0.01, *** p<0.001		

Table 5.19 shows a summary of the within-groups effects that grouping variables had on ratings of different types of disclosure. Service-users with a characteristic related to a question consistently rated disclosure as more helpful than service-users without the characteristic, and two of the three results were significant. It was only possible to draw this comparison on non-mental health questions, because it was not possible to have a comparator group of service-users without lived experience. The pattern was similar for practitioners: those with a characteristic consistently rated disclosure as more helpful than those without. The differences were significant for questions regarding sharing personal mental health and the mental health of a family member or friend, but not for any of the other types of disclosure.

Having a characteristic related to a hypothetical disclosure increased ratings of helpfulness for both practitioners and service-users. Where both practitioners and service-users shared a characteristic, service-users rated helpfulness higher, but where there was an absence of a characteristic practitioners rated questions higher. As may be expected, service-users rated questions higher than practitioners where they had a characteristic but practitioners did not, and practitioners rated questions higher than service-users where the practitioner had a characteristic but the service-user did not. This suggests that disclosure may be seen as more helpful where respondents have a personal connection with, or insight into, the disclosure subject, and also that service-users find disclosure more helpful than practitioners do. Although not all of the results were significant, the pattern was very consistent and it may be the case that non-significance is a result of relatively small sample sizes.

Table 5.19: Within-groups summary of grouping variables and question ratings

Disclosure	Highest rater (respondent with or without characteristic)	Significant (yes/no)
<b>Service-user with question's related characteristic compared to service-user without</b>		
Religion	With	Yes*
Sexual orientation	With	Yes*
Physical health	With	No
<b>Practitioner with question's related characteristic compared to practitioner without</b>		
Personal mental health lived experience	With	Yes**
The mental health of a family member or friend	With	Yes*
Difficult or traumatic experiences	With	No
Religion	With	No
Sexual orientation	With	No
Physical health	With	No
*p<0.05, ** p<0.01, *** p<0.001		

Without exception, service-users rated the disclosure of personal mental health lived experience as helpful (above 3 on the scale) when undertaken by all types of practitioner, except for non-clinical staff. Practitioners (as a whole group) only rated mental health disclosure by peer support workers as helpful.

Service-users rated mental health disclosures higher than practitioners across all types of job role except for peer worker, where ratings were the same, and the results were significant in all cases except for unqualified roles (peer worker, health care support worker or assistant, and non-clinical staff).

Doctors consistently rated disclosure of mental health as less helpful than non-doctors for all job types, and the results were significant for all job roles except for non-clinical staff. Doctors also rated disclosure of mental health by peer workers as unhelpful, despite lived experience and disclosure both being integral to the role.



## 5.9 Summary

In summary, service-users rated disclosure more helpful than practitioners did, except for hobbies which was less helpful. They found disclosure especially helpful where they had a characteristic related to the disclosure. They also found mental health disclosure helpful when undertaken by all types of practitioner, except for non-clinical staff, and rated it higher for each job type than practitioners did, except for peer workers, which were rated the same. Practitioners rated disclosure less helpful than service-users did, except for hobbies where they rated it as more helpful. Like service-users, they found disclosure more helpful where they had a characteristic related to the disclosure. Practitioners only rated sharing of mental health lived experience as helpful when undertaken by peer workers, and doctors rated sharing lived experience as less helpful than non-doctors when undertaken by all types of practitioner. Results were consistent and significant on mental health and related questions where service-users had a characteristic but practitioners did not. Having some level of personal, rather than proxy or vicarious, lived experience appeared to lead to higher ratings of mental health disclosure for practitioners (see section 5.3.1.1 and 5.3.1.2 of this chapter).

## **Chapter 6: Qualitative Results 1: Real Life Examples of Personal Mental Health and Other Types of Disclosure**

### **6.1 Introduction**

Three quarters of practitioner respondents said they had shared some information about themselves with service-users at some point, and all gave at least one example of something they had shared, totalling more than 300 examples overall. Just under half of service-users said that practitioners had shared something with them at some point. They gave almost 100 examples of information that had been shared with them. Examples were assigned to one or more of three broad categories according to whether they were about mental health lived experiences, mental health-related experiences, or experiences that were not related to mental health. This chapter explores these three broad categories in turn.

First, within each category, there is an exploration of the kinds of information that practitioners shared, what job role sharing practitioners had, and in what ways given examples were perceived as helpful or unhelpful. Although the survey asked respondents to indicate why the practitioner had shared information, responses were very similar to answers to the following question about the ways in which disclosure had been helpful or unhelpful, so no distinction is made between the two in reporting the results.

Second, there is a consideration of whether (and how) the job role of disclosing practitioners made a difference to perceptions of the helpfulness (or unhelpfulness) of sharing of *mental health* lived experience.

Third, the reasons practitioners gave for not sharing information about themselves is explored, along with the reasons why service-users thought practitioners do not disclose information about themselves.

Last is a short conclusion and summary of the main findings. All quotes are copied with original emphasis and spellings.

## **6.2 Sharing Mental Health Lived Experience**

The least frequent type of disclosure, for both practitioners and service-users, was sharing personal mental health lived experience. Personal mental health lived experiences were those that were personal to the practitioner, rather than about someone they knew, and which could have been likely to lead to diagnosis or treatment. This coding definition was chosen to distinguish between mental health experiences that might lead someone to use services and everyday stresses and issues that most people might face.

### **6.2.1 Frequency of sharing personal mental health lived experience.**

Practitioners reported sharing mental health lived experience about twice as frequently service-users did. 9% (n=10) of service-user respondents gave 13 examples of practitioners sharing personal mental health lived experience with them, while 18.5% of practitioner respondents (n=37) gave 46 examples.

### **6.2.2 Sharing mental health experiences: who is doing it and what they are sharing.**

Service-users most frequently reported that personal mental health disclosures were made by support workers, accounting for 7 out of the 13 examples given, though one of these took place in a voluntary sector organisation, rather than in a statutory setting. After support workers, the next most frequent mental health disclosers were nurses with 3 examples, and then peer workers with two examples. One example was given of a psychiatrist sharing their lived experience, and this was in relation to them having experienced therapy.

Of the practitioner respondents, nurses reported sharing most frequently, comprising 15 of the 37 practitioners who shared personal mental health experiences. After nurses, the most frequent disclosers were occupational therapists (n=8), health care support workers or assistants (n=6) and to a lesser extent therapists, including psychotherapists (n=3), clinical psychologists (n=2), peer workers (n=2), and one doctor. A breakdown of the number of practitioner respondents by job title is given in Chapter 5, section 5.2.3.

Numbers were insufficient to draw conclusions about differences in frequency between practitioners and service-users regarding what types of practitioner shared most frequently,

particularly as there were large differences between the numbers of practitioners in different roles who answered the survey, for example, 40% of practitioner respondents were nurses compared to 21% who were support workers. However, it appears that a wide range of practitioners shared, but doctors did so infrequently.

Mental health was the least often shared type of lived experience. When it was shared, both practitioners and service-users reported that the content ranged from low-level, generalised, or unspecified information, through to detailed examples that resulted in therapeutic interventions or hospitalisation.

Service-users reported practitioners disclosing that they had “been a service-user” (ID100); suffered with “mental illness” (ID005); undertaken “therapy” (ID094); experienced “severe depression & breakdown” (ID020), “anxiety & depression” (ID020), being “bad with [their] nerves” (ID012) and “anxiety and panic problems” (ID100); experienced “past alcoholism” (ID020); experienced hearing voices (ID042); and had experience of gender reassignment (ID007).

Practitioners gave many similar examples to service-users, ranging from the relatively low-level “experience of low mood” (Nurse, ID100), through to experiences of greater severity including being “admitted to a psychiatric hospital and thought I would never get better” (Psychotherapist, ID84) and “severe depression (including inpatient care)” (Psychotherapist, ID101). Practitioners also reported sharing: experiences of therapy and coping techniques they had used, including counselling, IAPT (Improving Access to Psychological Therapies), using self-help websites, and unspecified “strategies and tools that have helped me recover and stay well” (Peer support worker, ID173); past addictions such as “stopping taking recreational drugs” (Nurse, ID080), “long-term addiction” (Health care support worker, ID027), “past problems with alcohol” (Health care support worker, ID025), and “experiences of stopping smoking” (Health care support worker, ID096); self-harm including “how I overcame the need to do this” (Peer support worker, ID151) and “suicidal thoughts” (Nurse, ID186); and “recovery from an eating disorder” (Occupational therapist, ID089).

### **6.2.3 Helpful and unhelpful aspects of sharing personal mental health lived experience**

Examples of sharing personal mental health lived experience were almost exclusively positive. 85% of examples given both by service-users (11 out of 13 examples, 84.6%) and practitioners (39 out of 46 examples, 84.8%) were of a positive, helpful nature. Only a few were verifiably negative, 1 (8%) from a service-user, and 3 (7%) from practitioners. Other examples were not verifiable as either positive or negative, such as where practitioners stated they were unsure of the effect, or were neither helpful nor unhelpful:

“it wasn't particularly helpful, but I didn't mind her mentioning it. It certainly wasn't unhelpful.” (Service-user ID35).

In two cases, the practitioner reported that the service-user had verified the helpfulness of the disclosure.

#### ***6.2.3.1 Helpful examples of sharing personal mental health lived experience***

Service-users gave 13 examples of practitioners sharing their mental health lived experience. The most frequent effects reported by service-users concerned helping service-users to feel understood through the demonstration of empathy and personal insight, and helping to promote recovery:

“Because something so important requires good insight. The only way to do that is through personal testimonies.” (Service-user, ID007).

“My staff are human too!! Anyone CAN recover to a better life.” (Service-user, ID020).

Other helpful aspects of sharing included helping service-users to open up about their own conditions and normalising and destigmatising experiences:

“Made me feel comfortable in sharing my experiences/crisis.” (Service-user, ID042).

“it did show empathy, it also helped to understand I was not alone or unique even if the way i react to my illness was.” (Service-user, ID005).

A couple of service-users suggested that disclosure enhanced the credibility of practitioners’ interventions because shared information came from personal experience, though receiving mental health disclosures appeared to have been an isolated experience for one service-user:

“I could trust their comments, views, opinions, suggestions etc. I felt like I had an ally who REALLY understood my difficulties.” (Service-user, ID020).

“Valuable to hear the positives and negatives of a genuine lived experience. Admittedly only a sample of one, but sample of one trumps sample of zero.” (Service-user, ID007).

Practitioners reported that disclosure of mental health experiences was helpful in a number of ways which closely corresponded to the benefits described by service-users. A benefit of disclosure that was most frequently cited by practitioners was related to recovery, by inspiring service-users, increasing motivation, and increasing their knowledge of coping strategies. It was linked with normalising experiences to help service-users feel less unique in their difficulties and believe they too could recover:

“She said it helped her to know that someone else had experienced the desperation and despair that she was feeling and had managed to climb out of it. This gave her hope that she could have a more positive future.” (Peer support worker, ID151).

“It did persuade this person to persevere a bit more with an approach my team and I were taking in trying to address their anxiety...” (Doctor, ID047).

“Instilled hope and encouraged person to try the techniques for themselves...” (Occupational therapist, ID120).

For some service-users it was particularly relevant for practitioners to discuss their experiences of mental illness and recovery because of their status as working practitioners, since some service-users were concerned about their own future career possibilities:

“It was helpful because it made her ask questions about support that was available when you worked and we were able to discuss coping strategies and look at the plus and negative side of medication.” (Occupational therapist, ID199).

“This gave her hope that she could have a more positive future.... Over the time I worked with her she grew in confidence and as our work ended she had just returned to work on a part time basis. (Peer support worker, ID151).

Practitioners also saw building positive therapeutic relationships as a key benefit of sharing their lived experience with service-user. Building relationships involved removing barriers, reducing power imbalances, establishing trust, building rapport, and helping the service-user and practitioner to understand and relate to one another better. The direct clinical benefit of this was to enable the service-user to open up about their own issues:

“The patient opened up and was able to relate to my experience which then allowed her to discuss her situation more openly and reported that by me disclosing information she trusted me even when she was going through difficult periods and allowed me to challenge her thinking/ behaviour.” (Nurse, ID061).

“The power imbalance in a therapeutic setting can be immense. Some service-users are already feeling dis-empowered by their difficulties. Simple, authentic human contact can be greatly enhanced by a limited, considered sharing.” (Psychotherapist, ID084).

As with service-users, practitioners suggested that the demonstration of personal insight gained through personal experience helped to establish their credibility, and in some cases practitioners reported that this benefit was identified by the service-users themselves:

“She said that it was good to talk to someone who truly understood because, she said, unless you have been there it's hard to know what it's like. I think that this helped us to form a very honest, open and successful working relationship...” (Peer support worker, ID151).

“The person also said it was helpful because they felt I recognised their difficulties. I was very careful to say this was my experience and everyone is different so it is up to them to decide if this is helpful or not.” (Nurse, ID168).

“It helped... to show the service-user that my understanding stemmed from experience rather than something I have read in a text book.” (Health care support worker, ID025).

Practitioners, like service-users, reported that disclosure can help to humanise the practitioner, and to normalise and destigmatise the service-user’s experiences, which may help to relieve the loneliness and isolation that they experience:

“It seemed to have desired effect in that it, on a cognitive level at least they realised their experience was an extreme form of something normal.” (Doctor, ID047).

“The client appreciated knowing that they were not alone and that there was some hope of everything working out ok.” (Nurse, ID080).

Many practitioners indicated that desired effects had been achieved and in some cases they had also been verified by service-users:

“...example one was helpful and did instil a sense or hope I think (this was client's feedback).” (Psychotherapist, ID101).

“The patient... reported that by me disclosing information she trusted me even when she was going through difficult periods and allowed me to challenge her thinking/behaviour.” (Nurse, ID061).

“She said it helped her to know that someone else had experienced the desperation and despair that she was feeling and had managed to climb out of it.” (Peer support worker, ID151).

“The feedback from this service-user was that this was helpful and she wrote a note saying thank-you for my honesty.” (Occupational therapist, ID157).



### ***6.2.3.2 Unhelpful examples of sharing personal mental health lived experience***

The single unhelpful example given by a service-user related to the sharing of information about “anxiety and panic problems” (service-user ID100) where the disclosure appeared to have been inappropriate, misplaced, or misapplied, in that assumed similarities between the practitioner and service-user were incorrect, with the respondent stating “my issues were not similar to her” (service-user, ID100).

A second service-user example that contained a negative element was an example of non-disclosure, where it was made explicit that the lack of visible lived experience was a drawback of statutory interventions, and that the service-user got what they needed from the voluntary sector:

“It was VERY helpful, as it enabled me to trust their opinions and advice. They completely understood the precise difficulties of day to day living with a MH condition, and so were able to 'point' me in the right direction. The support staff of MIND have had an ENORMOUS impact on me and my recovery because of this - much more than any of the NHS staff in my care.” (Service-user, ID020).

The three examples that practitioners gave of negative outcomes concerned information being used against the practitioner in relation to disclosure of previous addiction, a complaint being made about a practitioner regarding alleged advice given about an eating disorder, and a disclosure that a service-user indicated was dissimilar to their own experiences:

“I thought this was helpful in that the service-users could see that recovery was possible. Unhelpful on one occasion when a service-user accused me of still being involved with my old addiction.” (Health care support worker, ID027).

“She told this doctor that I had said that self-induced vomiting was a great way to lose weight. That was not true.” (Occupational therapist, ID157).

[this example of sharing was] “Helpful from a normalising perspective. Questionable on some occasions as have had responses along the lines of ‘you haven't needed to be in services like this so can't have been that bad.’” (Occupational therapist, ID118).

In the first and third example, respondents indicated that disclosure went well, and suggested similar disclosures had also gone well on other occasions, though there were instances where disclosure and non-disclosure did not go well. In the second example, the practitioner went on to state that a complaint was made about them, but the complaint appeared to be about the advice they were alleged to have given, rather than about their disclosure of their eating disorder experiences. They further state that the allegation was untrue and that similar, reportedly untrue allegations had been made about other members of staff. This brings into question whether disclosure caused such complaints, and whether non-disclosure would have avoided them being made. Again, the practitioner reported having disclosed such information to other service-users to positive effect and that this may be an atypical incident.

Finally, although not an example of sharing, one practitioner reported being warned by a colleague and also, in a separate example, by a service-user, that service-users might use disclosure against them:

[Example 1] “Some staff advised me to be very careful about sharing as some patients could ‘use it against me.’”

[Example 2] “He [the service-user] appreciated some reassurance and acceptance. He also warned me to be careful about sharing this with other clients in case they tried to use it against me somehow.” (Nurse, ID152).

### ***6.2.3.3 Mediators of personal mental health disclosures***

Several practitioners and service-users mentioned factors that appeared to affect the helpfulness of disclosure. They included being brief and limiting disclosures, whether the practitioners’ and service-users’ issues are similar in nature to each other, the personality, level of illness, and situation of the person being disclosed to, the motivation for sharing, and whether the disclosure would shift the focus of the conversation.

“... she was also brief and to the point.” (Service-user, ID012, re. brevity).

“Simple, authentic human contact can be greatly enhanced by a limited, considered sharing.” (Psychotherapist, ID084, re. brevity).

“I was very careful to say this was my experience and everyone is different so it is up to them to decide if this is helpful or not.” (Nurse, ID168, re. acknowledging differences in experiences).

“What has been unhelpful is that people will often say to matters of health, 'it's hard whilst I'm in hospital due to boredom/ lack of freedom. I will make changes when I'm out.' So, sometimes all input feels ineffectual due to culture developed amongst fellow service-users.” (Health care support worker, ID096, re. service-user's circumstances).

“The acid test for this to be therapeutic and useful is to ask yourself the following questions before disclosing... ‘Who is this disclosure for?’ ‘Do you know where you end and the patient begins?’” (Psychotherapist, ID084, re. avoiding focus shift).

Overall, practitioners appeared to acknowledge mediating factors frequently, and more often than service-users did.

Finally, one practitioner felt that the lack of guidance on disclosure affected how decisions were made about whether to disclose:

“As there are no procedures or agreed consensus around the issue of sharing personal experience, it is hard to know what to share for risk of judgment or damage to reputation which is paradoxical to the values of social inclusion and equality our Trust promotes.” (Health care support worker, ID096).

### **6.3 Sharing Other Experiences Related to Mental Health**

Real life examples of sharing information that was related to mental health in some way, but which would not normally result (or had not explicitly resulted) in formal diagnosis or treatment, were given much more frequently than examples of sharing personal mental health lived experience. This category of disclosure encompassed a wide variety of issues, from low level,

everyday stresses, to more significant experiences that might impact on the respondents' wellbeing in some way, for example, how they feel, think or relate to others.

### 6.3.1 Frequency of sharing experiences related to mental health

17 service-users gave 24 examples of information that had been shared with them that related in some way to mental health. 80 practitioners gave 108 examples of sharing experiences that were related to mental health in some way.

### 6.3.2 Sharing experiences related to mental health: who is doing it and what they are sharing

For both practitioners and service-users, the two most frequent type of mental-health related disclosures concerned sharing difficult or traumatic experiences and sharing coping strategies. Practitioners and service-users also gave examples of other types disclosures in mostly the same order of frequency, including fears and anxieties, the mental health of a family member or friend, and experiences of taking medication. The exception was work experiences and stress, where service-users gave examples more frequently than practitioners did. In order of the frequency of examples given by service-users, table 6.1 below gives one example of each type of disclosure made. Frequencies in table 6.1 sum to slightly greater totals than to the overall category totals, because some examples of disclosure contained more than one disclosure subject, and were hence coded to more than one category.

Table 6.1: Examples of other disclosures related to mental health

Category & Description of mental health-related disclosure	Example Quote: Service-users (n=24 examples)	Example Quote: Practitioners (n=108 examples)
<b>Difficult or traumatic experiences:</b> Included sharing experience of relationship difficulties, exam stress, bereavement, divorce, non-specified traumas and difficult experiences, assault, domestic violence, anti-social behaviour, seeking asylum, being bullied, illness of a relative, being involved in an accident, family difficulties, and thoughts about death.	“About there ex husband separating (with them and how it made them feel).” (ID105)  (n=9)	“I have had a number of life changing events including serious illness of a child and loss of close relatives.” (Manager, ID161).  (n=37)

Category & Description of mental health-related disclosure	Example Quote: Service-users (n=24 examples)	Example Quote: Practitioners (n=108 examples)
<p><b>Coping strategies:</b> Coping strategies were often coded to other categories too, such as <i>fears and anxieties</i>, <i>personal mental health</i>, and <i>difficult or traumatic experiences</i>, because they overlapped. Examples were given of coping strategies used to deal with stressful situations, insomnia, personal finances, children’s behaviour, family issues, food management, bereavement, chronic pain, mental health problems, general problems, being in particular situations, pregnancy, and negative thoughts.</p>	<p>“A coping strategy that they use, mindfulness.” (ID005)</p> <p>(n=8)</p>	<p>“Techniques I use when I can’t get to sleep.” (Occupational therapist, ID013).</p> <p>(n=29)</p>
<p><b>Work experience and stress:</b> These were examples of everyday experiences, stresses and strains that affect most people. They are included here because they relate to mental wellbeing, but would not normally attract a diagnosis or treatment.</p>	<p>“It was about overworking. They shared that in the past they’d reached a point where they were doing too much and they’d had to acknowledge that &amp; give up some things.” (ID095)</p> <p>(n=3)</p>	<p>“I have shared my recent change in direction, career wise with people.” (Nurse, ID046)</p> <p>(n=5)</p>
<p><b>Fears and anxieties:</b> Included anxiety about flying, anxiety about driving, arachnophobia, general stresses or anxieties, fear of public situations, fear of heights, and being anxious before a job interview. Not categorised as being about <i>personal mental health lived experience</i> because there was no information to suggest that the fear or anxiety was of such a level that it would attract either a diagnosis or any kind of formal treatment.</p>	<p>“Told me about their anxiety over coping with a baby.” (ID027)</p> <p>(n=2)</p>	<p>“I have shared information about my spider phobia when working with phobic patients.” (CBT Therapist, ID052).</p> <p>(n=19)</p>
<p><b>Mental Health of Family Member or Friend:</b> Included sharing the mental health experiences of family members or friends related to dementia, psychosis, bipolar disorder, being a carer for someone with a mental health condition, the impact of mental illness on family dynamics, and recovery from mental illness.</p>	<p>“Support worker shared that her daughter has paranoid schizophrenia...” (ID020)</p> <p>(n=2)</p>	<p>“I have shared with families on two occasions that I have experience of supporting/ caring for someone with psychotic illness which involved acute admissions.” (Psychotherapist, ID101)</p> <p>(n=19)</p>

Category & Description of mental health-related disclosure	Example Quote: Service-users (n=24 examples)	Example Quote: Practitioners (n=108 examples)
<b>Medication:</b> Most examples of sharing information about medication were about mental health medication. One example was also given about physical health medication.	“medication, primarily a lithium.” (ID005)  (n=1)	“I worked with a lady ...struggling with the thought of taking medication ...after several months I disclosed that i took anti depressants ...and that it didn't always have to result in things ending badly which had been her previous experience... She really appreciated that fact that I was battling own problems at times but had found a way that helped me to continue with work and life.” (Occupational therapist, ID199)  (n=5)
<b>Techniques for interaction:</b> There was only one example of this, and as it did not fit neatly into other categories it was given a category on its own.	“Techniques in being able to relate to others in my group.” (ID042)  (n=1)	Not mentioned.  (n=0)

Service-users gave the job titles of 20 of the 24 practitioners who shared mental health-related experiences. Most often they were support workers (n=8), followed by nurses (n=6), and to a lesser extent counsellors and psychotherapists (n=3), doctors and psychiatrists (n=2), and one psychologist.

80 practitioners gave examples of their own sharing. Most commonly these examples were given by nurses (n= 28), followed by occupational therapists (n=16), and health care support workers or assistants (n=13, also including associate practitioners, therapy support workers, and carer’s support worker). A wide range of other practitioners also shared to a lesser extent, including psychotherapists or CBT therapists (n=6), peer support workers (n=3), psychologists (n=4, including clinical and forensic), doctors (n=2), and single cases (n=1) of adult safeguarding lead, dietician, drug liaison midwife, unspecified manager, outreach worker, physiotherapist, specialist practitioner, and user involvement worker.

### **6.3.3 Helpful and unhelpful aspects of sharing experiences related to mental health**

Of the 24 examples given by service-users, 18 (75%) were positive or helpful, 2 (8%) were negative or unhelpful, and in 4 cases (17%) there was no indication or there was insufficient information to determine whether the disclosure was positive or negative.

Of the 108 examples given by practitioners, 100 (93%) were positive or helpful, 4 (4%) were negative or unhelpful, 3 were neither positive nor negative (3%), and in 4 cases (4%) the practitioner was unsure whether part (n=3) or all (n=1) of the example was positive or negative. These sum to more than 108 because in 3 cases although practitioners had indicated that some aspects of the example was positive or negative, they were also unsure about other aspects of it.

As with mental health disclosures, most motivations for sharing and effects of sharing were interwoven, and are presented together here. Both service-users and practitioners mentioned a few specific motivations for sharing that were not directly related to a desired effect. Some information was disclosed because service-users had received information automatically or unavoidably that had led to further discussion, such as a practitioner being seen shopping for flowers for an ill relative, a practitioner having visible facial scars because of a violent attack, or because of the practitioner's absence from work. Such disclosures were made because the service-user asked a direct question, or because they indicated disclosure would be useful to them. Two practitioners mentioned that they disclosed because it was part of their peer support role.

#### ***6.3.3.1 Helpful examples of sharing other experiences related to mental health***

Service-users and practitioners mentioned similar benefits of mental health-related disclosure to one another, to similar frequencies, and these were similar in nature to the benefits of sharing personal mental health lived experience. For both practitioners and service-users, the most frequent disclosures were related to sharing information about difficult or traumatic experiences, and then coping strategies.

Service-users said disclosures were helpful because they: helped to normalise and destigmatise the service-users' experiences and offer hope for recovery; humanised the practitioner, while

maintaining their professionalism; enabled the service-user to feel understood through demonstrating first-hand experience and personal insight; established or enhanced the credibility of the practitioner; and affected the relationship in a positive way by gaining the service-user's trust, thereby helping the service-user to open up and talk about their own experiences:

"I saw the CPN as less official and more human, sensitive to my needs and had the confidence to share without compromising her professional status." (Service-user, ID061).

"To reassure me that the crises I was having were the same as others and that there was light at the end of the tunnel." (Service-user, ID042).

"Made me feel comfortable in sharing my experiences/crisis." (Service-user, ID042).

Foremost, practitioners mentioned hope for recovery as a major benefit of sharing mental related experiences:

"It [sharing a difficult or traumatic experience] helped build trust with the patient and made them realise that they would, with appropriate support, need to adapt and cope to their stressors." (Doctor, ID004).

"It [sharing examples of other people's mental health experiences] enabled a sense of positivity, hope and increased motivation." (Occupational therapist, ID156).

In very much the same way as for sharing personal mental health lived experience, practitioners spoke about the potential for disclosure to help build relationships, through better engagement, and rapport, reducing power imbalances, humanising the practitioner, and helping service-users to open up and disclose their own experiences. They also mentioned that disclosure was helpful to normalise and destigmatise a variety of experiences, including relationship breakup, anxiety, and coping with the difficult behaviour of children. Practitioners felt disclosures also helped service-users feel understood, demonstrated empathy and personal insight, and established practitioner credibility through displaying honesty and authenticity. These had the effect of "validating [the service-user's] feelings" (Nurse, ID134), and enabled service-users to



“feel believed” (Doctor, ID123) and taken seriously. One occupational therapist reported that her disclosure to a “medic” colleague about her own experience of taking medication enabled the medic to take the service-user’s views more seriously (ID187).

A couple of practitioners suggested that sharing information about loss and stress enabled them to challenge a service-user’s view that no-one could understand what they were going through:

“Client was able to engage more openly and would accept gentle challenging because she could not say you don’t know how it feels.” (Nurse, ID121).

Both practitioners and service-users appear to indicate that disclosures related to mental health could have similar benefits to disclosure about personal mental health lived experience.

### ***6.3.3.2 Unhelpful examples of sharing experiences related to mental health***

Although the majority of disclosures were helpful or positive, two negative examples of disclosure were given by one service-user, and three negative examples were given by two practitioners.

The two negative examples were cited by one service-user regarding disclosures by one or more counsellors. One example related to sharing childhood experiences, and the other related to the distressing effects of racial discrimination. In each case the service-user felt that the practitioner incorrectly assumed their experience would be of relevance and resonate with the service-user’s experience:

“This was unhelpful, I had already come to the conclusion that my treatment was wrong. If anything it served to alienate her from the process, and shortly after I refused any further treatment.” (Service-user, ID019, re. disclosure by mental health counsellor).

“It was irrelevant at the time because I was not worried about [the issues that the counsellor thought were important].” (ibid).

The three unhelpful practitioner examples were given by two practitioners; a nurse and a psychotherapist. The example given by the nurse, concerning bereavement, had both positive

and negative effects. It helped to normalise the service-user's experiences, but the service-user "wanted more information I wasn't able or willing to share" (Nurse, ID097).

The psychotherapist gave two unhelpful examples of sharing. Both examples concerned sharing information with the family of a service-user, rather than with the service-users, and both examples were about their experiences of the mental illness of a family member or friend. In both cases, mixed positive and negative effects were assumed. Helpful effects were described simply as 'helpful', while unhelpful effects might have resulted from perceptions of dissimilitude between the practitioner's situation and that of disclosure recipients, or disbelief about the practitioner's experiences:

"I think [disclosure] may have been temporarily helpful (perhaps at the moment in the conversation) but subsequently I think it may have got in the way with people assuming I couldn't really understand their particular experience."

"Carers find [the practitioner's experience] hard to believe and I suspect may sometimes have felt a bit 'dismissed' in the conversation, as though I may have been denying their current experience." (Psychotherapist, ID101).

While the two service-user examples appear to have led to refusing further treatment, and clearly had a significant negative effect, none of three practitioner examples were reported to lead to any significant or problematic issue, with reported effects being either low-level, assumed rather than verified, or potential.

### ***6.3.3.3 Mediators of disclosures related to mental health***

Mediating factors for mental health-related disclosures were similar to those cited against mental health disclosures. They included being brief and limiting disclosures (practitioners and service-users), whether the service-user had given consent to receive the disclosure (practitioner), and whether there was any attempt to verify the effect of the disclosure, with one service-user indicating that practitioners may not be aware of the power that disclosure might have:

“These things know no measure, when the message of recovery was imparted to me I wept through out, with no visible sign of hearing let alone any sense of inspiration yet here 13 years on I still remember and retell that story. I doubt the psychiatrist would remember or be able to evaluate the effect it had on me with any accuracy.” (Peer support worker, ID076).

Two practitioners suggested that the nature of a service-user’s illness, personality or situation might have an effect on disclosure, either because disclosure is particularly useful in a “stressful situation” (Doctor, ID123), or because disclosure might be less helpful when service-users are in a “negative thought cycle” (Occupational therapist, ID077).

Other mediating factors identified by practitioners suggested that disclosures closer to personal experience can be more effective, but also that disclosures should be close to (or match) the experience of service-users:

“i dont believe saying to the patient 'i have a friend who...' would have held any meaning to them” (Nurse, ID127).

“The person also said it was helpful because they felt I recognised their difficulties. I was very careful to say this was my experience and everyone is different so it is up to them to decide if this is helpful or not.” (Nurse, ID168).

#### **6.4 Sharing Experiences Not Related to Mental Health**

Both service-users and practitioners gave examples of sharing information unrelated to mental health most often, and as with service-users these disclosures covered a broad range of subjects.

##### **6.4.1 Frequency of sharing experiences not related to mental health**

Sharing experiences that were not related to mental health accounted for 62 examples given by 38 service-users.

119 separate practitioners gave 187 examples information not related to mental health.

**6.4.2 Sharing experiences not related to mental health: who is doing it and what they are sharing.**

The most frequent examples of disclosure given by both practitioners and service-users concerned hobbies and out of work interests, and family circumstances. Other types of disclosure were given much less frequently by both groups, and disclosure subjects followed a similar order of frequency. Frequencies and examples of disclosures not related to mental health are shown in table 6.2. They sum to slightly greater totals than to the overall category totals given in section 6.4.1, because some examples of disclosure contained more than one disclosure subject, and were hence coded to more than one category.

Table 6.2: Frequencies and examples of disclosures not related to mental health

Category & Description of mental health-related disclosure	Example Quote: Service-users (n= 62 examples)	Example Quote: Practitioners (n= 187 examples)
<b>Hobbies and out of work interests:</b> including general/unspecified hobbies and experiences, and more specific information about pets and lifestyle, methods of transport, taking holidays, playing musical instruments, the hobbies of family members, hobbies as coping strategies, and fitness and exercise, and family members' hobbies.	"Told me that her son and husband were both petrol heads like me." (ID018)  (n=27)	"Leisure Activities e.g walking, football, cycling." (Nurse, ID012)  (n=86)
<b>Family circumstances:</b> included non-specific information referred to as "family circumstances" and sharing more specific things such as: information about the practitioner's children; information about family make-up; the gender and other information about current or previous partners; information about other family members, such as parents.	"General info about living circumstances (boyfriend, dog, hobbies, what TV they watched etc.)." (ID027)  (n=27)	"I have always been prepared to share some personal information with others such as age, marital status, interest in sports, books etc." (Occupational therapist, ID009)  (n=74)
<b>Physical health:</b> included general, unspecified conditions, PMS (which is taken to mean pre-menstrual syndrome), headaches, having flu, and dealing with joint pain. Occasionally disclosures also referred to the physical health of a family member.	"I have had minor disclosures of physical health problems..." (ID004)  (n=8)	"I shared the fact that I have asthma during a discussion about empowerment/self management/taking personal responsibility for trying to stay well." (Consultant, ID029)  (n=14)
<b>Everyday information:</b> included information that was not attributable to hobbies out of work experiences, usually more about personal dispositions, how the practitioner operates in everyday life, rather than about something that has happened to them.	"[the practitioner was] feeling their age and needed to take more exercise." (ID069)  (n=4)	"service-users have known myself and my family for over 14 years. they listen and laugh about silly things i talk about like a friend" (Health care support worker, ID171)  (n=4)

Chapter 6: Qualitative Results 1: Real Life Examples of Disclosure

Category & Description of mental health-related disclosure	Example Quote: Service-users (n= 62 examples)	Example Quote: Practitioners (n= 187 examples)
<b>Religion or spirituality:</b> information about religious beliefs or spirituality, including atheism.	“Religion” (ID075)  “Spiritual matters.” (ID102)  (n=3)	“I have shared that i have a strong spiritual faith.” (Health care support worker, ID027)  “Atheism - in response to questions from service-user.” (Occupational therapist, ID067)  (n=5)
<b>Sexual orientation:</b> explicit mention of a practitioner’s sexual orientation, rather than implicit through mentioning the gender of a partner, which may or may not indicate sexual orientation.	“A doctors sexuality, the fact they were gay.” (ID075)  (n=3)	“Sexual Orientation and difficulty in ‘coming out’” (Nurse, ID194)  (n=5)
<b>Life experiences:</b> issues that were about previous life events, rather than current hobbies or out of work experiences	“Their experiences” (ID089)  (n=2)	“Information about past education and career choice.” (Nurse, ID128)  (n=17)
<b>Opinions and politics</b>	“That the person is a feminist.” (ID078)  (n=2)	Not mentioned.  (n=0)
<b>Other clients:</b> there was only one example of this, relating to talking about other clients.	“They kept talking about their own life, & other clients (no names were mentioned). Talked about her courses she was going to do. How many cats she had.” (ID065)  (n=1)	Not mentioned.  (n=0)
<b>Personal demographic information:</b>	Not mentioned.  (n=0)	“basic personal info after being asked, age, marital status etc” (Health care support worker, ID024)  (n=5)

Service-users gave the job role of 63 disclosing practitioners, most frequently nurses (n=25), followed by doctors, psychiatrists, GPs or consultants (n=11), and support workers (n=11). To a lesser extent, sharers also included counsellors (n=6), care coordinators (n=3), psychologists (n=2), peer support workers (n=2), social workers (n=2), one unspecified mental health practitioner (n=1), and in two examples job role was not stated. The sum of practitioner job roles exceeds the number of examples given because some examples of disclosure were reported to have been shared by more than one practitioner.

Of the 119 practitioners who gave examples, most were nurses (n=48), followed by health care support workers or assistants (n=20, including associate practitioners and therapy support

workers), occupational therapists (n=16), and doctors and consultants (n=9). To a lesser extent, examples were also shared by clinical psychologists (n=5), therapists (n=5, including psychotherapist, CBT therapist, counsellor, or psychological wellbeing practitioner), physiotherapists (n=3), and 13 single cases from a variety of disparate job roles.

#### **6.4.3 Helpful and unhelpful aspects of sharing experiences not related to mental health**

82% (n=51) of the examples given by service-users, and 96% (n=174) of the examples given by practitioners were of a positive or helpful nature. Service-users reported 13% (n=8) of examples as being negative or unhelpful, while practitioners reported fewer negative examples at 3% (n=5). As with all disclosures, some examples contained both positive and negative elements, contained insufficient information to be assigned as positive or negative, or were neither positive nor negative, for example:

“Was not helpful was just in general conversation.” (Service-user, ID023)

Practitioners mentioned disclosure being automatic or unavoidable more frequently than for mental health or mental health related disclosures. This may be because there were simply less examples of other types of disclosure, but it seems intuitive that more visible aspects of someone’s life are less likely to be deliberately hidden, or felt as if they ought to be hidden, than those that are concealable. There were ten justifications for disclosure linked to automatic or non-deliberate disclosure, including being visibly pregnant (two examples), wearing an engagement ring (two examples), seeing service-users in groups outside of work (one example), because they have a physical sign of a disability, or injury or had been absent from work with illness (three examples), and because their children were known by the children of the service-user (one example):

“service-user has met family and was aware of my daughters pregnancy.” (Support worker, ID011).

“I confirmed I was getting married when the family asked about my engagement ring, as it would have been obvious, due to symbolism of the second ring only a few months later.” (Clinical psychologist, ID066).

“It was obvious that I walked with a pronounce limp and people expressed concern that I could manage to get about. I could then assure people that I could cope.” (Nurse, ID155).

Group work also necessitated or involved disclosure, for example, because a practitioner demonstrated proficiency in a technique or skill in a group work setting (one example), or because sharing life history was necessary during an art therapy class:

“The facilitators participated in order to demonstrate the technique and to aid others engagement.” (Occupational therapist, ID009).

There were many more instances (n=28 compared to just a few in other categories) of practitioners saying they shared because the service-user asked a question of the practitioner which they felt obliged to answer because declining would have been rude or dismissive, or because there was no reason not to share the information and it was part of a reciprocal conversation:

“the patient asked and in order to maintain a therapeutic relationship and not seem rude or dismissive, i replied.” (Doctor, ID122).

“I was asked by a service-user who loves children and has a grandchild the same age. It would have been rude and damaged the therapeutic relationship to refuse to share the information.” (Nurse, ID142).

#### ***6.4.3.1 Helpful examples of sharing experience not related to mental health***

The number of positive, helpful examples given by both service-users and practitioners outweighed the number of unhelpful examples. Most of them concerned disclosures about hobbies and out of work experiences, and family circumstances, but there were also many positive examples of sharing physical health, religion, sexual orientation, everyday information, life experiences, opinions and politics and demographic information.

There was much agreement between service-users and practitioners about the beneficial effects of sharing, and many of these were similar to the benefits of sharing mental health and mental health-related disclosures. Disclosure could help to build relationships, normalise and destigmatise experiences, help service-users to open up about their own experiences, demonstrate empathy, establish practitioner credibility, humanise the practitioner, and promote recovery.

Service-users indicated that disclosures regarding family circumstances, such as struggles looking after children, helped to normalise and destigmatise the service-user's struggles in raising their own children, or produced recovery-oriented outcomes, such as helping service-users to cope by learning new techniques or coping strategies:

“I thought that it was because I was unwell my children wouldn't sleep. But it helped me to realise it wasn't and was normal part of parenting.” (Service-user, ID038, regarding parenting disclosure).

Disclosures regarding hobbies and out of work experiences helped to build rapport and relationships, and promoted recovery by helping service-users to take up meaningful activities. Many service-users also indicated that benefits applied to other types of disclosure, including physical health, everyday information, religion and sexual orientation. Three positive examples were given of the disclosure of sexual orientation, which helped to normalise and destigmatise the service-user's own sexual orientation, and reduced feelings of loneliness or isolation:

“Because I was discussing my sexuality, and my feelings about how revealing my bisexuality would be met by others. I recall her asking 'would it help if I told you that I am bisexual?' and I remember being so relieved that she would understand me, and that I wasn't alone. the conversation is very vivid to this day, even though it occurred many years ago.” (Service-user, ID035, regarding sexuality disclosure).

Physical health disclosures were reported to help build relationships by developing trust and breaking down barriers and power imbalances, and to normalise and destigmatise service-users' difficulties in dealing with conditions. Such disclosures also helped service-users to discuss their own conditions, and reduced fear and worry about them.



Religious disclosure helped to build “build up a connection and mutual respect” (service-user, ID102) for one service-user, while for another sharing “religion & experience of becoming a new mum” helped the service-user to feel that the practitioner could “understand and empathise with anxieties I had” (service-user, ID062).

As with service-users, most of the benefits given by practitioners regarding sharing information not related to mental health appeared to be centred around sharing information about family circumstances and hobbies and out of work experiences (and these were the most frequently shared subjects). For practitioners, the effects of disclosure were broadly similar to those regarding mental health and mental health related disclosures. However, building relationships, rather than recovery, was the most cited benefit, helping the practitioner and service-user to connect or relate better, develop rapport, lower barriers, establish trust, and help the service-user to open up or disclose:

“Helpful has helped build rapport and a therapeutic relationship.” (Occupational therapist, ID013, regarding sharing hobbies, what they had done at the weekend).

“It was an ice breaker, and helped put the patient at ease.” (Doctor, ID056, regarding sharing hobbies, football).

Practitioners indicated that disclosure helped to normalise and destigmatise service-users’ experiences but also helped to normalise therapeutic interactions by having ‘normal’ conversations about ‘normal’ things:

“Helpful has helped build rapport and a therapeutic relationship. Also mirrored “normal” conversations when asking and answering questions.” (Occupational therapist, ID013, regarding sharing the previous weekend’s activities).

Practitioners also mentioned recovery often in relation to promoting positive activities and pursuits, which may perhaps also have an impact on mental health:

“It ‘sowed the seed’.” (Nurse, ID012, regarding sharing information about having attended a football match to encourage the service-user to do the same).

“it helped the service-user to consider long term goals and think about breaking up a daunting task into achievable steps” (Doctor, ID022, regarding disclosure of hobbies and out of work experiences, previous marathon running).

Service-users also spoke about the potential for disclosure to shift the focus in a positive way, lightening the intensity of interactions and making clinical encounters “less tedious” (Service-user, ID047). Practitioners also made several mentions of using disclosure as a deliberate distraction technique, or deliberately shifting the focus in a positive way, to lighten the conversation. For mental health, there was no mention of using disclosure in this way, and there was only one mention of it for mental health-related disclosures.

#### ***6.4.3.2 Unhelpful examples of sharing experience not related to mental health***

The 8 unhelpful or negative examples given by service-users were most frequently in relation to family circumstances (n=3), religion (n=2) then single cases regarding hobbies, everyday information, physical health, personal opinions or politics, and other clients. Service-users reported feeling that practitioners were “offloading” (Service-user, ID026) or that disclosures were made because the practitioner was “unsure what to do within the counselling relationship” (Service-user, ID065). Other unhelpful aspects of disclosure cited by service-users included shifting the focus from the service-user to the practitioner; inappropriate assumptions that the practitioner’s and service-user’s conditions were the same or similar; burdening or distressing the recipients by exacerbating their emotions; and practitioners not making themselves understood. Some of these examples caused a significant amount of distress or unhappiness for the service-user:

“1st time we'd met & she'd visited my house. For the whole time spent talking she could relate everything about me back to her. Very annoying. Refused to see her again.” (Service-user, ID026, regarding disclosure of family circumstances).

“It was unhelpful because it was all about her and not me 'the client'. I was not asked about what I wanted to talk about.” (Service-user, ID065, regarding other clients & hobbies etc).

“I found it extremely unhelpful and upsetting as I felt he was dismissing my experience of pain & disability. I made a formal complaint & was referred to a different specialist who after an arthroscopy told me I needed... knee replacements.” (Service-user, ID075, regarding physical health, experience of dealing with knee pain).

Practitioners gave five examples of sharing information not related to mental health that contained negative aspects.

Religious disclosure was contentious in one service-user and one practitioner example. A service-user reported their sister, but not themselves, became upset when a religious practitioner offered to pray for the service-user and their dying father, though the reason for the upset was not given. Another practitioner reported ongoing difficulty caused by religious disclosure due to the disparity between their and the service-user’s beliefs:

“Unhelpful - this became (and remains) the one thing that the service-user remembers about me, and every time I see him he brings it up, tries to talk to me about my lack of faith.” (Occupational therapist, ID067, regarding religious disclosure).

One of these examples concerned disclosure of a physical health condition to colleagues, where it was felt that their professional views might potentially be seen as biased because of their personal experience:

“In the case of the man whose compression socks were not being put on correctly, after the fourth, fifth... time of finding him at serious risk of compression sores I became quite blunt in my communication, and it is possible that this could be seen as being about having an axe to grind rather than extra insight [i.e. it is possible that my concerns could be dismissed as LESS valid because they were based in my own experience].” (User Involvement Worker, ID018, regarding disclosure of physical health to colleague).

Two examples were given about sharing information about family circumstances. They led to feelings that the conversation had become too personal in the first instance, and in the second that the service-user might have felt the practitioner did not understand their situation. Verified negative consequences were not cited in either case, and in both cases helpful effects were also

indicated regarding building therapeutic relationships and building trust through openness and honesty.

Having shared their out of work experiences with a service-user, one practitioner reflected that doing so might have been intrusive or shifted the focus of the interaction, but these were balanced with potential positive effects, and effects appeared to be hypothetical rather than observed:

“Helpful: builds rapport and trust. Service-user can then see you as a human being, therefore feel more able to disclose information about themselves. Unhelpful: Don't like to go into detail about personal life as find this intrusive, and takes focus away from service-user.” (Nurse, ID169, regarding hobbies and out of work experiences).

In four of the five practitioner-given cases, the negative consequences were potential rather than actual or verified, where the practitioner reflected on what judgments might be made against them, or what could go wrong. The only case of a verifiable negative consequence given by a practitioner related to the sharing of religious beliefs, where the service-user became over-interested in the practitioner's lack of belief. The examples given by service-users were more clear: poorly made disclosures were upsetting and detrimental, mainly because practitioners talked too much about themselves, made inappropriate comparisons, or disclosed for inappropriate reasons such as offloading or because they lacked other skills. In a couple of cases disclosure caused disengagement.

#### ***6.4.3.3 Mediators of disclosures not related to mental health***

Service-users mentioned several aspects of disclosure that might be described as mediating effects in some way, or that related to how disclosure was managed. They included whether the service-user was asked if they wished to receive disclosure; the quality of the relationship; whether the service-user had asked a direct question; whether there was a shared experience or interest; whether comparisons were fair, or information was relevant; and how much information was given and how often.

Practitioners, like service-users, recognised the advantage of limiting the amount of information shared to avoid focus shift, and this was also a feature of mental health and mental health-

related disclosures. However, limiting disclosure too much might inhibit the effectiveness of disclosure in some circumstances, highlighting the need for practitioners to plan in advance what they were and were not willing to share so that disclosures could be made in a meaningful and effective manner:

“[Disclosure] was helpful as it encouraged others to participate and there was some joint expression of things that we enjoyed or didn't enjoy though our lives. However this was occasionally superficial because of concerns related to the potential power of the medium to breakdown boundaries. This should have been considered as part of the participatory group particularly in terms of the leaders relationships to the participants....You have to know where your own limits are and tell someone if they are getting too personal, as long as you are polite, respectful and consistent then this is not a problem.” (Occupational therapist, ID009).

The nature of the service-user's illness, setting, personality, traits, or situation was a factor for several practitioners who felt that these may have a bearing on whether disclosure should be made and the effects it might have, for example, disclosure might be helpful to: develop rapport with people with learning disabilities; reduce a service-user's paranoid delusions about NHS practitioners; help to keep conversation going when people with cognitive impairment are having difficulty with recall; challenge the expressed view of service-users who feel practitioners cannot understand them; and be particularly relevant to women who may be more likely to share naturally or use disclosure to help them feel more comfortable and at ease.

### **6.5 Why Practitioners Do Not Share Lived Experience**

Service-users put forward various reasons why they think practitioners do not share information with them, while practitioners revealed their reasons for not sharing. All service-users were asked this question, since even those who had received disclosure on some occasions might not have received it on others, but only non-disclosing practitioners were asked for their reasons for not disclosing. 68 service-users and 47 practitioners gave a written response. Mostly, non-disclosing practitioner respondents were doctors, nurses, and health care support workers, in almost equal numbers, accounting for 37 of the respondents. There was a lot of similarity in the responses given by service-users and practitioners.

Most commonly, service-users said that they thought practitioners did not disclose in order to maintain professional boundaries, professional distance, and professionalism. This was mirrored by practitioners, for whom this was also the most commonly given reason for not disclosing. They felt disclosure may lead to boundary transgressions, loss of professionalism, and inappropriate relationships. There were indications that being personal is not professional, and being professional means not being personal.

Vulnerability and various forms of risk were the second largest reason why service-users thought a practitioner might not share their lived experience, and the third largest for practitioners. Risks cited by service-users included making the practitioner “vulnerable” (service-users, IDs 093, 096); information being “misconstrued” (service-user, ID 021); sharing being “dangerous” (service-user ID 107); the potential for “misuse” (service-user, ID043) and “abuse” (service-user ID057) of information; to maintain “safety” (service-user, ID090); burdening or distressing the service-user (service-users, IDs 011, 086); and “accidentally saying too much” (service-user, ID095). Practitioners mentioned similar risks, with the addition that disclosure might damage the therapeutic relationship; lead to stalking; and be especially risky if users have “offending histories” (Forensic psychologist, ID093).

Service-users felt that practitioners may not disclose in order to maintain confidentiality and privacy, because personal information is not “the service-user’s business” (service-user, ID030) or that practitioner’s experiences are “personal” (service-users, IDs 023, 086, 088, 091). Such sentiments were echoed by practitioners, who suggested “my life is personal” (Nurse, ID125), or simply cited “confidentiality” (Health care support workers, IDs 112,129).

One of the major potential drawbacks of disclosure, and a potential reason why service-users thought practitioners might not share lived experience, was because disclosure might shift the focus of interactions from the service-user to the practitioner. This was also the second most frequent concern for practitioners.

Other reasons for non-disclosure cited by both service-users and practitioners included: maintaining objectivity and impartiality; avoiding influencing the service-user; disclosure being seen as irrelevant and of no benefit; the nature of a service-user’s illness, for example, not being able to understand what is said to them; and the practitioner’s personal preference.

A couple of service-users suggested practitioners do not share in order to maintain power and control, and one indicated they would have liked disclosure because it might have alleviated some feeling of unfairness about the lack of reciprocity in the relationship:

“I think some staff like to have the upper hand and if they say anything about their selves it will make them feel they haven’t got the same control.” (Service-user, ID033).

“I don't know but think it would be nice if I knew something about them. My CPN knows everything about me.” (Service-user, 037).

One relatively minor reason service-users gave for practitioner non-disclosure was because they thought they had been told or trained not to disclose, either “during their training” (service-user, ID035) or in order to “remain within the NHS code of conduct” (service-user, ID047). Explicit and implicit pressure against disclosure was a bigger concern to practitioners, not only in response to the question about non-disclosing practitioners, but elsewhere in the survey too.

Pressures cited by practitioners against disclosure included therapeutic models, being instructed not to disclose through training, professional codes of conduct, or employment contracts, facing negative judgment from colleagues, feeling threatened by potential disciplinary action, believing disclosure is unethical, believing that disclosure is unprofessional, and because there is a lack of guidance about disclosure:

“The psychotherapeutic training and model does not encourage personal disclosure; although not presenting as a completely "blank slate", the therapist's role is to remain opaque sufficiently to foster transference / unconscious projections that can be worked with in treatment.” (Psychotherapist, ID144).

“unsure how [disclosure] would be viewed by my manager or others in the team.” (Nurse, ID003).

“is embedded in me from my nurse training years ago in the 1980's. At that time it was deemed not appropriate to share personal information for fear of leaving yourself vulnerable.” (Nurse, ID071).

“It would be good to have some clarity on this in terms of professional guidelines, so that a professional can be assured they are not breaching their code of conduct in any way by sharing such information.” (Occupational therapist, ID089).

22% (11 out of 49) of non-disclosing practitioners cited some form of perceived pressure against disclosure, while elsewhere in the survey 17% (26 out of 151) of disclosing practitioners mentioned similar concerns. If this is expanded to include less specific forms of pressure, such as feeling the need to avoid being judged as ‘unprofessional’, then these figures rise to 55% of non-disclosing practitioners (27 of 49), and 32% of disclosing practitioners (73 of 151 respondents). This suggests that explicit and implicit pressures may influence non-disclosing practitioners more than disclosing practitioners, but that they also influence a substantial proportion of all practitioners, whether they disclose or not.

Unlike service-users, several practitioners cited the existence of *alternatives to disclosure* as a reason not to disclose, suggesting that: “empathy rather than sympathy” might be adequate (Social worker, 007); using “immediacy” may be preferable (Counsellor, 055); or giving “case studies without stating [it is] you they concern” (Nursing assistant, ID048).

### **6.6 Whether practitioners would feel differently about sharing if they were in a different job role**

All practitioners were asked if they would feel differently about sharing if they were in a different job role. Most (83%) of the non-disclosing practitioners said they would not feel differently. Their reasons for non-disclosure were supplied under the question asking why they do not disclose, and no further clarification was sought. Only those who said they would feel differently indicated why.

Of the 8 non-disclosing practitioners who said they would feel differently if they had a different job, the majority were psychologists, psychotherapists or doctors. Generally they felt that their position of authority and responsibility necessitated strict, non-disclosing boundaries, and they would feel more comfortable disclosing in roles with less responsibility where there was an opportunity to forge a different type of relationship. One doctor noted that maintaining strict non-disclosing boundaries was necessary when being responsible for depriving people of liberty, while a forensic psychologist felt that disclosure might indicate a lack of professional



competence:

“As a doctor I feel boundaries are particularly important because with so many patients our role can involve in treating patients against their will and obviously fundamentally shifting the therapeutic relationship e.g. by detaining someone - therefore overall I think it is fairest to patients to maintain fairly strict boundaries around our professional relationships.” (Doctor, ID81).

“If I did not hold so much clinical responsibility also I think the SU would be less likely to see a lack of professional competence.” (Forensic psychologist, ID93).

There were 50 disclosing practitioners who said they would feel differently about disclosing if they were in a different role. They came from a wide range of job roles, and within job roles there were wide ranging reasons for feeling different about disclosure if they were in another position. Overall, though, the most numerous job role/setting was forensic services, which was mentioned by 9 respondents who generally fell into two categories: those who did not work in forensic services said they would feel less inclined to disclose if they worked in forensic services, and those who worked (or had worked) in forensic services felt they would be more inclined to disclose outside of those settings. The reasons given were due to risk of information being used against practitioners, and personal safety. The second most numerous job role mentioned (by 5 respondents) was that of peer support worker, with respondents outside of the peer support role indicating they would share if they were peer worker, and one peer worker indicating they would feel less inclined to disclose outside of that role. Four respondents indicated they would not disclose in non-clinical roles, because the role was not clinical and did not involve supporting service-users or spending much time with them.

### **6.7 Validity Check**

Both practitioners and service-users reported that practitioners share personal mental health information least, followed by information related to mental health, and most frequently share information not related to mental health. Personal mental health information was not broken down into sub-categories in this analysis, but the other two categories were. Within the category of information related to mental health, sub-categories were mostly in the same order of frequency for both practitioners and service-users, with just one exception (work experiences

and stress) causing a minor change to the order for service-users. Looking at the category of information not related to mental health, again a similar pattern emerged for both service-users and practitioners: sub-categories mostly followed the same order of frequency with a couple of exceptions for service-users which altered the frequency pattern slightly. Since practitioners and service-users were largely in agreement about what was shared and how often it was shared, this suggests that bias, if it was operating, either affected both types of respondent in the same ways, or respondents reported fairly accurately what was shared in real life situations. It seems unlikely that bias would operate in the same way for service-users as it would for practitioners because, for example, they may each face different pressures regarding the social desirability of certain types of disclosure, and because respondents might be more likely to remember disclosure topics that they find most or least helpful, and which may differ between practitioners and service-users (see the helpfulness ratings for hypothetical disclosures in chapter 7, next).

The second indication of validity was that both practitioners and service-users reported that sharing all types of information was mostly helpful, with unhelpful disclosures being made in a small minority of cases. It therefore seems likely that this study captured a reasonably accurate picture of what practitioners shared in real life situations.

### **6.8 Conclusion**

Personal mental health was the least often shared type of lived experience, but examples of such disclosures included both low level and more severe experiences and conditions, and the vast majority of these, as with all types of disclosure, were helpful. Unhelpful disclosures, where they occurred, tended not to be dramatic or of great concern. In the very few cases that were of more concern, it was questionable whether disclosure had taken place and whether non-disclosure would have removed the risk. Poor disclosures were not restricted to the topic of personal mental health, but included physical health, religion, and the more commonly shared extratherapy topics, such as home life and family pets. Since validity checks indicated much agreement between service-users and practitioners regarding the sharing of lived experience and its helpfulness, it may be concluded that responses were a fair reflection of what happened in real life, rather than subjectively biased accounts. Disclosures of personal mental health lived experience promoted recovery, helped service-users to feel understood, demonstrated empathy, reduced stigma and normalised experiences, and enhanced the credibility of

practitioners' knowledge. Practitioners mentioned mediating factors often, and several indicated that they sought or received verification of effects of disclosure from service-users, indicating they share with care, consideration and reflection.

Many of the benefits of sharing personal mental health lived experience, such as destigmatisation, hope for recovery, and feeling understood, were also achieved by sharing information related to mental health, such as every day struggles, for example, low mood, phobias, anxiety or stress that would not or did not receive treatment or diagnosis.

Similarly, many of the benefits associated with sharing mental health experiences were also associated with sharing experiences unrelated to mental health, but in different ways. For example, sharing parenting experiences may help service-users to understand that parenting difficulties are a normal part of parenting, and not necessarily caused by their mental health difficulties. In this way, disclosure could destigmatise life struggles, and help to avoid compounding self-stigmatisation of such struggles with mental illness.

In light of this, sharing mental health related and non-mental health related information may be of use to practitioners who do not have personal mental health lived experience, or to those who do not wish to share it. Whether the degree or intensity of helpfulness was similar across disclosure types is explored in chapter 7, next, which considers how different types of disclosure were rated for their perceived helpfulness.

Non-disclosing practitioners tended to indicate that they would not feel differently about disclosing if they were in a different job role, indicating that they may have a fixed attitude towards disclosure. Half of disclosing practitioners said they would feel differently about disclosing in a different job role, perhaps indicating a more reflective and flexible attitude to disclosure.

Despite all of the benefits of sharing life experiences, including mental health experiences, some practitioners reported feeling pressured to avoid disclosure by therapeutic models, colleagues, codes of ethics and conduct, and training.

## **Chapter 7: Qualitative Results 2: Hypothetical Disclosures**

### **7.1 Introduction**

'Hypothetical' disclosures refer to the 7 types of disclosure that a practitioner might make to a service-user. They are labelled as hypothetical because they do not refer to past experiences of actual disclosure, but to potential future experiences.

What follows is an analysis of how many respondents made positive, negative, and mediating statements in relation to the unhelpful, middle and helpful ratings of 7 types of hypothetical disclosure that a practitioner might make. It is not an analysis of the number of positive and negative statements made. The total number of respondents making positive, negative and mediating factors may be more than the number of respondents who answered each question, because each respondent might make mixture of positive, negative and mediating statements.

Some descriptive quantitative information is also provided in this chapter where relevant, but detailed quantitative analysis of ratings scores is given in Chapter 5.

### **7.2 Overall Patterns Across All Seven Disclosure Subjects**

When practitioners and service-users gave unhelpful ratings across all seven disclosure subjects, most mentioned negative potential effects of disclosure, very few mentioned positive effects, and very few mentioned mediating factors that might affect whether a disclosure was helpful or unhelpful. This suggests they both viewed all types of disclosure as mainly negative, with few, if any, redeeming features.

When practitioners and service-users gave middle ratings to disclosures, there was greater balance between the number of respondents who gave positive, negative and mediating statements.

On helpful ratings, the pattern for service-users was the reverse of that seen in relation to unhelpful ratings: most service-users made positive statements, and few made negative statements. Few also made mediating statements in relation to helpful ratings. This suggests that these service-users viewed all types of disclosure as mainly positive, with few drawbacks.

Similarly, in relation to helpful ratings, many practitioners made positive statements, relatively few made negative statements, and the proportions were similar, but in reverse, to those made in relation to unhelpful ratings. However, practitioners mentioned many more mediating factors when they gave helpful ratings compared with unhelpful ratings: 3 times as many regarding personal mental health, 3 or 4 times as many regarding mental health-related disclosures, and between 2 and 7 times as many regarding non-mental health disclosures. A greater proportion of practitioners made negative statements and mentioned mediating factors compared to service-users. This suggests that practitioners who rate disclosure as helpful take a more rounded view of the potential positive and negative effects of disclosure than those who rate disclosure as unhelpful.

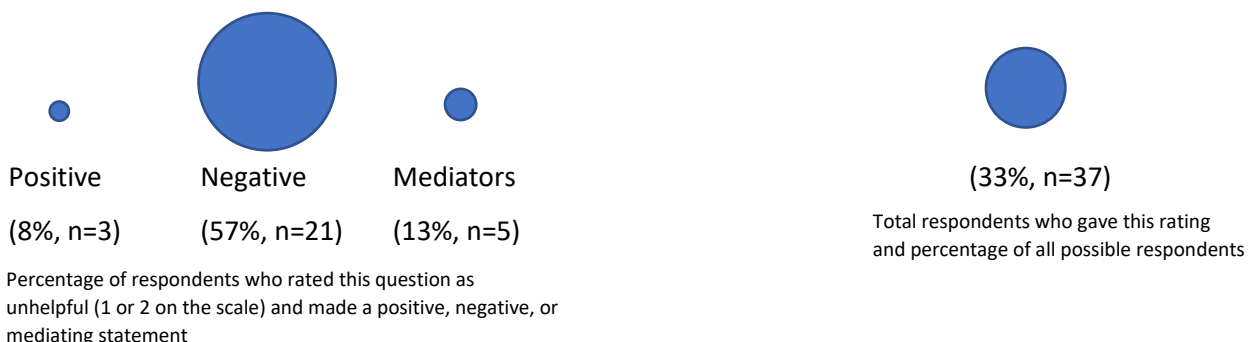
### **7.2.1 Unhelpful ratings**

#### ***7.2.1.1 Unhelpful ratings of sharing personal mental health lived experience***

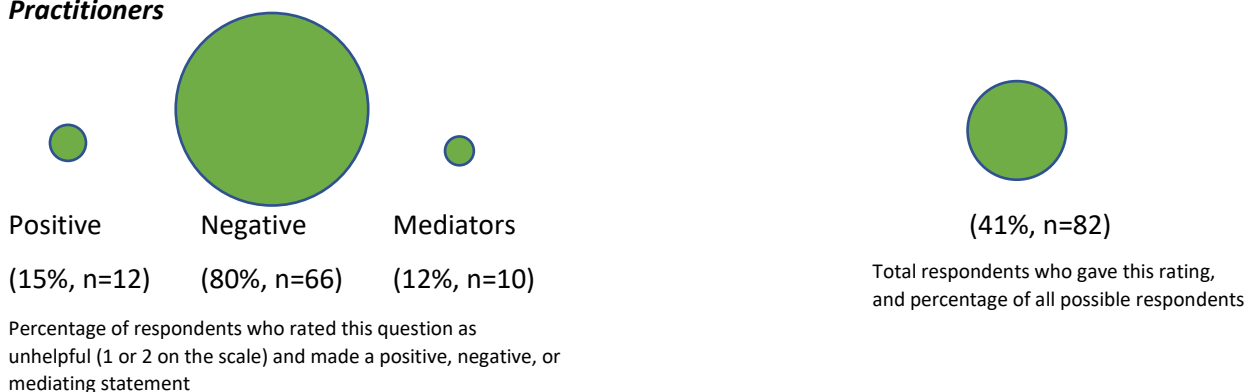
The majority of service-users who rated sharing personal mental health lived experience as unhelpful mentioned negative potential aspects of sharing when giving reasons for their ratings. Relatively few of this group of service-users mentioned positive effects. The same was also true of practitioner respondents and, although practitioners were more likely than service-users to acknowledge potential positive effects, they did so infrequently. Figure 7.1, below, gives a visual representation of the proportions of service-users and practitioners who made positive, negative and mediating statements.

Figure 7.1: Sharing personal mental health lived experience: ratings of 1 or 2, unhelpful

**Service-users**



**Practitioners**



First, a greater proportion of practitioners than service-users rated sharing personal mental health lived experience as unhelpful, 41% (n=82) compared to 33% (n=37).

Potential positive effects were in the minority. 3 out of 37 service-users (8%), and 12 out of 82 (15%) practitioners mentioned them. Those mentioned by service-users included reducing feelings of loneliness and isolation, and helping the practitioner relate to the service-user more effectively. Practitioners mentioned potential positive effects which included enhancing the service received; demonstrating recovery; normalising experiences; sharing coping and recovery strategies; increasing mutual understanding; reducing barriers between practitioners and service-users or the ‘them and us culture’; and humanising the practitioner.

Just over 10% of service-user and practitioner respondents qualified their responses by mentioning mediating factors that might affect whether a disclosure was helpful or unhelpful. This suggests that those practitioners and service-users who viewed sharing personal mental

health lived experience as unhelpful tended to express their views in a partial manner without, in the main, considering competing views.

Service-users mentioned mediating factors such as: whether service-users had been asked if they wished to hear the disclosure; disclosure subject matter; whether experiences are similar in nature; limiting the disclosures in terms of frequency and detail; and which service-user the disclosure is made to. These were mentioned rarely, but where they were mentioned it was often indicated that disclosure might be more helpful if such issues were taken into account.

Mediating factors for practitioners included: the motivation and rationale for sharing, including whose benefit it is for and whether the practitioner is offloading; service-users' circumstances, context, illness severity and ability to understand information; practitioner levels of comfort in sharing, how discomfort might perpetuate stigma, and comfort with information being shared and known more widely; practitioners' skills, knowledge and experience; and the maintenance of boundaries.

80% of practitioners (n=66) compared to 57% (n=21) of service-users mentioned potential negative effects of sharing. This may be a result of an overall tendency for practitioners to give longer and more varied written responses throughout the survey, perhaps due to higher levels of illness in the service-user population than the practitioner population at the time of responding. It may also indicate that practitioners think about disclosure in more detail than service-users do, perhaps due to an understandable desire to justify practice interventions which service-users would not feel similarly pressured to do.

Practitioners and service-users were often concerned about similar things. The greatest concern was with potential focus shift, and they also mentioned similar concerns regarding comparisons of dissimilitude, conveying practitioner illness or weakness, and undermining practitioner professionalism in some way:

“A practitioner "hi-jacking" the time from his service-user, to talk about him/herself cannot in any way be helpful.” (Service-user, ID107)

“In my role as a practitioner the focus should be on the service-user and to share my own details puts the focus on me. It may also influence how they view me and they become concerned etc particularly if they have a tendency to ‘look after others’.” (Psychological wellbeing practitioner, ID113)

“I feel shared information would be unhelpful because mental illness affects each individual differently. (Service-user, ID058)

“Sometimes I do not like sharing my experience due to not wanting to be a burden. If I believed they suffered any mental health issues, I would not share the more detestable aspects of my life.” (Service-user, ID019)

Practitioners additionally mentioned that disclosure might interfere with the therapeutic model, including transference and counter-transference, and placed more emphasis on the effect that disclosure might have on the relationship and boundaries, and on whether disclosures might burden or distress the service-user:

“It would go against the therapeutic model to do so, preventing the development of transference, projection and unconscious phantasies which are a mainstay of therapy.” (Psychotherapist, ID144)

“Depending on individuals mental health problem, there is a risk of breaking down of therapeutic boundary/ relationship, which is very important for a doctor/ psychiatrist to treat a patient.” (Doctor, ID177)

#### ***7.2.1.2 Unhelpful ratings of sharing difficult or traumatic experiences***

The overall pattern of positive, negative, and mediating factors associated with the sharing of difficult or traumatic experiences mirrored that seen in Figure 7.1 regarding sharing personal mental health lived experience: the majority of both service-user and practitioner respondents mentioned negative aspects of sharing, while a minority mentioned potential positive aspects and mediating factors.



The potential for disclosure to burden or distress service-users was mentioned more often in relation to sharing difficult or traumatic experiences than sharing personal mental health lived experience, by both service-users and practitioners. It indicates an expectation that talking about trauma might itself be traumatic:

“Unhelpful - would be very distressing for me to deal with and process their trauma.” (Service-user, ID110)

“Service-users do not need to know about any traumatic experiences i have had in my life i think they have enough of there own to deal with without me telling them mine and also it is confidential to myself.” (Health care support worker, ID130)

Conversely, disclosing difficult or traumatic experiences was less frequently seen as likely to shift the focus of the interaction away from the service-user, and also less frequently seen as raising concerns about practitioners’ illness or weakness, than for mental health disclosures. It is not clear why this might be the case, but it is possible that difficult or traumatic experiences might be perceived as external to the practitioner; events that perhaps acted on, rather than within, them. If this is the case, then disclosers might be less likely to get ‘wrapped up in themselves’ when describing external, factual events, hence creating less concern for focus shift, than if they were disclosing internal, emotional concerns such as mental health lived experience. If difficult or traumatic events are viewed as external actors, they might also be less likely to indicate internal deficits on behalf of the discloser, hence giving rise to fewer concerns about practitioners’ ‘wellness’ or practice performance.

### ***7.2.1.3 Unhelpful ratings of sharing information about the mental health of a family member or friend***

Sharing information about the mental health of a family member or friend, for both practitioners and service-users, was less often associated with burdening or distressing service-users than the disclosure of mental health lived experience. It may be because such experiences are viewed as less potent and less personal, being removed from the personal experience of the practitioner. This type of disclosure is also less frequently associated with concerns about professionalism and practitioner illness or weakness, perhaps because again they do not indicate practitioner

deficit. Whereas these concerns are reduced, others are increased for both practitioners and service-users, including such disclosures being seen as less relevant and as more private and personal to the person being disclosed about. New concerns were raised about confidentiality and consent not only in respect of the person about whom the disclosure is being made, but also, for practitioners, about the potential for service-users to assume their confidentiality might be similarly breached:

“The friend/family may not have consented so I don't think it is appropriate.”  
(Service-user, ID090)

“Again it is not professional to give information about someone else. This may have serious consequence of patient losing trust in my adherence to confidentiality.” (Consultant, ID197)

#### ***7.2.1.4 Unhelpful ratings of sharing information not related to mental health***

For service-users, unhelpful ratings of sharing information not related to mental health followed the same patterns as for mental health and mental health-related disclosures. Most respondents mentioned potential negative aspects of sharing, relatively few mentioned potential positive effects, and few mentioned potential mediating factors.

Services users had least to say about sharing hobbies compared to all other types of disclosure. Hobbies were seen as largely irrelevant by many negative-rating service-users, negating the need for further elaboration or reasons for unhelpfulness:

“I don't think somebody's social life has any realistic benefit to any part of my life.”  
(Service-user, ID097)

However, some service-users did mention potential positive effects alongside potential negative effects:

“Depends if it is to build rapport/make client feel comfortable, but need to be careful not to develop unequal relationship e.g. what if client really poor and can't afford holidays.” (Service-user, ID064)

Practitioners' responses also followed mainly the same pattern as for disclosures about mental health and mental health-related disclosures. There was a heavy emphasis on negative effects, little emphasis on positive effects, and little focus on mediators.

Of the non-mental health-related disclosures, sharing religion attracted most negative comments from practitioners. Practitioners variously viewed religion and religious disclosure as having the potential: to cause, contribute to, or exacerbate mental health conditions; to be irrelevant; to impose religious beliefs on others; to create clashes between practitioners and service-users regarding personal values and beliefs; and to interfere with transference. Religious disclosure might also be negated because practitioners do not have any faith to share, or be avoided because of practitioners' anti-faith or atheistic views.

### **7.2.2 Middle ratings**

These ratings were not generally 'neutral' or ambivalent, and did not merely represent default positions for respondents who could not decide on a helpful/unhelpful rating. They represented complex considerations of how contextual factors might affect disclosure outcomes. Overall, both service-users and practitioners mentioned mediating factors more often in relation to middle ratings of disclosure than in relation to unhelpful ratings, ranging from twice as often to 48 times more often. Middle ratings of sharing personal mental health lived experience might therefore be described as 'context driven'.

#### ***7.2.2.1 Middle ratings of sharing personal mental health lived experience***

Compared to respondents who gave unhelpful ratings, double the number of service-user respondents and four times the number of practitioner respondents mentioned mediating factors in relation to middle ratings of sharing personal mental health lived experience.

Mediating factors that affected whether a disclosure would be helpful or unhelpful tended to focus on 'helpful if' statement rather than 'unhelpful if' statements:

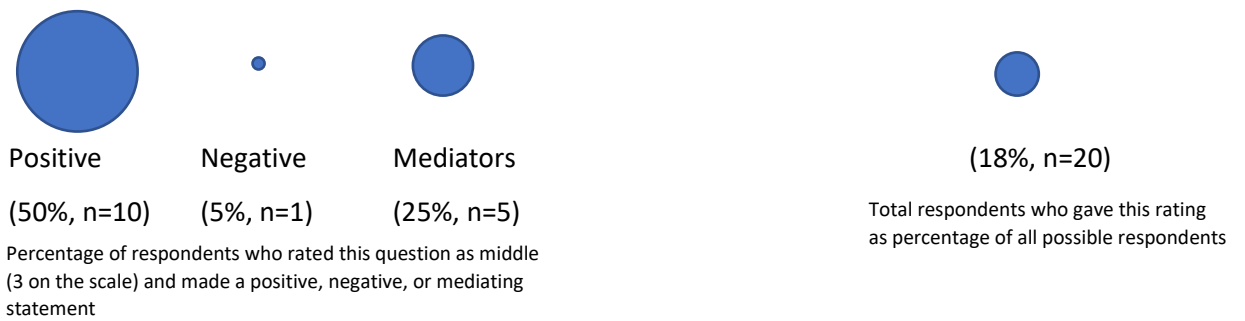
"It would depend why they shared and if was relevant to me. If it helped me to understand myself better it would be helpful." (Service-user, ID038)

Half of service-user respondents mentioned positive aspects of personal mental health disclosure, sometimes accompanied by mediating factors. Negative references were almost absent.

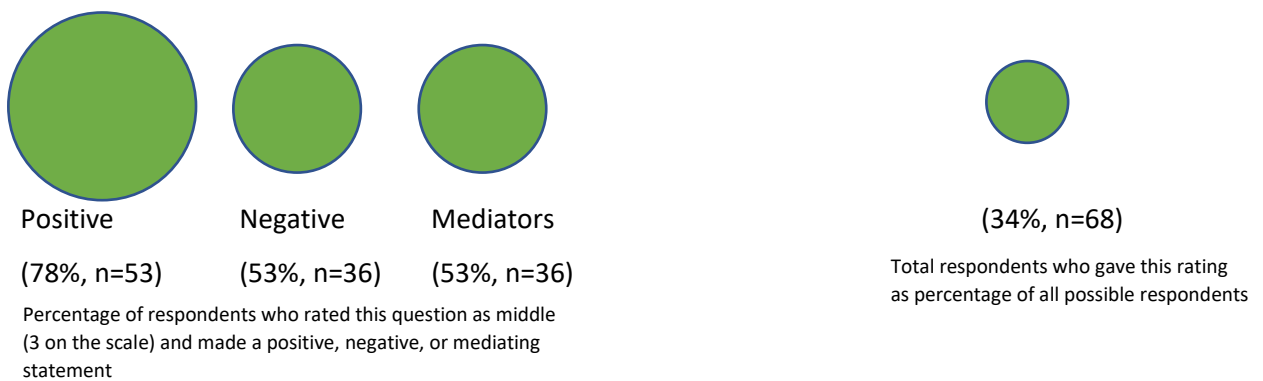
Most practitioners (78%) also mentioned positive aspects of disclosure, but about half also mentioned negative aspects. About half of practitioners also mentioned mediating factors that might affect the helpfulness of disclosures, double the frequency of service-users. Figure 7.2 illustrates the percentage of respondents who made statements that were coded as either positive, negative, or mediators, for ratings of 3 on the scale (middle, or context-driven).

Figure 7.2: Mental health ratings of 3: middle, or context-driven

**Service-users**



**Practitioners**



It is possible that practitioners mentioned positive things and mediators more often than service-users because practitioners gave more detailed answers in general throughout the survey. However, the overall pattern is visually different for practitioners and service-users. It suggests that, when respondents rated sharing personal mental health lived experience as

context-driven (3 on the scale), a substantial proportion of practitioners considered the issue in rounded way, weighing up both positive and negative potential effects, and qualifying their views with mediating factors:

“I don't feel able to say this would be helpful or unhelpful as it would depend too much on the circumstances and the type of information shared and the reason behind this. i.e: Helpful if the person can use this experience to empathise and provide support and/or hope to the service-user. Unhelpful if this experience is on-going or unresolved and service-user feels a sense of responsibility or stress from learning this information or if the level of detail is inappropriate or triggering for that person.” (Occupational therapist, ID021)

Although service-users qualified their responses with mediating statements, they did so less often than practitioners, and hardly mentioned potential negative effects at all, suggesting they viewed disclosure in a less rounded way than practitioners did, and there was a tendency to think of disclosure as ‘positive if’ rather than ‘negative if.’

The main positive themes identified by service-users included disclosure helping to normalise and destigmatise mental illness and experiences, and helping to increase their knowledge or understanding in some way, perhaps by having greater insight into the causes of mental illness and understanding themselves and others better.

For practitioners, the main positive themes included helping the service-user to feel understood through demonstrating personal insight, and normalising and destigmatising service-users’ experiences. Practitioners were more aware than service-users about how disclosure might help build trusting relationships, and enhance recovery and hope for recovery. They were also more concerned than service-users regarding potential mediating and negative factors, such as making disclosures of dissimilitude, or shifting the focus away from the service-user towards the practitioner.

### ***7.2.2.2 Middle ratings of sharing difficult or traumatic experiences***

Those service-users who rated sharing as context-driven were more likely to make positive statements regarding the sharing of difficult or traumatic experiences and were five times more likely to mention mediating factors than those who gave unhelpful ratings. They also mentioned negative aspects of disclosure more often than they did for sharing personal mental health lived experience on the same rating. This indicates that service-users felt that sharing difficult or traumatic experiences may be positive and helpful if done in the right way, but may require more careful management than sharing personal mental health lived experience. Compared to sharing personal mental health lived experiences, sharing difficult or traumatic experiences was less frequently cited as helping to normalise or destigmatise service-users' experiences, and more frequently seen as potentially leading to disclosures of dissimilitude. It may be that with mental health disclosures some similarity of experience is assumed, whereas external experiences may be more disparate.

A similar pattern emerged for practitioners: those who gave middle ratings gave more equal consideration of positive, negative and mediating factors than those who gave unhelpful ratings. It suggests that higher scores are accompanied by more complex thought processes. Practitioners mentioned negative factors less than they did for sharing personal mental health, indicating perhaps that sharing difficult or traumatic experiences is less risky, which may be because it is assumed to be less about the person, and more about dealing with external events.

### ***7.2.2.3 Middle ratings of sharing information about the mental health of a family member or friend***

Sharing the mental health of a family member or friend followed the same pattern as sharing difficult or traumatic experiences, for both service-users and practitioners who gave a rating of 3 on the scale. They focused heavily on positive and mediating factors. They also focused to a significant extent on negative factors, more so for service-users than for sharing personal mental health, but less so for practitioners. It suggests a complexity and balance of thought processes, but also a bias towards 'positive if' rather than 'negative if' views.

Practitioners frequently cited disclosure of personal mental health and the mental health of a family member or friend as helping service-users to feel understood, indicating they see second

hand experience as helpful in similar ways to first-hand experience. Although service-users did not mention this to any great extent, they frequently mentioned that disclosure might be helpful as long as there is similarity of experience. Practitioners may therefore assume similarity, whereas service-users do not take that for granted.

#### ***7.2.2.4 Middle ratings of sharing information not related to mental health***

For both practitioners and service-users, compared to unhelpful ratings on the same subjects, middle-ratings of disclosure not related to mental health showed more positive, fewer negative, and more mediating factors. This pattern was also observed for mental health and mental health-related disclosures, comparing middle ratings to unhelpful ratings. It indicates a consistent tendency to consider and balance competing views of disclosure, weighing up potential positive and negative effects, nuanced by consideration of mediating factors that might influence effects in either positive or negative directions.

For both practitioners and service-users, sexual orientation was often seen as either irrelevant, with indifference, or only relevant to disclose where there is a shared, minority (lesbian or gay) issue, and where it was necessary to address mental health issues connected with sexual orientation or help someone to disclose their sexual orientation. Religion was seen by many service-users as irrelevant or simply with indifference. However, for practitioners there were wider ranging views about whether faith was shared, the importance of spirituality to mental health and recovery for some people, and whether it were necessary to address service-users' personal struggles with religion and belief.

### **7.2.3 Helpful ratings**

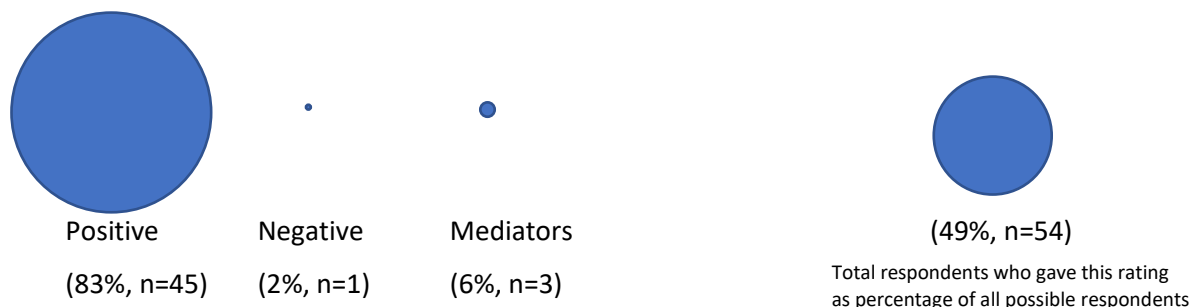
#### ***7.2.3.1 Helpful ratings of sharing personal mental health lived experience***

Over 80% of both practitioners and service-users who rated the sharing of personal mental health lived experience as helpful mentioned positive aspects of disclosure, while only a minority of each mentioned negative effects. For service-users, the near absence of mediating factors suggests one-sided, partial view of disclosure. However, about a third of practitioners mentioned mediating factors that might affect helpfulness, and a significant minority (14%, n=7) of practitioners mentioned negative potential effects too, suggesting that a substantial

proportion of practitioners felt that helpfulness was contingent, not fixed, and that practitioners, more so than service-users, viewed the subject from multiple perspectives.

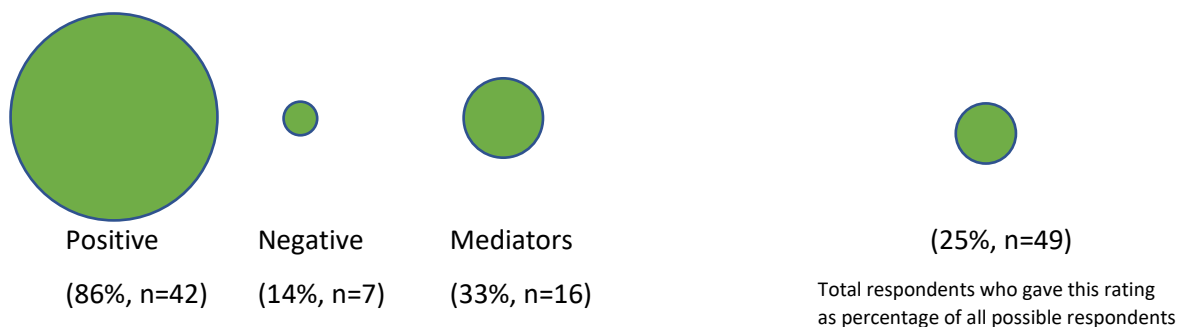
Figure 7.3: Mental health ratings of 4 or 5: helpful

**Service-users**



Percentage of respondents who rated this question as helpful (4 or 5 on the scale) and made a positive, negative, or mediating statement

**Practitioners**



Percentage of respondents who rated this question as helpful (4 or 5 on the scale) and made a positive, negative, or mediating statement

There was close similarity between the key themes mentioned by practitioners and those mentioned by service-users, including the frequency with which they were raised. Potential positive effects of disclosure included normalising and destigmatising service-users experiences:

“could be helpful to service-users so they know that they are not alone with their experiences and that mental health difficulties can be experienced in all walks of life.” (Clinical psychologist, ID033)

“shows empathy, give first hand experience and alleviates some of the stigma as if 'they' suffer then it engenders 'its not just me then' feelings.” (Service-user, ID005)



Other positive effects included authenticity, empathy, building trusting relationships, helping service-users to feel understood through the demonstration of personal insight, enhancing recovery and the hope for recovery, and, more frequently for service-users than practitioners, establishing practitioner credibility:

“It would make people feel a lot more comfortable to know a professional has gone through/is going through a similar situation. It could get people to open up more and let them know that the practitioner can actually relate, instead of sounding like they are repeating a medical textbook.” (Service-user, ID068)

“I would trust their judgement much more. I would know their advice came from experience & not just from their educational qualifications - BIG DIFFERENCE.” (Service-user, ID020)

This suggests that rather than shifting the focus of interactions, disclosure may lead to better interactions that are more focused on the service-user and their issues.

### ***7.2.3.2 Helpful ratings of sharing difficult or traumatic experiences***

For service-users, sharing difficult or traumatic experiences followed the same pattern as for sharing personal mental health lived experience on the same rating. Mostly statements were of a positive nature, and there were hardly any negative statements. This suggests a one-sided view of disclosure, rather than balancing positive and negative factors against one another. There were, however, increased mediating factors associated with sharing difficult or traumatic experiences, compared to personal mental health, and they were most commonly concerned with ensuring similarity of experience. It may be that similarity of experience is more likely to be assumed when disclosures about mental health than when they are about external factors that service-users may or may not have experienced themselves.

For practitioners, sharing difficult or traumatic experiences was similar to sharing personal mental health lived experience: mainly positive, with some consideration of negative factors, and substantial and consistent consideration of mediating factors. Mediating factors were mentioned at similar levels to middle-ratings on the same disclosure subject. This suggests that

practitioners not only considered multiple perspectives when they gave middle ratings of sharing personal mental health and mental health-related information, but they also did so when they rated such disclosures as helpful. Their responses were not polarised in the same way as they were for negative ratings. They were also less polarised in their views than service-users.

For service-users, the most frequently cited issues associated with sharing difficult or traumatic experiences were in relation to recovery, feeling understood, and normalising and destigmatising mental illness. Practitioners also mentioned similar issues. There was most negative concern about potential dissimilitude of disclosure in relation to difficult or traumatic experiences, but the numbers were low.

### ***7.2.3.3 Helpful ratings of sharing information about the mental health of a family member or friend***

A similar picture emerged regarding the sharing of information about the mental health of a family member or friend as described in section 7.2.3.2, above. Again, it suggests that practitioners who viewed disclosure as helpful justified their position in a more balanced way than practitioners who rated disclosure as unhelpful, and more so than service-users.

### ***7.2.3.4 Helpful ratings of sharing information not related to mental health***

Service-user respondents were heavily disposed towards making positive statements, with almost no negative statements at all, and few mediators. The greatest proportion of mediating factors were mentioned in relation to religion, and suggested that sharing might be helpful if the practitioner and service-user shared the same beliefs. However, since very few service-users rated sharing religion as helpful, this only amounted to two responses.

Practitioners also mainly made positive statements, though they generally mentioned negative statements more often than service-users, and mediators were all higher for practitioners than service-users. This suggests that practitioners took a more rounded view in their thinking about disclosure than service-users do. Practitioners also mentioned mediating factors more often than those who rated disclosure as unhelpful, suggesting greater complexity of thought and a less rigid, one-sided view of disclosure.

### 7.3 Common Themes

Some issues and themes were mentioned in relation to several, or all types of disclosure, and in relation to one or all scores of helpfulness rating. The following summarises some of the key themes that occurred in the responses to the hypothetical questions, with observations, where relevant, regarding what rating and disclosure they occurred with most.

#### 7.3.1 Risk, pressure and positive negative split

Overall, without splitting responses by rating (taking all ratings into account together) service-users were most likely to make negative statements about sharing religion and sexual orientation, and least likely to make negative statements about sharing personal mental health lived experience and sharing hobbies. Service-users were most likely to make positive statements about sharing personal mental health lived experience and hobbies, and least about religion and sexual orientation. Both observations seem to point in the same direction: mental health was the most positive thing to share, and had least negative issues associated with it.

Practitioners were least likely to make negative statements and most likely to make positive statements about sharing hobbies. While, sharing personal mental health lived experience was the second most likely subject for practitioners to make positive statements about, in contrast to service-users, practitioners were also most likely to make negative statements about sharing personal mental health lived experience. This suggests that service-users had a more positive-focused view of sharing mental health than practitioners, while practitioners were more likely than service-users to mention both positive and negative aspects of sharing mental health lived experience, suggesting they take a more balanced view.

Two main themes might help to shed some light on why this happened: pressures against disclosure and risks associated with disclosure.

Service-users associated risks and dangers of disclosure most often with sharing personal mental health lived experience, though references did not make double figures and, across all types of disclosure, there were very few references to risk and danger in relation to any disclosure topics. Practitioners also mentioned risk and danger most often in relation to sharing personal mental health lived experience, but they mentioned it significantly more often than service-users did,

and significantly more often in relation to sharing personal mental health than any other type of disclosure.

When looking at pressures on practitioners not to disclose, practitioners indicated two main drivers: being told not to disclose in some way, for example directly by a written policy or by colleagues, and feeling pressured more subtly not to disclose, for example, by feeling the need to act 'professionally' and avoid 'unprofessional' behaviour. Issues around professionalism appeared to be the most common driver against disclosure for practitioners, with low double figures of respondents mentioning it, while direct, explicit pressure not to disclose only reached low single figures.

Although the figures were low, they form a coherent picture. For practitioners, sharing mental health experiences, more so than other types of disclosure, was viewed as negative and risky and was associated with pressures against disclosure.

For service-users, sharing personal mental health lived experience was the most positive and least negative thing to share, and although risk and pressures against disclosure were rarely mentioned, where they were mentioned they were associated most with mental health disclosures.

### **7.3.2 Hope for recovery**

Recovery related to illness or symptom management was associated most with sharing personal mental health lived experience by both practitioners and service-users, and also with sharing difficult or traumatic experiences. Hope for recovery in a wider sense, including trying new activities, the demonstration of new possibilities and choices, and motivating service-users to set and achieve goals, was associated most with sharing hobbies and out of work experiences by practitioners, and by service-users with sharing personal mental health lived experience. This suggests that for service-users, recovery goals were more illness-oriented, and for practitioners they were more behaviourally-oriented:

“It would demonstrate that the condition can be managed and people can still hold a responsible position and functional despite the condition.” (Service-user, ID010, mental health disclosure)

“this can be informative and also help service-user take up a hobby choose a holiday destination” (Senior support worker, hobbies disclosure)

Among service-users who rated disclosures as helpful, recovery was mentioned in relation to all types of disclosure except religion. This was similar for practitioners, though they also indicated that sharing religion may be helpful for recovery too.

### **7.3.3 Building relationships**

Building relationships was mentioned by both service-users and practitioners most often in relation to sharing hobbies foremost, then personal mental health. Hobbies were associated by practitioners and service-users with rapport building and conversation, either to generate conversation as a route to focusing on mental health issues, or to provide a distraction from difficult conversations:

“... might be nice just to start a conversation, it can get a bit heavy talking about yourself and your mental health for an hour.” (Service-user, ID078, hobbies disclosure)

“...there are at times gaps that are usual to fill with everyday pleasantries instead of heavy stuff.” (Nurse, ID192, hobbies disclosure)

### **7.3.4 Normalisation and stigma reduction**

For practitioners and service-users, normalisation and stigma reduction were most associated with sharing personal mental health lived experience then second with sharing the mental health of a family member or friend.

Although sharing information about the mental health of a family member or friend also concerned sharing mental health information, it was less useful than sharing personal experience because practitioners felt it was less close to personal experience, because both practitioners and service-users questioned whether a third party would be able to consent to disclosure, and because service-users felt that if a practitioner shared information that was not

theirs personally they may be more likely to break the service-user's confidentiality by disclosing their experiences to others.

### **7.3.5 Increasing knowledge and understanding**

For practitioners increasing knowledge and understanding was mostly associated with sharing the mental health lived experience of a family member or friend, perhaps because of a reluctance by some practitioners to share personal mental health lived experience, but it was nearly as often associated with sharing personal mental health. For service-users, it was mainly associated with personal mental health, closely followed by sharing information about the mental health of a family member or friend. There were a number of different aspects to increasing knowledge and understanding, including increasing knowledge and understanding of the self and of the practitioner, increasing mutual understanding, and gaining new perspectives on experiences and conditions.

### **7.3.6 Credibility and personal insight**

For practitioners and service users alike, increasing practitioner credibility through the demonstration of personal insight was most associated with sharing personal mental health, though for service-users sharing the mental health of a family member or friend might also offer similar benefits.

### **7.3.7 Risk and danger of disclosure**

Risk and danger were associated by both practitioners and service-users with sharing personal mental health lived experience, though for service-users the number of respondents citing risks and dangers was very low.

***Burdening or distressing service-users:*** Out of all the potential risks, burdening or stressing service-users appeared to be the main concern, though there were many other risks too. For service-users and practitioners burdening or distressing service-users was mostly associated with sharing difficult or traumatic experiences, then for practitioners with personal mental health disclosure, along with a heavy emphasis on exacerbating practitioner emotions, and exacerbating service-user emotions:

“Personally I have been through a traumatic life event and I would not like to re live it in any circumstance... I think there may be a worry that you would upset / make service-user feel sorry for you and that is not your role as a nurse.” (Nurse, ID095, difficult or traumatic disclosure)

It is intuitive that difficult or traumatic experiences disclosures might have potential to cause burden and distress, but while practitioners also associated sharing personal mental health lived experience with causing distress, service-users did not.

**Practitioner illness or weakness:** Concerns about the stability and wellness of practitioners were most commonly expressed by practitioners in relation to sharing personal mental health lived experience, but such concerns were not voiced much by service-users.

**Proximity to personal experience:** Practitioners mentioned this often in relation to sharing information about family members or friends. Practitioners indicated that disclosure was less helpful when it concerned other people’s experiences because it is not as personal or powerful, but also that disclosure may be less risky because it is removed from direct experience. Although it may be less risky to disclose, if disclosure is less powerful it might minimise potential benefits:

“This makes the experience you are sharing one step removed. I don't think it carries the same weight.” (Health care support worker, ID027), disclosure of mental health of family member or friend)

Service-users did not mention this, and may find disclosures about the mental health of family members or friends as well as personal mental health disclosures could be helpful:

“I would feel they understand mental health.” (Service-user, ID006, disclosure of mental health of family member or friend)

However, service-users were concerned that disclosures about family members or friends may be dissimilar to their own, and hence less relevant than personal disclosures.

**Boundaries:** were mostly referred to by practitioners and mostly in relation to sharing personal mental health experiences, difficult or traumatic experiences, and the mental health of a family member or friend. Service-users rarely mentioned them. Practitioners indicated that sharing

may simply be a boundary violation, or that making one disclosure could lead to more disclosures based on increased demands from service-users for more information, or a blurring of where to draw the line on disclosure. Boundary violations were also tied closely to pressures against disclosure, wherein practitioners were concerned about judgements that might be made about them by other practitioners, and professionalism, which will be undermined if disclosure was seen to take place:

“I have referred to peer support workers in the past because a client needs to be able to talk about lived experience and it feels as though qualified staff are classed as "un-boundaried" if they disclose information.” (Nurse, ID080, disclosure of personal mental health)

***Shifting the focus:*** of interactions was mentioned most often in relation to sharing personal mental health lived experience than any other type of disclosure, by both service users and practitioners.

***Disclosures of dissimilitude:*** sharing religion was most commonly associated with potentially making comparisons of dissimilitude by both practitioners and service-users, because of the potential for faith differences. For practitioners, personal mental health was second most commonly associated with making inappropriate situation comparisons, but for service-users it was sharing the mental health of a family member or friend.

#### **7.4 Job Roles and Sharing Mental Health Information**

One section of the survey asked respondents to rate the helpfulness of sharing personal mental health information when disclosed by different types of practitioner, and to indicate why they gave that rating. Quantitative analysis of these ratings is given in Chapter 5 (see table 5.15, with p values and effect sizes), but an overview is given in table 7.1 below, which gives mean ratings scores against each job type, whether differences are significant, and effect sizes where applicable:



Table 7.1: Mean ratings of the disclosure of personal mental health lived experience by different types of practitioner

Type of Practitioner	Service-user Mean Rating on 1 to 5 Scale (1 = unhelpful, 5 = helpful)	Practitioner Mean Rating on 1 to 5 Scale (1 = unhelpful, 5 = helpful)	Significant difference & effect size
Peer support worker	3.6	3.6	No, none
Counsellor	3.3	2.5	Yes, medium
Psychologist or psychotherapist	3.3	2.4	Yes, medium
Doctor	3.3	2.4	Yes, medium
Health care support worker or assistant	3.3	3	No, none
Nurse	3.2	2.8	Yes, small
Occupational therapist or physiotherapist	3.2	2.8	Yes, small
Social worker	3.1	2.6	Yes, small
Non-clinical staff	2.4	2.3	No, none

Service-users indicated mental health disclosure was helpful (above a rating of 3) when undertaken by all types of practitioner except for non-clinical staff. Practitioners only rated disclosure of personal mental health lived experience as helpful when undertaken by peer support workers, and as context driven when undertaken by health care support workers. Based on this observation, there appears to be a distinction for practitioners between qualified and unqualified staff that is not there for service-users.

The following analysis is drawn from these responses and from other parts of the survey in which respondents made unsolicited comments related to job roles, for example, ratings of disclosure subjects. Where these are quoted, whether the respondent gave a helpful or unhelpful rating is indicated. Although mainly focused on the disclosure of personal mental health lived experience, other types of disclosure are mentioned where relevant.

#### **7.4.1 Qualified staff**

##### **7.4.1.1 Doctor**

Doctors' positions of authority and seniority, and the nature of their role, can either make disclosures more or less helpful.

Practitioners indicated that less frequent meetings with service-users, shorter appointments, and more focused, less flexible appointment agendas limit doctors' potential use of self-disclosure. Doctors and psychiatrists were seen to require greater objectivity and detachment than other roles, and need to preserve perceptions of authority, status and responsibility:

“In certain roles, to clients, you represent something. for example, clients tend to view their doctor as the top of the hierarchy. They tend to think that the doctor can fix their problems and is the person to go to for help. If this view is jeopardised, for some people this could be really unhelpful. For someone who they rely on for more everyday help like nurses and support workers, sharing experiences might be more 'normal'.”  
(Forensic psychologist, ID059)

Other practitioners suggested that doctors, as with other qualified staff, lack permission to share because disclosure may breach expected professional standards, behaviour, and codes of conduct:

“I find this difficult to answer since, at present, the guidance from the Royal College of Psychiatrists are not supposed to share any personal information at all. Sometimes I think it might help a particular patient to know that I have mental health problems too... They may then take more seriously the things I am trying to help them implement re self-management, staying well strategies etc... As a consultant, although I would, in some ways, like to be a bit more open with colleagues about my mental health struggles -and although I would, in some ways, love to be part of the Trust network for employees with lived experience... I am the treating consultant for some other Trust employees and think it might be very unhelpful/inappropriate to "bump into them" as part of the lived experience network because they would then know certain information about me which I am "supposed" (in keeping with guidance from Royal College of Psychiatrists) to keep completely separate from clinical encounters..” (Consultant, ID029)

The above quote indicates that disclosure might be helpful in gaining credibility among service-users and in promoting hope for recovery, and that the practitioner would share if they felt they were allowed. It also illustrates that some practitioners felt unable to be 'out' about their mental health status with colleagues. Several other practitioners also indicated the need for doctors to

maintain an image of 'wellness' for fear that illness would reduce service-users' faith in their ability to look after them effectively.

Service-users echoed many of these views, but also presented alternatives. Several service-users shared the view that doctors' time and agenda is strictly controlled, and that they wished to be treated by 'well' practitioners, or at least not to know whether they had been 'unwell' in the past, and some also suggested that disclosure is antithetical to professional expectations and codes of conduct:

"It is more important that a doctor's mental health is good than say the support worker as he directly impacts your life with his decisions." (Service-user, ID056)

"Doctor Depends on info disclosed! Got a professional code of conduct to follow." (Service-user, ID026).

However, several service-users, like the consultant quoted above, suggested that disclosure could enhance practitioner credibility, because of the combination of first-hand experience and medical training:

"Because sometimes doctors come across as robots just regurgitating text books, not really empathising with patients. Feel less embarrassed and more open to tell them the truth. They shouldn't have to be too specific." (Service-user, ID088, helpful rating, personal mental health disclosure).

"I think it would be helpful from doctors or psychologists because they could talk about their own experiences in relation to what they know about mental health from a professional point of view." (Service-user, ID078)

Several doctors suggested that disclosure might detract from focusing on service-users' needs. However, service-users indicated that, because of the elevated status of doctors, disclosure might be especially effective at helping them to feel less intimidated and more inclined to talk about their own issues:

“To hear about experiences from nurses or doctors is what will mostly make people feel better. Knowing that a true professional has/is going through similar will make people feel much better. They are not alone.” (Service-user, ID068).

“I think in all health practitioner roles it would be more helpful, especially doctors - who can be quite daunting to speak to. Sometimes doctors can come across as 'inhuman' as in they have no heart and feelings sometimes. I know they have to be a certain way to be professional - but sharing experiences can help.” (Service-user, ID088).

Some practitioners also echoed the belief that a doctor’s professional status and role could convey powerful messages regarding the normalisation of mental health experiences, and help “[break] the hierarchy/parental role [doctors] often adopt” (Nurse, ID017). However, few practitioners rated disclosure by doctors as helpful, and fewer still indicated specifically why they had given a helpful rating.

#### **7.4.1.2 Nurse**

The reasons why practitioners and service-users saw disclosure as helpful or unhelpful were very similar to those cited regarding doctor disclosure. Practitioners felt disclosure might undermine boundaries, and that it was necessary for service-users to see nurses as ‘well’, while others felt that disclosure might offer hope for recovery by demonstrating that they are able to maintain ‘wellness’ despite their experience of illness:

“I have witnessed staff sharing and the service-user feeling that they wanted a nurse who was 'well' to look after them.” (Nurse, ID017)

“It can make you seem more human... I know a RMHN who discloses their use/experience of antipsychotic medication with some SU to good effect. He’s been well for years.” (Nurse, ID183)

As with disclosure by doctors, practitioners felt that disclosure might create barriers within the relationship or remove barriers, helping patients to talk about their own experiences or silencing them. Again, some practitioners made a distinction between qualified and unqualified staff,

citing perceived pressure against disclosure through negative judgement by colleagues, or a lack of permission to share, among qualified staff compared to unqualified staff:

“I have referred to peer support workers in the past because a client needs to be able to talk about lived experience and it feels as though qualified staff are classed as ‘un-boundaried’ if they disclose information.” (Nurse, ID080)

However, even among unqualified staff disclosure could still be perceived as belonging to the domain of peer support workers:

“If there was an explicit expectation that I would be sharing Lived Experience I would share more often. I overheard a conversation a peer support worker was having yesterday with a service-user and it felt authentic, informed and meaningful. I would like the freedom to help others in the same way.” (Health care assistant, ID092)

Service-users felt it was easier for nurses to share their experiences than doctors or psychologists because they see service-users more frequently, have a closer working relationship with them, and have less need for detachment, resulting in more freedom and more opportunity to develop relationships and for disclosure to be made. As with doctors, nurses were seen as potentially conveying positive messages regarding recovery by service-users, which might be enhanced by their professional status:

“I would like to be a nurse and don’t think I could because I have a mental health illness but if I knew it was possible it would be good to know.” (Service-user, ID038).

#### ***7.4.1.3 Occupational therapist or physiotherapist***

Among the few written responses, there was some crossover with how practitioners and service-users viewed disclosure by occupational therapists and physiotherapists compared with nurses. Like nurses, but unlike doctors, they were seen as having more time, frequency of contact, and flexibility of agenda to be able to use disclosure effectively. Disclosure was also seen as a means to help service-users talk about their own experiences (rather than detracting from them). Unlike nurses, their role was seen as more practical and less emotional, so disclosures might be less personal and more factual, thereby making them less controversial.

#### **7.4.1.4 Psychologist or psychotherapist**

No respondents gave any reasons why they had rated disclosure by psychologists and psychotherapists as helpful, though many did indicate why they thought disclosure was unhelpful, and it was for many of the same reasons given about disclosure by doctors. For practitioners, this included: the frequency and nature of contact, time constraints and stricter role focus; the need to maintain objectivity and detachment; and to keep the focus on the service-users.

Some practitioners mentioned the need to adhere to therapeutic models requiring non-disclosure, for example so as not to interfere with the process of transference. However, one practitioner respondent reflected on their personal experience of having undertaken therapy and said that they “would have preferred a slightly less formal approach, and some degree of shared information would have been preferable” (Health care support worker, ID025).

Service-users saw time, frequency of contact, and nature of contact as being restrictive for psychologists and psychotherapists as they had with doctors, with psychotherapists being “there to listen to service-users” (service-user, ID026) and needing “to remain in a role of advice and so knowing more about them is not helpful” (service-user, ID027). Like doctors, the elevated professional status and role of psychologists was seen as a reason for them not to disclose, accompanied by concerns about practitioner illness or weakness:

“I... want to know that this person above all others was in control of things and their experience did not affect my treatment...” (Service-user, ID010).

While for some, disclosure by psychologists was seen as antithetical to their position, role, or purpose for others, disclosure seemed “more relevant in the relationship in talking therapy” (Service-user), perhaps because, for therapists, personal insight is a valuable addition to textbook knowledge and gives them more credibility:

“It would be very useful for CBT therapists to know more than what medical textbooks say. Some real insight would help a great deal at times.” (Service-user, ID068).

#### **7.4.1.5 Counsellor**

Practitioners mentioned most of the same issues for counsellors as they had for psychologists and psychotherapists, perhaps because they are all talking therapies. One practitioner thought disclosure might be more appropriate in counselling but not psychotherapy, the latter being “more scientific” (Nurse, ID127).

Service-users appeared to mainly be concerned that the focus remained on them, but also felt that disclosure might help them to feel that the practitioner understood them.

#### **7.4.1.6 Social worker**

Only two practitioners gave reasons for their answers that specifically addressed the social worker role. They were both in relation to unhelpful ratings, and concerned the need for objectivity, the frequency and nature of contact, and the need to maintain authority and status, as with doctors.

Service-users saw the frequency and nature of contact with social workers as enabling a close working relationship with service-users in which disclosure was seen to be helpful, but another service-user felt that social workers are there “for other important roles” (service user, ID026) than to build close relationships, negating disclosure.

### **7.4.2 Unqualified staff**

#### **7.4.2.1 Peer support worker**

Peer support worker was the only job role that practitioners rated as helpful regarding sharing personal mental health lived experience. They gave it the same rating as service-users did.

Throughout practitioner responses, there was an indication that the peer support role is less professional, clinical, formal, boundaried and therapeutically aligned than other mental health roles. It was also seen as less ‘qualified’ in contrast to other practitioner roles. Disclosure and sharing were also seen as essential elements integral to the role of peer support, without which “the value of peer support would be depleted” (Nurse, ID005).

Practitioners saw disclosure as helpful by peer support worker because they have more direct contact with service-users than other practitioner roles, and a different relationship with service-users, allowing them time and opportunity to disclose and convey messages of recovery. Even so, disclosure by peer support workers came with caveats, where disclosure “could be more helpful in the right circumstances (if the mentor or peer supporter was not seeking significant support from the person they were in place to support)” (Clinical psychologist, ID066), with one practitioner reporting they “had feedback from a service-user recently that a peer worker sharing experience upset them but they didn't say anything because they felt rude” (Psychotherapist, ID101).

In several instances, practitioners indicated that the peer support role was seen as less professional than other roles, for example, peer support workers have a different relationship to service-users than “professionals” (Nurse, ID057) rather than *other* professionals, and one clinical psychologist (ID066) saw the role as being “based more around shared experience and emotion” than “a science practitioner role.” One doctor felt that with “medical professions... the therapeutic relationship... is of central importance” while for peer support roles it was more about “shared experience” (Doctor, ID047).

Practitioners indicated there may be benefits for non-peer professionals to be “a tabula rasa” (Nurse, ID082), particularly within psychotherapeutic interventions which do not “have room for own issues to be brought into the therapeutic process” (Occupational therapist, ID120). For these reasons, the peer support role may be seen as having “less need for professional boundaries” (Psychotherapist, ID144) whereas “medical and nursing staff should maintain professional boundaries” (Doctor, ID107).

For service-users, disclosure was seen as helpful when given by peer support workers because peer support roles “are roles in which more personal attention is given in a less formal environment” (service-user, ID073), because disclosure was seen as “vital” (service-user, ID090), and because disclosure “could help people take more notice as they would be thinking they had a better insight into their own personal scenarios” (service-user, ID096) For one service-user (ID030), peer support roles are more “personal” and other practitioner roles are seen as requiring “professional” distance. There were no references that explained negative ratings of disclosure by peer support workers.



#### **7.4.2.2 Health care support worker or assistant**

Health care support workers (HCSW) were rated similarly to peer support workers by practitioners regarding the disclosure of personal mental health experiences.

While there was one example of poor disclosure given by an HCSW which had led “to inappropriate relationships/poor boundaries” (Occupational therapist, ID064), practitioners gave other reasons why disclosure might be helpful in the HCSW role, most of which were the same as for peer support workers, including the frequency and length of contacts which enable relationships to be formed and disclosures to be used for positive effect, in contrast to clinical roles.

In terms of their professional status doctors were seen as being at the “top of the hierarchy” and trust in them to be able to “fix [the service-users’] problems” was more marked than for those lower down in the hierarchy, such as “nurses and support workers” (Forensic psychologist, ID059, and others who expressed similar sentiments), indicating that disclosure of a mental health condition would undermine the belief in the doctor’s competence or ability to practice effectively but may not do so for other, including non-qualified, roles. One doctor indicated that this was because support workers and non-clinical staff would be “less at risk of causing harm” if they disclose because they do not have “direct responsibility for treating the patient’s mental health problems” (Doctor, ID123), again, as with peer support workers, indicating that such roles are seen as supportive, rather than therapeutic. Despite disclosure being seen as more helpful in these roles, one HCSW felt that permission to share was lacking, in contrast to peer support roles.

Service-users felt that disclosure by health care support workers or assistants may increase their credibility and increase service-users’ trust in the advice given by them. In addition, because of the frequency and length of contacts disclosure is more appropriate and possible.

#### **7.4.2.3 Non-clinical staff**

Disclosure by non-clinical staff, such as administrators, cleaners or receptionists was generally seen as unhelpful by both practitioners and service-users because it was seen as irrelevant to their role; because non-clinical staff would not have had training (which might mean they

disclose inappropriately); and because service-users have less direct contact with them. However, for one service-user, although disclosure would generally be unhelpful, it might be helpful if “said person was going through or is going through an identical or almost identical situation” (service-user, ID065).

## 7.5 Validity Checks

Frequencies of qualitative coding closely match and support quantitative findings, providing evidence of the validity of both quantitative and qualitative findings. Some of these are listed below.

### 7.5.1 Most helpful types of disclosure & coding

Practitioners rated hobbies as the most helpful type of disclosure (see table 7.2, below), they shared it most often in real life (see Figure 7.4, below, or Chapter 6 for greater detail), and they associated more positive and fewer negative factors with it than any other type of hypothetical disclosure (see Figure 7.5, below). It may be expected that practitioners would share more of the things they think are most helpful and least unhelpful, and this is indeed the case. This alignment of disclosure frequency and positive/negative coding suggests that the coding strategy was adequate and results are not due to coding inconsistency or inaccuracy.

Table 7.2: Practitioner mean ratings of disclosure helpfulness

<b>Descriptive Statistics: Practitioners</b>	<b>N</b>	<b>Mean</b>
Hobbies and out of work experiences	194	3.402
Physical health	192	2.74
Personal mental health	199	2.709
Mental health family or friend	195	2.677
Difficult or traumatic experiences	194	2.433
Religion	193	2.109
Sexual orientation	187	1.957

Figure 7.4: The 4 most frequent types of real life examples of sharing

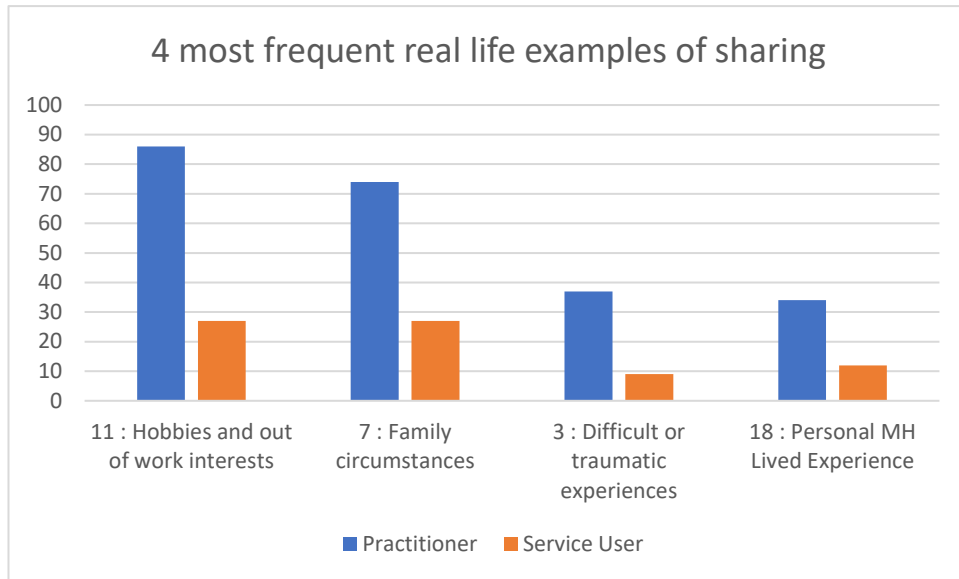
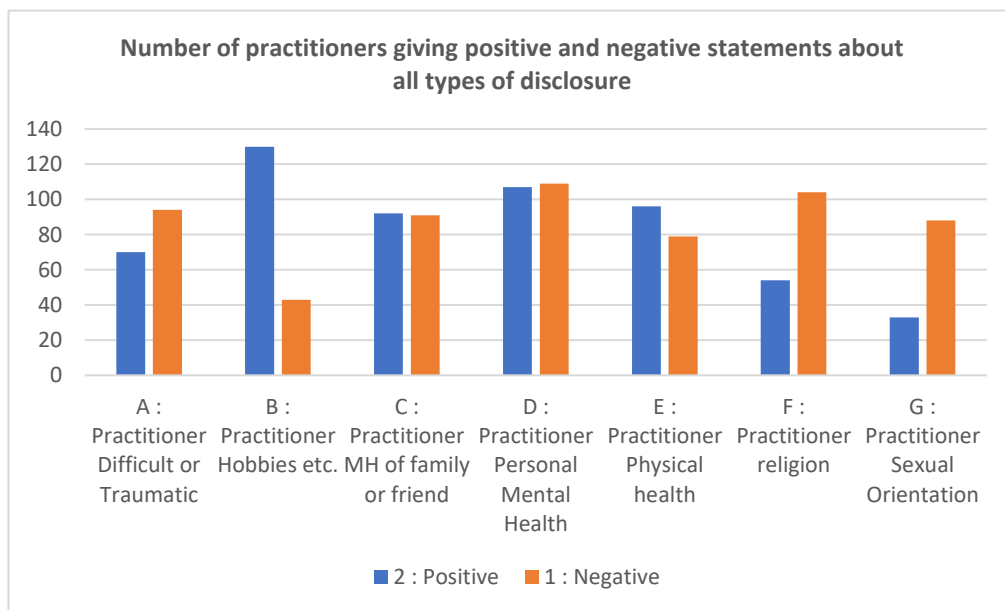


Figure 7.5: Positive and negative statements about different hypothetical disclosure types, practitioners



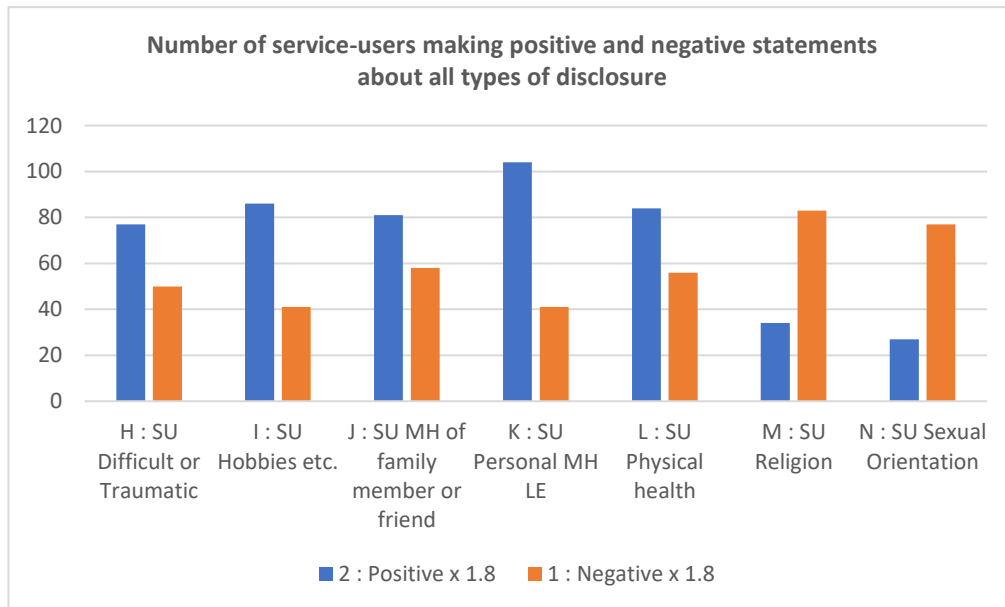
A similar picture emerged for service-users, on different criteria. Quantitative evidence suggests that service-users rated the sharing of personal mental health lived experience as most helpful to them (see Table 7.3, below). Service-users, like practitioners, reported that hobbies were the (joint) most often shared subject in real life, along with family circumstances, which practitioners reported as the second most often shared subject (see Figure 7.4, above). More service-users said positive things about practitioners sharing personal mental health lived experience than any other type of hypothetical disclosure, and fewer service-users had negative things to say

about sharing personal mental health than any other type of hypothetical disclosure (except for hobbies, which had the same number of negative statements, see Figure 7.6, below, adjusted by factor of 1.8 for comparability, since 1.8 times as many practitioners responded to the survey as service-users).

Table 7.3: Service-user mean ratings of disclosure helpfulness

<b>Descriptive Statistics: Service-users</b>	<b>N</b>	<b>Mean</b>
Personal mental health	107	3.29
Mental health family or friend	103	3.019
Hobbies etc.	100	2.94
Difficult or traumatic experiences	98	2.837
Physical health	103	2.796
Sexual orientation	95	1.979
Religion	103	1.951

Figure 7.6: Positive and negative statements about different hypothetical disclosure types, service-users



Overall, this suggests that messages emerging from service-users and practitioners are broadly in line, and do not contradict each other. It also suggests that the positive/negative coding of hypothetical disclosures is likely to be sufficiently accurate to support the given conclusions.

### **7.5.2 Patterns of positive, negative and mediating factors**

The pattern of positive, negative and mediating statements given by service-users was consistent across all 7 disclosure subjects for unhelpful ratings. It was also consistent for all 7 middle ratings, and consistent for all 7 helpful ratings. The same was true of practitioner responses. The highly consistent nature of these findings suggests coding was consistent enough to uncover an underlying pattern that findings were not the result of coder error or researcher-interpretation.

## **7.6 Conclusion**

### **7.6.1 Hypothetical disclosures**

Service-users tended to take a singular position about sharing all types of lived experience. Where disclosure was rated as unhelpful they rarely mentioned helpful aspects, and where it was helpful they rarely mentioned unhelpful aspects. In either case they rarely mentioned mediating factors. This polarisation was especially evident regarding helpful-rated disclosures, where they mainly mentioned positive aspects, few negatives or none, and few mediating factors. This pattern was consistent across all types of disclosure, including the sharing of personal mental health lived experience. Service-users who gave middle ratings gave greater consideration to mediating factors, predominantly concentrated on potential positive effects and hardly mentioned potential negative effects of sharing. This suggests that service-users' views of sharing were skewed towards positivity and helpfulness overall, and that mediating factors did not play a major role for those whose views were polarised towards the helpful or unhelpful ends of the scale.

The pattern was different for practitioners. Practitioners who gave middle ratings considered mediating factors more often than practitioners who gave unhelpful ratings. Practitioners were also between 2 and 7 times more likely to mention mediating factors on helpful ratings than on unhelpful ratings. This indicates a more fixed, less reflective attitudes among practitioners who rated disclosure as unhelpful, and less fixed, more reflective attitudes among practitioners who rated disclosure as helpful.

Practitioners mentioned fewer mediators and negative factors for sharing hobbies than any other subject, including personal mental health and mental health-related disclosures. This is significant because hobbies were also the most frequent type of disclosure that practitioners shared, suggesting that practitioners viewed the sharing of hobbies as straightforward and uncontroversial.

Service-users rated sharing of personal mental health lived experience as more helpful than practitioners did. Practitioners and service-users often mentioned similar benefits and risks of disclosure to similar extents. Making personal mental health disclosures might increase practitioner credibility, demonstrate personal insight, help to promote recovery, help to build relationships and develop rapport, normalise and destigmatise service-users' experiences, and increase knowledge and understanding for both parties. Service-users and practitioners also felt that mental health disclosures might shift the focus of interactions unhelpfully away from the service-user, and were similarly wary of religious disclosures, due to concerns about potential clashes caused by differences in faith. Both parties also agreed that sharing difficult or traumatic experiences might cause service-user distress.

Practitioners and service-users also differed in some respects. Practitioners valued the sharing of hobbies to promote recovery activities, while service-users valued illness-related recovery messages gained through personal mental health disclosures. Practitioners focused more on risk and danger than service-users did, particularly in relation to sharing mental health lived experience, perhaps explaining some of their preference for sharing hobbies. Practitioners worried that disclosure of mental illness experience would cause service-users to see them as ill or weak, and would burden or distress them, though service-users did not mention such concerns to any great extent. Practitioners mentioned boundary transgressions often, while service-users did not. Practitioners were concerned that disclosure about the mental health of family members or friends would be less helpful because it is not so close to personal experience, while service-users seemed to value it in addition to personal mental health disclosures, albeit with concerns regarding confidentiality and consent.

### **7.6.2 The influence of job role on helpfulness of sharing mental health lived experience**

There was some suggestion from practitioners that disclosure may be less compatible with qualified practitioner job roles, because of increased pressures against disclosure, than for unqualified staff, including peer support workers. These pressures may be explicit or implicit, and included: the perceived need to demonstrate wellness and competence; professional guidance and codes of conduct forbidding disclosure; potential negative judgements from colleagues; frequency and length of contact; and the need to adhere to specific models of therapeutic interaction that exclude disclosure.

There was some evidence to suggest from both the real life examples of disclosure (see chapter 6), hypothetical disclosures (see chapter 7), and the quantitative analysis of job role provided in chapter 5, that the job role of disclosing practitioners may influence how disclosure is viewed. Such pressures impact more on doctors who are at the top of the professional hierarchy, than on other qualified staff, and least on unqualified staff such as peer support workers who also have explicit permission to share. Conversely, higher professional status and qualified status was suggested by several service-users to increase the impact of disclosure, because it may help to break down power imbalances that can deter their own disclosures, reduce stigma and loneliness, and increase the credibility of advice because it draws on a combination of professional and personal knowledge.

These findings, however, were difficult to identify on first-stage analysis, and initially it was unclear why or how job roles influenced disclosure dynamics. As outlined in chapter 4, focus groups were planned to enable further investigation of emerging issues and deal with any gaps in data and understanding of data. For this reason, the second UK practitioner focus group specifically focused on the part that practitioner job role plays in disclosure (see section 8.5.15). This enabled re-analysis of survey responses, leading to those conclusions outlined here in section 7.6.2. Chapter 8, next, outlines how emerging issues were explored in more depth in subsequent focus groups, including whether findings were felt to be confined to UK respondents, or whether they were shared by Australian counterparts.

## **Chapter 8: Qualitative Results 3: UK and Australian Focus Groups**

### **8.1 Introduction**

Focus Groups were held in the UK and in Australia to gain a deeper understanding of the data collected from the surveys, and to explore issues that had not been adequately explained by survey responses. These discussions led to new insights enabling further iterative analysis of the survey data regarding the pressures that deter practitioner disclosure.

The UK and Australia use different terminology to describe people being worked with, and those working with them. In the UK, those working with are referred to as practitioners, whereas in Australia they are referred to as clinicians. Those being worked with, i.e. patients or clients, in the UK are referred to as service-users, and in Australia as consumers. The results presented here attempt to mirror that terminology by using the most appropriate term for the context. Where issues were shared cross-culturally the UK terminology is used. Small numbers of participants and higher levels of co-facilitation in the UK focus groups meant that it was possible to attach anonymised names and actual job roles to quotes from participants, but this was not possible in Australia and so quotes are only attributed to either clinicians or consumers.

Focus groups were semi-structured and different issues were discussed in different groups, so some themes might be identified primarily or solely with one group and not with others. The second UK focus group concentrated solely on risk and job roles, and is presented separately at the end of this chapter.

Evidence supplied in the following sections is grounded in the data collected from participants, rather than comprising author interpretation or extrapolation. Assertions and comments should therefore be attributed to participant responses, rather than author opinion.

### **8.2 Participants**

#### **8.2.1 Service-user participants**

In the UK two service-users took part in one focus group in Leeds, and additionally one service-user took part elsewhere in a semi-structured interview, as they did not feel confident to take



part in a focus group. Another service-user focus group was organised to take place in York, but insufficient participants were forthcoming. In Australia, three service-users took part in one focus group.

### **8.2.2 Practitioner participants**

In the UK, ten practitioners from the NHS Trust took part in two focus groups. 4 took part in York, and 6 in Leeds. 4 indicated that they had no personal experience of a significant or problematic mental health condition of their own, 6 indicated they had. Practitioner job roles included support workers/assistant (n=3), Occupational therapist (n=1), adult safeguarding lead (n=1), outreach worker (n=1), nurse (n=2), psychological wellbeing practitioner (n=1), and psychiatrist (n=1).

In Australia, 9 clinicians from a statutory mental health organisation took part in two focus groups in Melbourne, three in the first group, and six in the second. Of these, 6 indicated they had no personal experience of a significant or problematic mental health condition of their own, 2 indicated they had, and 1 did not indicate. Clinician job roles included social worker (n=6), nurse (n=2), and clinical psychologist (n=1).

## **8.3 Practitioner Use of Disclosure**

Practitioner focus group attendees were asked if they do, or would consider, sharing lived experience with service-users, and if so, what kinds of information they might be willing to share.

### **8.3.1 UK practitioners and disclosure**

In the first UK practitioner focus group (York), three out of the four participants said they did, or might, share lived experience in some circumstances, and one said they would not under any circumstances. One member of the focus group was prepared to share some things about himself in some circumstances (doctor), one member was very open to sharing personal mental health experiences (support worker), one member was not prepared to share under any circumstances (nurse), and one member preferred to make generalised statements as alternatives to personal disclosures, but did not entirely rule out disclosure in all circumstances (therapist). In the second UK focus group, all six participants said they had shared something with a service-user. In total, of the 10 participants, only one (nurse in a secure setting) ruled out

disclosure completely, though during the discussion his stance seemed to be less strict than it first appeared, with some admissions of sharing limited out of work experiences, such as going to the cinema or watching football.

### **8.3.2 Australian clinicians and disclosure**

In Australia, there were no clinicians who would not consider sharing some aspect of themselves, and most of them had shared something at some point. However, clinicians indicated that sharing mental health lived experience was felt to be less acceptable than sharing other types of experience, for example, watching or supporting football teams, and participants were largely unaware of colleagues who shared mental health lived experience. One Australian clinician who said they did not have a mental health condition did feel able to disclose an experience of having “heard a voice” (Australian Clinician), and although participants mentioned a couple of high profile clinicians in Queensland and New Zealand who were known for being open about their lived experience, they seemed to be notable because of their rarity, and there was felt to be a general ‘silence’. Despite the general consensus that disclosure is discouraged, participants said they were themselves generally willing to disclose information about themselves, though there was perceived pressure against disclosure:

“I’ve always been someone who wants to push the boundaries a little bit, with self-disclosure, but the risk and the judgments are part of it. I’ve had a supervisor say to me... you’re going to lose credibility if you let people know that’s how you’re working with people, and interestingly, particularly with doctors, was the point.” (Australian clinician)

### **8.3.3 UK service-users and disclosure**

In the UK focus group and semi-structured interview, comprising three service-users, one participant reported a preference for non-disclosure of mental health experiences, and said he had received none. At the beginning of the discussion he indicated that he was generally pleased about this, but later strongly felt that disclosure would have been welcome and that lack of disclosure had been a damaging experience. The second participant reported a preference for mental health disclosure, had received disclosures, and said these had been mostly welcome. The third reported a preference for mental health disclosure but had not received it. They felt

the lack of disclosure was unhelpful, in contrast to the helpful disclosures they had received in the voluntary sector from an ex-social worker.

#### **8.3.4 Australian consumers and disclosure**

In Australia, all three consumers expressed a preference for mental health disclosure. Initially they reported that statutory mental health clinicians did not share lived experience with them, and this was unhelpful, while helpful disclosures had been received in the voluntary or private sectors. Later in the discussion, one participant said nurses might share things with you “once they get to know you” (Australian consumer) but this did not relate to mental health, while one participant later recalled that some nurses had shared mental health experiences with her.

### **8.4 Benefits and Risks of Disclosure: Striking a Balance**

Feedback from UK and Australian service-users and practitioners indicated that there are many benefits associated with disclosure, but that there are also risks. To avoid risk, practitioners said they might consider non-disclosure, but that this carried risks too, and whether disclosure was helpful depended on several mediating factors.

#### **8.4.1 Benefits of disclosure**

There was much agreement among service-users and practitioners in the UK and Australia regarding the benefits of disclosure, and these mirrored many of the benefits that had emerged from the surveys (see Chapters 6 and 7). Among other things, participants spoke about how disclosure can help build therapeutic relationships, humanise practitioners, increase their credibility, help service-users to feel understood, normalise and destigmatise service-users’ experiences, and act as a positive distraction when conversations are difficult. However, they also spoke about related risks.

#### **8.4.2 Risks of disclosure**

Participants identified a number of key risks, including boundary transgressions, burdening service-users, closing down conversations and creating barriers in the relationship, shifting the focus unhelpfully from the service-user to the practitioner, discrediting the practitioner to

service-users and colleagues, and service-users misusing information in some way. To avoid risk, practitioners indicated they might choose not to disclose.

#### **8.4.3 Benefits of non-disclosure**

Non-disclosure was attempted by practitioners sometimes or all of the time. The benefits associated with non-disclosure in many respects were simply the opposite of the risks of disclosing: if service-users might misuse information shared with them, then not disclosing could prevent this from happening; if disclosure causes negative focus shift, then not-disclosing means focus shift is potentially minimised or eliminated; and where disclosure may be used against the practitioner, non-disclosure might help protect them. Practitioners felt that non-disclosure could enable practitioners to be detached and professional, adhere to certain therapeutic models, and conform to workplace pressures and cultures. Although there were several benefits associated with non-disclosure, there were several risks associated with it too.

#### **8.4.4 Risks of non-disclosure**

The risks of non-disclosure might generally be described as the opposite of the benefits of disclosure: if disclosure could help build relationships, then non-disclosure might not enable such benefits to be achieved; and if disclosure might help to destigmatise mental illness, then non-disclosure might allow stigma perpetuation. Non-disclosure did not simply lead to an absence of disclosure benefits, but created its own risks, such as damaging relationships, and increasing feelings of stigma and isolation. However, some participants did suggest positive alternatives to disclosure that might be helpful in some circumstances.

#### **8.4.5 Alternatives to disclosure**

Participants suggested alternatives to disclosure that might potentially be helpful, or in some cases problematic. Alternatives included practitioner competence in other engagement or therapeutic techniques, sharing generalised, anonymised information about the self or others, exploring the need to know, avoiding answering difficult questions, refusing to disclose, lying, and referring to another service. Several of these strategies were felt to be potentially viable and helpful, but some were also problematic.

#### 8.4.6 Mediating factors

Focus group participants, like survey participants, mentioned several mediating factors that could affect the helpfulness of disclosure. They included the amount of information given; pre-planning for disclosure; practitioner comfort in disclosing; the quality of the relationship; the motivation for sharing; making efforts to avoid shifting the focus of the interaction; the timing of disclosures; contexts, intervention types and types of service-user condition; attunement to difference in experience; the role of supervision and team discussion; boundary maintenance; the existence or lack of training and guidance; the type of therapy; and the job role, status and hierarchy of disclosing practitioners.

### 8.5 Benefits, Risks and Mediators of Disclosure: Major Themes

Issues associated with benefits and risks of disclosure and non-disclosure, mediating factors, and alternatives to disclosure are explored below in further detail.

#### 8.5.1 Recovery and turning points

Recovery and hope for recovery were consistent underlying and explicit themes in both the UK and in Australia. Practitioners often mentioned promoting recovery as a motivating factor for disclosing, and service-users mentioned that disclosure gave them hope for recovery. It was evident that non-disclosure could have strong, negative effects on individuals, while in contrast disclosure could have profound, life-changing effects on individual service-users and their recovery vision:

“[Disclosure from a social worker] was the catalyst that shifted me from utter desperation to I can do this... There’s a relief that somebody has recovered from something that you think is beyond the point of no return for yourself. It gave me respect for them, it gave me hope.” (UK service-user 2)

Although mental health disclosure could create turning points in recovery, service-users in both countries felt that disclosure was lacking in the statutory sector, where many respondents had neither met a disclosing practitioner nor been offered peer support. Some service-users

reported disengaging from statutory services in preference for voluntary or private sector services where they got the disclosure and connection they desired:

“I can honestly say that when I was in hospital it wasn’t any health professional that helped, it was the health consumers, just talking to them, and knowing that I wasn’t bad... that’s why I’m alive today. That’s why I feel that it has power if clinicians can share to some extent, no details, but share a little bit.” (Australian consumer)

“the relief when I found out that this fantastic, strong, vibrant woman, sorry I’m becoming quite emotional [crying]. It was just like, you’ve had mental health problems? You mean, I can do it?...it was such a contrast to what I’d been told, or not told, by other services previously...it gave me hope.” (UK service-user 2)

### **8.5.2 Building human relationships: engaging and disengaging**

Disclosure of a wide variety of information, not only mental health, helped practitioners to build relationships with service-users. Efforts were made for a purpose, on one hand because building positive relationships is inherently beneficial in itself, by increasing communication, building trust, and establishing rapport, but also because this is potentially beneficial to therapeutic interventions, as it helps service-users to talk more freely about their experiences:

“[sharing information about hobbies and out of work experiences] also serves a clinical purpose because as a psychiatrist I’m observing and assessing how they’re responding to it and how they’re able to or not to have a human dialogue like that, and it can reveal signs of illness, or personal problems, just a simple thing like that.” (UK psychiatrist)

“what I’m saying, here are two people who’ve never met before, and they have to get something going between them, you know?” (Australian consumer)

However, depending on the subject matter, disclosure could close down conversations and create barriers:

“... I think that in the instances where practitioners have shared experiences, many times it has helped me to open up that bit more. I can think of times it hasn't, it's kind of gone the other way and shut me down... has been a bit overwhelming, a bit too close to the mark.” (UK service-user 3)

“If someone came out with this is my sexual orientation, what's yours? That would generate all sorts of barriers going up immediately, doors would be shut. That wouldn't be a safe opening gambit for me at all.” (UK service-user 1)

Service-users indicated that the most powerful connections tended to form between service-users and practitioners who had lived experience and who were open about it, not least because disclosure of lived experience helped to humanise the discloser but also the service-user and the interaction:

“I can only think of one clinician, a psychiatrist [private practice], has lived experience... I'm going there because I haven't seen my psychiatrist since my initial breakdown, because I don't like them. But this one, he's human. He's human, and he doesn't talk about himself, but I can feel it, you can't fake it.” (Australian consumer)

“... thinking about people that have [disclosed to me] ... it kind of makes me feel like a human being, not just an alien, it makes me feel more real.” (UK service-user 3)

“...it's humans dealing with humans, that's the whole point of it... we're not robots. Being robotic won't effect what you're trying to achieve.” (UK psychiatrist)

Service-users who knew about the life experiences of practitioners said they may make proactive choices to gain services from those they feel are best able to provide the service they feel they need:

“I think you'd find people would sign up to be on the patient list of somebody with [lived] experience...” (UK service-user 2)

### 8.5.3 Matching and mismatching experience

Where practitioners had similar life experience to service-users, disclosure could be seen as helpful. However, disclosure could be unhelpful where practitioners incorrectly assume similarity of experience. Participants indicated that the helpfulness of disclosure might be improved in two main ways: by acknowledging likely differences of experience; and potentially by proactively matching practitioners with service-users based on mutual interests.

Incorrect assumptions that two people who have had a similar illness or experience have been affected by it in the same way might lead to disclosures that are non-affiliative, distancing, and indicate lack of empathy. Acknowledging differences of context and experience may help to mediate whether disclosures are perceived as helpful:

“People are individuals, different things work for different people. Sharing lived experience can be good regarding medication, as long as individual differences are acknowledged, what works for one person may not for another.” (Australian consumer)

Australian clinicians suggested that it may be helpful to match the skills and life experiences of clinicians with those of consumers, making some types of disclosure explicit and expected:

“I don’t have any mental health experiences, but I have two kids, so I was actually picked by a team leader to take over as a key clinician for someone who’s just had a child, because I’ve got that experience. It felt uncomfortable at first, because it’s not something I was used to doing... but it seemed to benefit the consumer.”

(Australian clinician)

In Australia, such matching was also felt to be applicable to drug and alcohol service delivery, where staff having personal experience of substance use was expected and accepted, and it was also suggested that matching life experiences might have benefits not only in terms of mental health and substance use but more widely regarding other identities and demographics:

“... I also wonder whether the match is important, in terms of the age group, cultural background, belief system of the consumer.” (Australian clinician)



However, it was also felt that sharing mental health lived experience was not as well accepted as sharing substance use experiences, and because this may lead to criticism and negative judgements practitioners were reluctant to share:

“...why would you put yourself out there?” (Australian clinician).

In the UK, disclosure regarding substance use seemed to be more controversial than in Australia. One UK practitioner gained permission to run a substance use group based on sharing experiences only after repeated attempts over a significant period of time. When permission was gained, the matching and sharing of practitioner and service-user experience was felt to be therapeutically beneficial:

“... a guy who didn't speak throughout the whole group... came up to me afterwards and he said that was really good what you did in there and I need to start opening up. And that was the whole point of doing it, that was the whole message really, to get people to start opening up and sharing their experiences.” (UK support worker)

#### **8.5.4 Credibility**

Focus group participants indicated that disclosure could either increase practitioners' credibility or decrease it.

Non-disclosure could indicate a lack of experience among practitioners, meaning that they had little direct insight into conditions other than what they had learned from their training:

“... I just assumed [lack of disclosure] meant they'd never had any experience.” (UK service-user 2)

Demonstrating understanding drawn from personal experience, as an accompaniment to expertise gained through professional training, was felt to potentially increase practitioner credibility, helping service-users to take their advice more seriously, and helping practitioners to challenge service-users where their credibility is questioned or challenged:

“I think in times of crisis, you may need someone to say to you, actually I do know what you’re going through, and not just because I read a textbook, or I’m a clever doctor or a clever nurse or whatever, but because I’ve actually been through that experience.” (UK service-user 1)

“... if someone says well come on guys, you don’t know how it feels, I can say well I do actually, and you can get through this, and this is maybe how you can do it, so I’ll be looking more at recovery methods and models.” (UK support worker)

Some UK and Australian practitioners expressed fears that having experienced mental illness may cause others to be concerned about their stability:

“...the person might lose respect, or feel put off, or they can’t rely on you so they can’t lean on you, on the other hand they might feel much more deeply understood, they might feel better rapport with you, might feel encouraged and comforted, it could be either.” (UK psychiatrist)

“If you went to an orthopaedic surgeon and they said I’ve broken my leg, and this is how long it took, these are the problems I had, you’d think fantastic, what a great guy, he’s shared his experience and now he’s up and walking again, but with mental health problems there’s always be a fear that your patients would be thinking, well, what if it goes wrong again? What if they relapse? I would worry that even practitioners in the field of mental health would have similar worries...” (UK service-user 1)

Service-users, however, felt that having dealt and coped with mental health issues was a sign of strength, and that such attitudes were discriminatory or stigmatising in a way that would not apply to the disclosure of physical health conditions:

“... rather than being seen as a weakness, there is a relief that [disclosing practitioners] are human. There’s a relief that somebody has recovered from something that you think is beyond the point of no return for yourself. It gave me respect for them, it gave me hope... it was a breakdown and then a breakthrough, but because of people who were sharing and who were strong as well, they were displaying strength, and they were teaching by their example, rather than preaching at you.” (UK service-user 2)

### 8.5.5 Normalisation and stigma

Service-users and practitioners in both countries suggested that stigma can be reduced and service-users may feel better understood and less isolated in their experiences when they speak to others who have also had such experiences. Normalising was not simply about normalising having a mental health condition itself, but also normalising service-users' reactions to their mental illness:

“...having a staff member openly say to me I've been through this experience, I can understand, made me feel more like I was being heard and understood, rather than just “I'm here again, it's this person again”, I wasn't just being over the, it was actually a natural response, a natural reaction.” (UK service-user 3)

“...that's one of the first things I learnt from coming [to voluntary sector organisation]...on the scale of being extremely anxious and depressed, you're behaving normally, it's normal to not want to get washed, it's normal to not want get out of bed, it's normal to not want to interact with people.” (UK service-user 2)

“... you can use it [disclosure] as a normalisation or an affirming process.” (Australian clinician)

Practitioner disclosure might also serve to destigmatise and normalise service-users' experiences to families and carers, whose increased knowledge and understanding of conditions could help them and the service-user to deal with the impact of mental illness:

“But do you know where it would be really helpful, for a clinician to disclose their mental health? It's to family and carers. My family had left me for dead for those few months. How dare you do this? You're doing it for attention. If clinicians took the time to talk to family and carers and explain to them, this is not their [the consumer's] doing, they do not do this on purpose....this is where the real gap is, so [family] can understand us, and can be more supportive.” (Australian consumer)

“There’s often times when I think about saying to people here [voluntary sector organisation] why don’t you bring your relatives here?... because in their isolated family unit you just think it’s just you, don’t you? Or it’s your family member. You don’t have any perspective on it.... If you’re like my parents, you only believe something if it comes from a policeman or a doctor. You know what I mean? Nobody else has got any validity.”  
(UK service-user 2)

In contrast, a potential drawback of non-disclosure was that it may help to perpetuate stigma, because it “silences the consumer, as much as it silences our staff” (Australian clinician), and this silence might imply underlying negative beliefs about the acceptability of having experienced mental illness and being open about it:

“I would like nothing more than if they engaged with me, and let that guard down more. I feel quite humiliated by it to be honest with you. I feel quite degraded... I feel quite angry as well... you’re made to feel that you’re on a different level, that somehow you’re a substrata.” (UK service-user 2)

“It keeps and us and them mentality. That’s what it does. It’s us and it’s them, we’re different, we’re separate.” (Australian clinician)

### **8.5.6 Focus shift**

Disclosure may take the focus of the interaction away from the service-user towards the practitioner, distracting attention in a negative, unhelpful way. This was seen as a danger by one UK practitioner:

“...when I go to the doctor, I go because I’ve got a problem and want an answer, so if I was seeing a mental health professional, I’d want to go and see him, or her, and get an answer from them, I don’t want to go and see them, and then they give me their problems.” (UK nurse)

Although it was echoed by a UK service-user as a potential danger, they stated that such a scenario had never arisen, and that practitioners tended to be “quite restrained” (UK service-user 1)

In Australia, focus shift did not arise as an issue for service-users, but was mentioned once by a clinician as a potential risk found within counselling and therapeutic literature:

“I’ve read a lot of theoretical books about trauma work, counselling, whatever, and they usually mention somewhere in them about if the clinician self-discloses then there’s a risk that... it’s going to be all about their own issues, and that’s, I think, behind this secrecy and silence.” (Australian clinician)

In contrast, UK practitioners and service-users recognised the positive potential of disclosure to shift focus in a positive way. Disclosing hobbies and out of work experiences was seen as a positive distraction, helping to lighten the mood and encourage service-users to think about positive things instead of dwelling on negative subjects:

“... you can encourage the person to talk more about [hobbies and out of work experiences] as something that they enjoy that’s outside of just mental illness...” (UK therapist)

“Mental health is a hard thing to experience, and... to have a bit of a release within that, to have a bit of a joke or a bit of a laugh, I think for me helps. If you’re in somewhere for two or three weeks, it’s all focused on ‘this is what we’re going to do, this is your recovery plan’... I get bored, I’m in that state, I need to get out of it, and if we talk about people continuing doing things, and that enables someone to continue to go and watch the rugby match, that’s a good thing to me, I think it’s positive that people share.” (UK service-user 3)

While disclosure might shift focus negatively, it might also do so positively, and both UK and Australian practitioners suggested that it is possible to disclose while also maintaining focus on the service-user. As long as this requirement was fulfilled, disclosure need not shift focus in an unhelpful way:

“...[disclosure] has to be focused on the patient, and the therapeutic relationship between the consultant, the patient, and the team as a whole.” (UK psychiatrist)

“So you can use [disclosure] as a normalisation or an affirming process, but then it’s got to be about the consumer and not about you.” (Australian clinician)

### 8.5.7 Boundaries

Disclosure of mental health experiences could lead to boundary violations, putting practitioners and service-users at risk, for example, by developing inappropriate relationships, or by service-users becoming over-familiar with practitioners. For some, disclosure was either considered to be a boundary violation in itself (for which they may be disciplined), or to potentially lead to boundary violations:

“[if anything was disclosed] I’d be in my manager’s office with a verbal warning.” (UK nurse)

“...the danger is... where do you stop having the boundaries, do you start then having a friendship outside of the working environment, do you start going beyond that, is there a danger that you start to lose sight of when do I stop disclosing, and where’s my role here?” (UK therapist)

However, the majority of practitioners indicated that boundary transgressions, although acknowledged as risks, could be avoided if disclosures were made within particular parameters, for example, using it sparingly, for a specific purpose, or limiting its use to particular people or situations:

“I believe you can still have very firm professional boundaries in place whilst you’re disclosing personal lived experiences. For me there’s boundaries that are set in stone, like you don’t borrow money or lend money to a service-user, you don’t disclose where you live, you don’t buy things or sell things. That’s boundaries, isn’t it?” (UK support worker)

“As a psychologist I know in our training there was a lot of emphasis on very clear boundaries and very limited personal disclosure and using it extremely cautiously, when there was a specific therapeutic aim or reason to do so.” (Australian clinician)

Boundaries were also important for one service-user who, despite stating they preferred strict boundaries and minimal disclosure felt that:

“...in the right situation, at the right moment, in the right context, sharing an experience with a service-user, even with me, that would be a good thing.” (UK service-user 1)

### **8.5.8 Nature of illness and setting**

Practitioners in the UK and Australia expressed various fears about what might happen to practitioners if they disclosed. One fear was that service-users might use the information they gained against the practitioner, for example, by targeting them with accusations or threats, or by stalking them, particularly in forensic services where service-users may be seen as more dangerous.

“Where we work [low secure unit] ... we’re not allowed to disclose personal information to our patients, due to the nature of the patient group we deal with, and all that is based around risk.” (UK nurse)

“...I first started out on a psychiatric intensive care unit, with a lot of high risk male clients, a lot who had offending behaviours, stalking behaviours, so I was very boundaried, not giving out any personal information. I lived in the same town that I worked, so I could easily bump in, there were risks, and the person that’s giving them medication, in manners that they don’t want to be given medication, rescinding their leave because they’ve become unwell, so having to do a lot of nasty things, so I was very clear on not sharing information...” (Australian clinician)

However, other practitioners contended that safe disclosure may be possible in such settings because it could be managed in ways that minimised risk:

“We’ve had patients waiting outside in the car park, getting in the back of staff cars, being seen outside people’s houses several miles from the hospital. However, I believe you can still share. For me, I can share a certain amount of my own experience in life, without compromising or putting myself at risk.” (UK support worker)

One UK service-user suggested disclosure about hobbies and out of work experiences had been particularly useful in their experience in inpatient settings, where ordinary conversations helped to break down isolation and lighten their mood.

For some UK practitioners, increased risk and the need to be cautious about disclosure were associated with service-users who had more complex issues such as dual diagnosis, and with disclosures about religion especially where it was linked with illness or delusional beliefs. Among Australian clinicians more caution was advised where “relationship issues and personality issues are strong” (Australian Clinician). Australian clinicians also suggested that more mainstream, well-known illnesses which have been spoken about by celebrities have less stigma attached to them, and may be easier for clinicians to share, for example, depression and anxiety are commonly talked about, while bipolar and affective disorders are spoken about more comfortably than schizophrenia.

Working in community settings and in people’s own homes could make disclosure more relevant because interactions are more intimate and some level of mutual exchange is expected, particularly where relationships are built over a number of years.

In the UK, regarding crisis situations, one service-user felt disclosure had been useful in a real life experience, because it helped to calm them down, but another service-user felt that disclosure may not be helpful when they are ill and inward-looking because they would not be able or willing to hear another person’s perspective.

#### **8.5.9 Burdening the service-user**

There was some concern that disclosure might burden service-users by causing them to worry about the practitioner’s wellbeing, or because the practitioner could burden them by offloading their problems, and this seemed to be more of a concern in the UK than in Australia:

“...is that person then going to start worrying about you, oh this person’s had depression, are they alright?” (UK therapist)



“Part of the reason I started with mental health problems was taking on other people’s feelings and responsibility for the way they felt, and then in the midst of an episode of treatment, to have somebody doing the same thing to me again, telling me about their own experience... part of me says ‘look it’s my problem we’re here to talk about.’” (UK service-user 1)

Although this was of concern to some, others indicated that avoiding burdening service-users might be achieved by limiting the level or depth of information shared with them, that burdening service-users is not inevitable, and that disclosing in the right way at the right time can still be helpful:

“I’ve recently had some ill health, so I’ve now got a different perspective which I would be happy to touch on with some of my consumers as long as it’s going to help their recovery, I’m not offloading, and I’m in a state of wellbeing to share that.” (Australian clinician)

#### **8.5.10 Amount and timing of disclosure**

Getting to know the service-user as an individual was seen as important in choosing whether and what to disclose. Limiting disclosures earlier in the relationship may help practitioners gauge what types and how much disclosure could be useful for individual service-users, and it is important to recognise that this may change over time. For some service-users, disclosure may be unwelcome when they are very unwell, but welcome at other points in their recovery, while for others disclosure may be particularly helpful when they are in crisis. It was also suggested that the likelihood of disclosures being helpful could be increased by making lighter disclosures first, to check out whether the service-user is open to hearing the practitioner’s views and experiences, and allowing time to assess the service-user’s politics and prejudices before disclosing personal information. Disclosures may also be more helpful according to the length of the relationship with practitioners, how intimate it is, and how often they meet. Meeting more often may offer more opportunities for disclosure and also greater potential for disclosures to go wrong, but it was generally felt that workers who have ongoing, intimate relationships with service-users (for example, nurses or support workers) are less at risk than those who see service-users less often and for more limited periods (such as psychiatrists).

### 8.5.11 Self and team awareness

For practitioners, being self-aware was important in determining whether disclosures are made and whether they go well. They may be “put on the spot” (UK psychiatrist) when service-users ask direct questions, and “may say something that [they] really haven’t thought about saying” (Australian clinician). Different practitioners have different levels of comfort about what they are happy for others to know about them. Thinking reflectively about what they are comfortable sharing, and for what purposes, may help practitioners prepare for such eventualities, and experience can help practitioners to negotiate both disclosure and non-disclosure. It may also be helpful for practitioners to consider their motivation for sharing to ensure they are not “offloading” (several UK and Australian practitioners), and to ensure that disclosures are made primarily for the benefit of the service-user rather than the practitioner.

It was felt that good management of disclosure should include open conversations within teams and in supervision, as this may help to consider different perspectives. Several practitioners felt able to discuss disclosure in supervision, others did not. Open discussion of disclosure was felt to help minimise risk, and also increase practitioners’ understanding of how disclosure is used by others:

“...taking it back to discussion with the team can be useful, because [the service-user is] probably going to try it with other people, and what’s the best way we can, discuss this with the team?” (UK nurse)

“I think in general, I have asked what are your [the supervisor’s] views about it, do you ever disclose your own experiences, just to get different people’s ideas about it, because I do think it’s kind of an individual thing, and people have different levels of comfort.” (Australian clinician)

### 8.5.12 Pressure, culture and permission

While in the UK it is known that some statutory mental health organisations write the presence, but not the disclosure of, mental health lived experience into non-peer job descriptions as a desirable criterion (St George’s, London, for example, see Appendix 2), in Australia clinicians had not seen this happen, except in “...non-clinical roles, mental health community support services”

(Australian clinician), and permission to share at an organisational level was felt to be lacking. In Australia, consumers suggested that there was explicit pressure on peer support workers against disclosure, and that there would be more pressure for those in non-peer roles. This was echoed to some extent by practitioners, who felt they would be likely to receive negative judgments from work colleagues:

“If we’re getting stopped talking about it, I don’t know how hard it is for them.”

(Australian consumer)

“...my supervisor said, you’re going to lose credibility if you let people know that’s how you’re working with people, and interestingly, particularly with doctors, was the point.”

(Australian clinician)

Australian practitioners, who included some UK-trained practitioners, generally indicated that disclosure was mentioned to some degree in their training, either explicitly, or as a discussion about boundaries and values. Clinicians said they were instructed to use self-disclosure with caution, limit what they shared, keep boundaries, and avoid becoming over-involved with clients, but they had not been told that they must avoid disclosure altogether. However, one supervising social worker cautioned their own students against disclosure “due to risk” (Australian clinician), another suggested that disclosure was discouraged, and one UK service-user who was also a doctor cited their training as a reason for not disclosing:

“...as a general rule in training we are taught, irrespective of discipline, to be very wary of what you can and can’t share with consumers, and how that will affect them, and how it will affect you, how that will play out.” (Australian clinician)

“... I’m a doctor, so I’ve been trained in that [clinical, detached, non-disclosing] way myself... I almost expect that degree of detachment that I use in my own professional life.” (UK service-user )

Non-disclosure was seen by some as necessary in order to adhere to psychotherapeutic or other practice models, but others saw psychotherapy as a “collaborative process” (UK psychiatrist) wherein generalised, non-personal disclosures may be made. Further, psychotherapeutic training might encourage consideration of disclosure:

“I can remember counselling training where we [were told] we may disclose something, and how you would go about that.” (Australian clinician)

“...and different psychological therapies have quite clear views on that stuff too...”  
(Australian clinician)

There appeared to be more pressure where practitioners worked in secure settings, and more pressure against disclosure coming from doctors or psychiatrists than from other practitioners. Sanctions for disclosure included negative judgments from colleagues and disciplinary action:

“[if anything was disclosed] I’d be in my manager’s office with a verbal warning.” (UK nurse)

“I’ve had a supervisor say to me... you’re going to lose credibility if you let people know that’s how you’re working with people, and interestingly, particularly with doctors, was the point.” (Australian clinician)

In the UK, explicit pressures against disclosure were reported by a service-user regarding social work students on placement who had been told on their training not to disclose, and by a practitioner regarding their own in-house training in a secure unit. In Australia, one supervising social worker indicated they would “...often tell students not to share personal information due to risk” (Australian clinician). Other UK practitioners said they had not received any specific training or instruction about disclosure, but that there was implicit, often unspoken, pressure against disclosing. It was suggested that guidance or permission may be useful to help practitioners negotiate disclosure, or to give them permission to share:

“The implied taboo about disclosure can be a barrier... it would be helpful if you could say certain things, and it would be beneficial for them and for your therapeutic relationship with them, but there aren’t written rules about how. Sometimes it feels like there’s an opportunity here to use personal information that might be therapeutic, but it’s not clear, and you feel unsure about it. And you’re inhibited by this unspoken, almost intuitive thing about taboo.” (UK psychiatrist)

In both the UK and Australia, participants indicated there is a need for guidance on disclosure and permission to share. Suggestions for content included promoting practitioner autonomy in decision making about disclosure, and ensuring they are not pressured to use disclosure where this makes them uncomfortable or they do not wish to for personal or professional reasons, such as adhering to preferred practice models or wishing to keep personal information confidential. It was felt that training and guidance should: take account of contextual factors, rather than advocating fixed rules; make a distinction between disclosure, ethics and boundaries; address timing of disclosures and level and depth of disclosures, with less information in the initial stages, and more information later if appropriate; provide information on how to decline giving answers to direct questions in a sensitive way, for example, if asked where they live, giving general rather than specific information, rather than refusing to answer the question, or referring to another service, such as peer support or external organisation where service-users can talk to others with lived experience; acknowledge that not all disclosures go well, as with other interventions; and include the risks of non-disclosure.

### **8.5.13 Alternatives to disclosure**

Where practitioners wished to avoid disclosure in order to minimise potential risks, a range of alternatives were suggested. They included gaining and using alternative skills; sharing generalised, anonymised information instead of personal information; exploring service-users' need to know something; avoiding answering questions through deflection; refusing to disclose; lying; and referring service-users to another service.

Where clinicians do not have lived experience to share, other skills and training (for example, trauma informed care) might present suitable alternatives to disclosure. However, there was also a feeling that such alternatives might themselves be delivered in unhelpful ways, such as where a practitioner develops insufficient insight into the service-user and their experiences:

“I just find that people who have been trained in trauma informed care can ask the right questions, they have an understanding. Lived experience as well, but trauma informed care, more education, would make a huge difference.” (Australian consumer)

Some UK respondents suggested that generalised or anonymised statements about themselves may enable practitioners to convey knowledge and understanding, normalise experiences, and reduce feelings of stigma, without putting themselves or the service-user at risk:

“In... CBT ... I might talk about, well we all have negative thoughts, or we all suffer anxiety, so it’s inclusive, it’s a common thing... without me saying explicitly... it’s not personalised.” (UK therapist)

Alternatively, a practitioner may talk about other service-users’ experiences to ground statements within personal experience, even if that experience is not theirs directly. This may also be useful where practitioners are reluctant to disclose their feelings about certain treatments, for example, about taking medication:

“the pharmacist ... she’d say well, what happens on other wards with other patients, who are on this medication is that they have problems with these side effects, so she won’t talk about her experiences, and she won’t talk about patients on other wards by name, but she will talk about patients in the hospital who are on that medication.” (UK nurse)

“I’m not inclined to give a personal opinion. I’ll say “some people might think...” or “This is what I think, however I know some people who think X, Y and Z.” (Australian clinician)

Where service-users ask for personal information, exploring why they want to know may help the practitioner to explore the issues that concern them, explore the service-user’s motivation for asking, assess risk, and then either avoid disclosure or make a more informed decision about whether to disclose. This may help to halt the discussion where desired, or turn the conversation back towards the service-user:

“I think if you say to somebody, why is that important to you, it exposes their interest in why they’re asking, and... most times you’ll find it’ll probably end the conversation. If it’s a genuine question, it may lead into a discussion, see where it goes.” (UK support worker)

“...I think, often consumers...particularly if it’s around something like, say, gender, sexuality, like you have no idea what their family attitudes, cultural attitudes, and I think sometimes they’ll [ask] questions to suss out whether it’s going to be safe, and how they’ll be received. And that’s where I... stick with a more open, accepting, or what do you think, this is about you...” (Australian clinician)

In the UK, a couple of practitioners suggested, especially where the issue may be contentious, such as with religion, sexual orientation, suicide or drug use, they may explicitly refuse to share information, conceal aspects of their identity where possible, or lie about their identities or experiences:

“...if they do ask questions and say, are you religious, we say, you know we can’t answer that....” (UK nurse)

“I’m gay myself, and people often assume I’m heterosexual, and ask me direct questions about it, and I don’t tend to put them right, I keep that undisclosed, especially if I think they’re heterosexual.” (UK psychiatrist)

“I know occasions, various clinicians have not actually stated the actual truth, they’ve said they are married, because of sexual preferences, just to get the consumer on board, and I can understand that but I don’t think it’s the best way... I’m thinking in the long run that may complicate things if you’re not open at the beginning...” (Australian clinician)

However, it was also felt that avoiding answering questions in some circumstances was felt to be negative and damaging to the relationship:

“...some people will ignore it and just gloss over it, which is no good, it spoils the relationship between them, or has a negative impact on the relationship with the patient” (UK psychiatrist)

“Consumers will directly ask, have you felt suicidal before, have you tried particular drugs... I can see pros and cons of answering both ways, but you also don’t want to feel like you’re very closed, because I think that can work against trust, and I think my general

response is usually, look I don't usually talk about my personal experiences because this space is about you and the focus is on you." (Australian clinician)

Meeting with others who have experienced a mental health condition can help to normalise experiences and promote recovery. Referral to specialist organisations was a strategy endorsed by one UK practitioner in relation to meeting religious needs, rather than discussing such issues and offering support directly:

"... what we can do is offer you a religious service, so we can get in touch with [the relevant religious organisation] who'll come down and see you on the ward." (UK nurse)

Some mental health service-users do not come into contact with other who share similar experiences, and this may compound feelings of isolation and cause service-users to feel they are alone or unique in their experiences. In these circumstances, referral to internal peer support services or external organisations may be useful. However, service-users in both the UK and Australia spoke about not being referred to either peer support or external organisations:

"I was at the psychiatrist for a good two years extremely ill, and getting iller, and thinner, and on more and more medication, and eventually I had decided to kill myself, or find someone who could help me, because I'd reached the end of the line, and I did, thank goodness, find here [voluntary sector organisation]. But when I went to see my psychiatrist for my next appointment, and they said what have you been doing, and I said I've actually been down to [voluntary sector organisation], they sort of sloped over to a filing cabinet in the corner of the room, got out a leaflet, and went, oh yes, I should have told you about them. And I was too ill to really care at the time, but afterwards I was so angry... they clearly knew about [this organisation] but they hadn't bothered to tell me." (UK service-user 2)

"I'm a little bit confused as to why peer support wasn't offered to me" (Australian consumer)

It was suggested that referrals may not be made to peer support in Australia because the peer support role is not well respected or valued by some practitioners, with such referrals being more likely where the practitioner has personal insight into why referral might be useful because



they have lived experience. This may also be the case in the UK, where service-user 2's lack of referral may stem from a lack of understanding about why such services may important.

Using humour or banter instead of disclosure to help build relationships and establish rapport was felt to be helpful, but such strategies may carry risks of their own:

“... we use the element of humour and banter... and as long as everyone's buying into it, then it's fine, but it's when it oversteps that mark, then it has to be reined in.” (UK nurse)

“I can remember one psychiatrist, a really skilful psychiatrist, and he does use humour and minor disclosures with patients up to a point, on occasion, with one person though he did use a joke and they were a bit too paranoid, they were a bit too unwell and it backfired, they got very offended, they wouldn't let go of it...” (UK psychiatrist)

#### **8.5.14 Limitations and risks of non-disclosure**

One way of minimising risk associated with disclosure is by choosing not to disclose. However, non-disclosure was felt to be a limited strategy for three main reasons: first that it may circumvent potential benefits that disclosure might have had; second that it may lead to additional risks of its own; and third that non-disclosure may have limited effectiveness as an information-concealing strategy because service-users may gain information about practitioners in other ways.

In the absence of real information about a practitioner, service-users may invent information or find other ways of causing distress, suggesting that non-disclosure does not necessarily eliminate risk:

“My point is that we can still get that abuse, we can still get things thrown back at us that don't even exist, that are not real anyway.” (UK support worker)

“I remember [a patient] who, when she was well, I had a good rapport with her, but when she became unwell would get very aggressive... and she made some comment about my parents that was calculated to hurt and did some weird black magic ritual on the ward, directed at my parents, and I found it very disturbing, and that was without any disclosure, so these things can happen anyway.” (UK psychiatrist)

There are many ways in which service-users may gain information about practitioners, and these are not always through direct disclosure. Various ways of being known without deliberately disclosing were suggested in Australia and in the UK. They included: service-users overhearing conversations between practitioners; practitioners having photographs of family members in offices that service-users visited; practitioners’ surnames being seen on their identification badges and these being used by service-users to find where practitioners lived, resulting in one service-user turning up outside a practitioner’s house; being visibly pregnant; being of an identifiable ethnic group; sexual orientation, through mannerisms or dress; the way in which practitioners project themselves; being involved in out of work activities where practitioners come into contact with service-users; being part of the same geographical community; practitioners’ and service-users’ children going to the same school; the amalgamation of small, incremental disclosures to indicate wider (and reportedly accurate) practitioner life stories; and generalised information given during therapy that reveals, over time, the practitioner’s personality, fears and anxieties. These may not be seen as ‘sharing lived experience’, but they illustrate a limit of non-disclosure: it may not be possible to prevent being known simply by choosing not to share lived experience. As a strategy, non-disclosure may have limited viability. These issues affected practitioners’ practice in various ways. Although visible pregnancy gives away information about a practitioner unavoidably, nevertheless if a colleague was present one Australian clinician felt “uncomfortable” and in “fear of judgment” (Australian clinician) if they answered service-users’ questions about their pregnancy. Body language, personal traits and characteristics that lead to stereotypical, but nevertheless accurate and revealing, assumptions about people, such as their sexual orientation, may lead to them being verbally attacked (UK psychiatrist). In other cases, practitioners made attempts to conceal the concealable (for example, removing photographs from offices), or made efforts to manage their boundaries where their personal information was revealed or where they came into contact with service-users in their lives outside of work.

Practitioners also reported making disclosures because they were asked a question and responded without thinking about it first, revealing information that they may otherwise have chosen not to reveal, or revealing information that seemed to be so inconsequential and every-day that they had not recognised it as constituting disclosure.

Finally, several participants in the UK and in Australia indicated that non-disclosure could create barriers in the relationship. Australian consumers reported disengaging from services “still carrying the same problems they came with”, with one service-user feeling “more suicidal, because there was no engagement” (Australian consumer). UK practitioners and service-users suggested that non-disclosure by practitioners may prevent service-users from engaging and disclosing themselves, creating an unbalanced, non-reciprocal “one-way street” of information exchange (UK service-user), or creating feelings of wanting to withhold information themselves:

“... my psychiatrist, I have referred to them in the past as Ice-maiden, that’s a good description of them, they’re very, very detached and cool, there’s very little human response from them, although I’ve been seeing them for quite a while... you are tempted as a human being to think, well sod you, I’m not going to give you anything then, you know, like a tit for tat situation.” (UK service-user 2)

Practitioners and service-users spoke about how disclosure may be discouraged within some therapeutic models, such as psychodynamic psychotherapy, and were critical either of the model itself or of its applicability and suitability to individuals:

"Being too cognitive, being too theoretical, people might be able to mentally grasp it, but they don't feel it. So it doesn't really have any therapeutic... you need those emotions to engage the human mind. It's emotions that add importance to things... adding some humanity and an element of personal experience can be helpful, but you have to do it very carefully." (UK psychiatrist)

“My understanding is it comes from the psychodynamic model, from the Freudian days, when the professionals could sit behind a desk and... not be this professional all-knowing person, and the poor old consumer is getting judged and assessed and labelled on all sorts of stuff, and it's just a carry on from, in my point of view, the dark ages.” (Australian clinician)

“My relationship with my therapist, it was straight out of the Freudian textbook... I never made an attachment, apart from to dislike them... it was a bitterly cold relationship, it lacked any humanity. There was no human interaction between us at all. I think that’s the danger of being detached, you produce a relationship that’s completely devoid of human warmth.” (UK service-user 1)

#### **8.5.15 Job role, status & hierarchy**

Disclosure from authority figures was felt to be helpful in reducing stigma and demonstrating recovery, not only for service-users, but for families and carers too. The impact of a disclosure could be increased where it was made by higher status practitioners such as doctors, psychiatrists, and social workers, because social conditioning was felt to cause people to look up to such figures, and because, in comparison to those in lower status roles they are paid more, and have more responsibility.

Despite the potential benefits of disclosure from those in positions of authority, in Australia such disclosures were uncommon. Doctors and psychiatrists, in Australia, were felt to be judgmental about disclosure, and because disclosure is seen as risky, and they are more responsible for risk management, they are more likely to make efforts to reduce risk as much as possible. Coupled with this, it was seen as harder for doctors to make unpopular and impartial decisions if there is a good rapport or personal relationship with a patient, so professional distance is useful. Risk was seen as particularly relevant where practitioners had greater responsibility for making unwelcome decisions about service-users, making them a bigger target for retaliation, especially doctors:

“...there’s a guy who hit a doctor at the [setting] a few years ago and I still hear service-users congratulating, and they wouldn’t do that with say a health support worker, they’d be saying, what did you do, that wasn’t good was it.” (UK support worker)

“...the person that’s giving them medication, in manners that they don’t want to be given medication, rescinding their leave because they’ve become unwell, so having to do a lot of nasty things, so I was very clear on not sharing information...” (Australian clinician)

Like Australia, in the UK doctors were seen as being at the top of the hierarchy. They contributed to non-disclosing cultures by exerting implicit or explicit pressure on others against disclosure, and by generally being seen as non-disclosing themselves. There were various reasons why doctors may be reluctant to disclose, one of them was because they have stricter time constraints than other professional roles, and time spent with service-users is primarily focused on treatment and review, rather than holistic needs and relationship building. However, one UK service-user, who also coincidentally happened to be a doctor, challenged this view, suggesting that time spent by doctors on disclosure (such as hobbies or interests) may increase the efficiency of consultations, because the patient can be more relaxed and likely to open up about their own conditions, and a UK doctor practitioner in another focus group indicated was supportive of disclosure and indicated that they used it sometimes themselves.

Doctors were seen to be most at risk if disclosures went wrong. Doctors were seen as primarily accountable to their professional bodies first, the General Medical Council and the Royal College of Psychiatrists, and second to their employer, and are more likely to take notice of professional bodies' guidance, ethics, and codes of conduct than those laid down by their employing organisation. Positive messages about sharing lived experience from employers were therefore less likely to impact on practice unless they were backed up by messages from professional bodies.

Doctors were also seen as being more at risk than others because of their unique role as responsible medical officer, being legally liable for any mistakes in treatment. If a complaint were to be made against them, doctors would have more to lose than other practitioners because of their legal liability, professional status, level of accountability, and the length of time it takes to train. This meant that doctors had more to lose if, for example, a complaint were made against them and they faced investigation, disciplinary procedures, or being struck off. If they were struck off it would have life-changing consequences for them, and they would find it difficult to find further employment in their field. This makes them risk averse, and less likely to disclose information about themselves. More than other roles, doctors are expected not to have personal problems, weaknesses or illnesses. They tend to be seen as mavericks if they do share, which indicates that sharing is not the norm. For doctors, sharing lived experience might be likely to reduce perceptions of authority and capability among colleagues and service-users.

It was seen as less risky for nurses and other types of practitioner (occupational therapists, psychotherapists, social workers etc.) to disclose than for doctors, but riskier than for peer support workers. Qualified staff were felt to be accountable to their employing organisation first, and to their registering bodies second. Therefore, these types of practitioner may be more likely to hear and respond to positive messages about disclosure and lived experience in the workforce than doctors. Training for these roles is shorter than for doctors, they are less personally and legally liable than doctors, and there might be a less serious reaction from employers if a complaint were to be made against them. Compared to doctors, the impact of disciplinary action was seen as less severe, but would be more serious than for unqualified staff. There may be a social expectation for qualified practitioners to be illness-free, but this is not as great as for doctors.

Nurses and other qualified practitioners meet with service-users more frequently and for longer periods than doctors, so they have more opportunity to build relationships, and more opportunity for general discussion and disclosure. However, they have less time to spend with service users than peer support workers, and their time also has a focus on treatment and review, rather than on social and qualitative outcomes. Although they might be responsible for making and enforcing treatment decisions that service-users may not like, nurses and other qualified practitioners were not felt to be as big a target as doctors might be, as they have less power than doctors, and are less symbolic of the system. Nevertheless, they may be unpopular, and viewed negatively, regarding treatment decisions and enforcement than unqualified practitioners.

Peer support workers (like health care support workers) were felt to be accountable only to their organisation, not to a professional body. There is therefore no pressure to follow any professional codes of conduct or ethics, so there is less fear of professional misconduct allegations because they disclosed, if they operated within local policies, agreements and procedures. Peer support workers and health care support workers, had the least to lose if they were to face any kind of disciplinary action, as their training is not as lengthy, and they do not stand to lose professional registration. Employers' reactions to complaints are likely to be less severe than for qualified practitioners, because their status and role are lower in the hierarchy. They may be more likely to secure comparable employment if they were to lose their position, than nurses or doctors. Peer support workers have a relatively large amount of time to spend with patients, and greater freedom in how to spend it, compared to other practitioners, so

opportunities for dialogue and disclosure are greater. This is similarly true for health care support workers, though they were not felt to have as much time or flexibility as peer support workers.

Since disclosure is part of the peer support role, participants felt that peer workers are less likely to feel pressured against disclosure, or receive negative judgments from colleagues, compared to other practitioners. This relative lack of external pressure may enable them to more easily cope with some types of risk and be experimental in their practice, as they are less fearful of negative results. Peer support and health care support workers were felt to have more affiliative relationship with service-users that is less confrontational or problematic, so any unhappiness with services is less likely to be directed at them, and disclosure is less likely to result in repercussions.

However, peer support was not without risk or criticism. It was suggested that the greater amount and frequency of sharing involved in the peer support role may be more emotionally taxing in comparison to other roles, and it was questioned whether they have the right support for the impact that sharing might have on them personally. In the UK disclosure by peer workers seemed to be generally well accepted, but it was more controversial in Australia where there was felt to be a general lack of understanding and recognition of the peer support role, and criticism of them sharing their lived experience in their work.

## **8.6 Conclusion**

UK and Australian feedback was similar in many respects. Service-users valued the disclosure of mental health lived experience a great deal, for similar reasons. It could offer hope for recovery, enhance therapeutic relationships, and reduce stigma. Despite the benefits, and despite several service-users reporting positive and helpful practitioner disclosures at some point in their history of service use, many profoundly negative effects of non-disclosure were also reported which led to deterioration in therapeutic relationships, compounded feelings of isolation and despair and, in Australia, disengagement from services.

Practitioners in the UK and Australia were also very much in agreement. They felt implicit and explicit pressure against disclosure, though many of them had shared their experiences and identities, including mental health, at some point, and reported largely positive effects. In

Australia, feedback suggested that both disclosure practice, and the discussion of disclosure were taboo subjects. This indicated that while practitioners may disclose, they may also conceal this practice from their colleagues, which may prevent mutual reflection, practice development, and opportunities for learning. Despite this, some agencies in Australia and in the UK gave some limited examples of proactively matching service-users to practitioners with similar identities or experiences, either within or outside of their agencies.

Although UK practitioner focus group feedback did not highlight any issues with peer workers sharing their lived experience, this was more controversial in Australia, where service-users reported that some practitioners do not see the value of the peer worker role, nor of peer workers sharing their experiences with service-users.

Many benefits of practitioner disclosure were reported in both the UK and Australia, by both practitioners and service-users, and they were often interconnected. Establishing practitioner credibility through the demonstration of lived experience and personal insight into mental health conditions helped service-users not only to take what practitioners said more seriously, but they also felt more understood, which in turn helped to reduce feelings of loneliness, isolation, and stigma. Such benefits of disclosure were not simply ends in themselves, but were connected to achieving recovery goals. Since the promotion of recovery is not confined to peer support roles, most practitioners are potential contributors towards achieving and promoting recovery goals, and confining the benefits of disclosure to some practitioners and not others may be inadequate. Service-users reported that they wanted to feel understood by, and connect better with, a wide range of practitioners, particularly those they had ongoing or important relationships with, such as psychologists and psychiatrists.

Disclosure by peer workers could be very helpful, but it could also be helpful and sometimes more powerful when made by qualified practitioners with higher status and authority. However, in the absence of disclosure from any kind of practitioner, some service-users found the connection and disclosure they needed in the voluntary sector, and were critical of its absence in statutory settings. Reluctance to disclose may be due to a lack of awareness regarding the power and helpfulness of well-made disclosures, explicit and implicit pressure against disclosure, and lack of permission to share. In the UK, risks of disclosure were associated more with practitioners of higher status particularly doctors, and in Australia doctors were associated most with discouraging practitioner disclosure. Since doctors' may have greater concerns about



self-protection and risk-aversion strategies than other practitioners, this may cause them not only to regulate their own disclosure behaviour, but also to deter disclosure by others. This may be particularly effective because of doctors' high status and authority.

Although various alternative strategies were employed instead of disclosure to either reduce risk or gain similar benefits through different means, many of these strategies were either less effective, less preferred, or less powerful than disclosure, or were not used frequently or consistently enough, for example, referral to peer support or external agencies.

## Chapter 9: Discussion

This chapter presents a review of the research in comparison to previous literature. It is organised into 10 main sections, some of which are sub-divided thematically. An overview is provided below:

**9.1 Main Findings:** a brief synopsis of the main qualitative and quantitative findings of this research are presented in table form.

**9.2 Comparison with Previous Research and Literature:** the findings of this research are discussed in relation to the existing general literature from chapters 1 and 2, and the more specific literature from chapter 3. 8 thematic subsections consider: (1) the impact of personal identity on the helpfulness of disclosure; (2) sharing lived experience by peer and non-peer staff; (3) the risks of non-disclosure, pressures that lead to disclosure avoidance, and whether non-disclosure is viable and achievable; (4) how disclosure might be supported to break the cycle of silence, reduce stigma, and promote recovery; (5) how intimacy affects disclosure; (6) what and how disclosures might best be made; (7) the various benefits of disclosure; and (8) the risks of disclosure.

**9.3 Validity checks:** this section draws together various validity checks from previous chapters and some additional observations to assess the validity of current findings.

**9.4 Strengths:** briefly covers some of the strengths of the current research

**9.5 Limitations:** briefly covers some of the limitations of the current research

**9.6 Implications for Clinical Practice:** some of the implications for future clinical practice are suggested.

**9.7 Implications for Future Research:** suggestions for potential future research inquiry are presented.

**9.8 Implications for Policy:** policy implications indicate how disclosure might contribute to national anti-stigma campaigns, and how local policy can support sharing lived experience to better effect.

**9.9 Postscript:** some observations from activities outside of this research are shared that offer additional validity checks and suggest that training and guidance may be helpful to practitioners.

**9.10 Conclusion:** the overall message arising from this research is presented.

## 9.1 Main Findings

### 9.1.2 Chapter 5: Quantitative Results

Service-users rated disclosure of mental health lived experience as the most helpful disclosure subject compared to six other types of information. Practitioners rated hobbies as the most helpful. Service-users' mean rating of disclosure of mental health lived experience was helpful (above 3 on the scale) when undertaken by all types of practitioner, except non-clinical staff. Practitioners' mean rating was only helpful regarding mental health lived experience being shared by peer workers. Where personal identity and lived experience matched the subject of a potential disclosure, service-users and practitioners tended to rate such disclosures as more helpful than those who did not share that identity. Doctors rated disclosure of mental health lived experience by most types of practitioner as less helpful than non-doctors rated it. Regression analysis indicated that characteristics that increased practitioners' helpfulness ratings of sharing mental health lived experience included having a family member or friend with lived experience, having ever shared something with a service-user, being non-white, being non-heterosexual, and not being a doctor. Having mental health lived experience did not appear to influence helpfulness ratings of sharing mental health lived experience directly.

### 9.1.2 Chapter 6: Survey Results 1. Real Life Examples of Sharing Personal Mental Health Information.

Personal mental health lived experience that may lead to diagnosis or treatment was shared least often, followed by mental health related experiences. Information not related to mental health was shared most often. The majority of real-life disclosures were helpful, and a small number were unhelpful. Unhelpful examples were spread across personal mental health, mental health-related, and non-mental health-related disclosure categories.

### 9.1.3 Chapter 7: Survey Results 2. Hypothetical Disclosures.

Practitioners who rated mental health and other disclosures as helpful considered potential effects in a more comprehensive way than those who rated disclosures as unhelpful. Service-users tended to see disclosure in simpler terms: if they found it helpful they rarely mentioned potential drawbacks; if they found it unhelpful they rarely mentioned potential benefits. Explicit and implicit pressure against disclosure was cited by practitioners as reasons for non-disclosure, and these pressures may have greater impact on qualified staff compared to unqualified staff.

#### **9.1.4 Chapter 8: UK and Australian Focus Groups**

Disclosure of personal mental health lived experience was very powerful in some cases and led to turning points in service-users' recovery. Some practitioners shared lived experience to positive effect. Service-users reported that the absence of sharing was damaging, not only regarding mental health, but also other types of lived experience, leading to difficult, alienating and cold relationships with practitioners that sometimes resulted in disengagement. Practitioners did not disclose due to fear and implicit and explicit pressure against disclosure, increasing with professional authority, with doctors at the top of the hierarchy.

### **9.2 Comparison with Previous Research and Literature**

#### **9.2.1 Identity and disclosure subjects**

Henretty & Levitt (2014) suggest that disclosure of shared minority characteristics may be helpful when working with minority groups in counselling contexts. Quantitative findings from the current research resonate with this view, extend the beneficial effects to mental health contexts, and widen the list of relevant minority group beneficiaries.

The current research suggests that sharing personal mental health lived experience is the most helpful and the most powerful type of information that can be shared in statutory mental health services, rather than other types of experience or personal characteristics. This may be because all service-users by default have mental health lived experience so the subject is common and relevant to all. It may also be the case that mental illness is the factor that impacts most on service-users' lives, rather than other identities or problematic experiences. The mental health information that practitioners shared included severe and debilitating episodes of illness, as well as low-level mental health problems. Both types of disclosure were seen as helpful, and service-users in both the Australian and UK focus groups cited disclosure as marking a turning point in their recovery. Although the current research suggests that sharing personal mental health is most associated with recovery, service-users who gave helpful disclosure ratings suggested that most other identities and experiences can contribute to recovery too (see section 7.3.2) agreeing with Dixon et al's (2001) and Leamy et al's (2011) assertions that disclosure of a range of identities may be helpful to service-users, not just mental health.

When considering hypothetical subjects, disclosures appeared to be perceived as especially helpful where identities and experiences were relevant and shared by both parties. All 9 within-group comparisons in table 5.19 showed higher ratings where the disclosure subject matched the discloser's or the recipient's identity, and five of these differences were significant. Between groups comparisons (see table 5.18) show a similar picture: where respondents shared the characteristic associated with the disclosure they consistently rated sharing that information as more helpful than those without, with the results being significant in 6 of the nine cases. Although these results were not always significant, their highly consistent nature suggests that effects may be real, and instances of non-significance may have been the result of low numbers of respondents with particular characteristics, for example, non-heterosexual respondents. Having a particular identity may increase insight into why sharing that identity could be helpful and, conversely, practitioners and service-users without such characteristics may be limited in their ability to understand the helpfulness of sharing them. Qualitative feedback on some of the hypothetical questions supports this view in part, with some respondents reporting that they cannot see the relevance of sharing sexual orientation (see section 7.2.2.4) or religion (see section 7.2.1.4). Although irrelevance was not cited as a major factor deterring mental health disclosure, those practitioners without mental health lived experience may have less insight into the helpfulness of sharing it (see section 7.3.1), and may be less able to understand why colleagues with certain identities and experiences share them with service-users.

Between groups comparisons also revealed that service-users consistently rated the helpfulness of all types of disclosure higher than practitioners rated them, where both groups shared the question's related characteristic (see table 5.18). Although none of these differences were significant, their highly consistent nature suggests that the effect may be real, that non-significance could have been the result of low numbers of respondents, and that practitioners may underestimate the value of disclosure compared to service-users. De Vos et al's (2016) study reported that while the proportion of service-users and practitioners who valued experiential knowledge were similar, the majority of practitioners also cited disadvantages while only a minority of service-users did so. Similar results emerged in the current study, with practitioners being more likely in hypothetical disclosure questions to cite both helpful and unhelpful aspects of disclosure than service-users, who tended to view disclosure in a more one-sided way, as either helpful or unhelpful. This may be responsible for differences between practitioners and service-users in mean ratings of hypothetical disclosures in the current study.

Where neither the service-user's nor the practitioner's identity matched the subject of the disclosure, practitioners rated disclosure as more helpful than service-users did (see table 5.18). Although these results were not significant, since all three cases gave consistent results, non-significance may be due to low numbers of respondents with those identities. This agrees with the findings outlined in Chapter 7 which indicated that practitioners are more likely to consider a mixture of positive, negative, and mediating factors in their decisions about disclosure than service-users do. These results might be expected, since it is part of the role of practitioners to understand the needs of service-users and assess the likely impact of any interventions, while there is little equivalent pressure on service-users to consider the potential needs of other service-users.

### **9.2.2 Peer and non-peer roles**

Initial analysis of survey data was insufficient to draw conclusions about whether, or how, practitioners' job roles affected the dynamics of disclosure. There was little to explain why disclosure might be more risky for some practitioners, such as doctors or nurses, than for others such as peer workers and support staff. To understand the influence of job role in perceptions of disclosure, the second UK focus group focused solely on this topic (see section 8.5.15), which led to new insights and re-analysis of survey data resulting in the commentary included in section 7.6.2. It also enabled a comparison to be made between doctors and non-doctor ratings of mental health disclosure described in the logistic regression (see section 5.4 and 5.5.2) and an explanation of the results (i.e. why doctors rated disclosure as less helpful than other practitioners).

This analysis indicated that there was a tendency for practitioners to believe that qualified staff were at greater risk through making disclosures than non-qualified staff such as peer workers and support workers. Risk was particularly prevalent for doctors, who were at the top of the hierarchy, and who may be seen as representative of the services that service-users may be unhappy with, making them a greater target for misuse of disclosed information and complaints. However, real life examples indicated that disclosure was used by all types of practitioner, that repercussions were rare, and not confined to psychiatrist disclosure, nor any other specific job role. In addition, some service-users suggested that qualified-practitioner disclosure could be especially helpful and powerful in reducing stigma, and normalising experiences.

Personal mental health lived experience was prevalent among non-peer practitioner research respondents, and may be more prevalent in mental health services than among the general population (see section 1.4.1), supporting suggestions by Curtis & Hodge (1994) and Marino et al (2015) that no neat dichotomy exists between practitioners and service-users. This research fills the gap in research knowledge identified by Davidson et al (1999) regarding the part that self-disclosure of lived experience plays in both peer and non-peer clinical roles. The findings of this research suggest that practitioners generally pursue and promote many of the central elements of peer support roles identified in section 1.3.4, namely recovery, hope, role modelling, stigma reduction, and developing good relationships with service-users. This thesis supports findings from previous literature that suggest peer support can reduce “isolation, despair and demoralization” (Davidson et al, 2006, p. 448), and can positively impact on hope and recovery (Lloyd-Evans et al, 2014; Morgan & Lawson, 2015; de Vos et al, 2016; Marino et al, 2015) and self-efficacy (Lloyd-Evans et al, 2014). It also supports Kottsieper’s (2009) view that the benefits of sharing lived experience are not restricted to the peer support role, but may be realised by other types of practitioner support and disclosure. The dual status of practitioners who have experience of mental illness increased their credibility among some service-users, in line with Schiff’s (2004) assertions, and as Yarek (2008) and Asad & Chreim (2016, in relation to peer workers sharing lived experience) suggested, practitioner disclosure to other practitioners sometimes helped to increase their knowledge and understanding of service-users’ situations and conditions. Although some of these aims were also achieved by sharing identities and experiences other than personal mental health, service-user responses to hypothetical questions and feedback from focus groups indicated that sharing personal mental health lived experience was the most helpful disclosure subject, while real life examples of disclosures indicated it was shared least often. This agrees with Adame’s (2011) finding that therapists disclose lived experience rarely, and Geppert & Taylor’s (2014) finding that the majority of psychiatrists would be reluctant to disclose relevant mental conditions to service-users.

Service-user mean ratings indicated that they found personal mental health disclosure helpful when undertaken by all types of clinical practitioner, whereas practitioner mean ratings were only helpful for peer worker disclosure. Although service-users rated mental health disclosure as most helpful when delivered by peer workers, some non-peer worker disclosures were especially powerful because of the discloser’s higher professional status, as evident in the UK and Australian focus groups, and in responses to hypothetical questions (see sections 7.4.1.1 and 8.5.1). Real life examples of sharing also indicated that mental health disclosure by nurses

and support workers helped to make them more human, increase the credibility of their professional knowledge, and build therapeutic relationships. Thus, the helpfulness of disclosure appears to be increased by higher professional status, while disclosure simultaneously removes barriers and professional distance that higher status might create.

This study suggests that practitioners could share their mental health lived experience as effectively, and in some cases more effectively, than peer workers, but in real life sharing tends to be restricted to peer worker roles. This could be interpreted as diminishing the value of peer workers sharing, but powerful focus group testimonies indicated peer worker disclosure offered hope for recovery to service-users who did not receive it from other sources. However, in both the UK and Australia there were instances where service-users were not referred to or offered peer support. Respondents reported that the lack of peer support was damaging to them, and they felt practitioners did not understand the peer support role or its importance to individuals (see section 8.5.12). This supports previous reports of peer workers feeling inferior to other practitioners (Gillard et al, 2013), and indicates some ambiguity among practitioners about the nature of the peer support role (Gillard et al, 2013; Cabral et al, 2014; Asad & Chreim, 2016).

Despite personal mental health being the most helpful disclosure subject, the prevalence of lived experience in the workforce, and recognition among some employers that lived experience can be a helpful asset in non-peer job roles, service-users' real life examples indicated most disclosures of personal mental health information came from peer workers and support workers. Although the overall low number of examples of this type of disclosure limit the accuracy of conclusions about the frequency of sharing by job role, since validity checks indicate overall general accuracy it may be correct to assume that most mental health disclosures are being made by peer and other support workers (see section 9.3). This suggests qualified staff are more reluctant to share personal mental health lived experience, and unqualified staff are providing the bulk of helpful mental health disclosures in real life. Practitioners, in contrast, indicated that most mental health disclosures came from qualified staff. However, since qualified vastly outnumbered unqualified practitioner respondents, this observation does not necessarily refute service-users' indications.



### 9.2.3 Non-disclosure

A quarter of practitioners said they had not disclosed anything to service-users in the past, and a significant number rated disclosure of mental health lived experience, and other types of lived experience, as unhelpful. While non-disclosure appears to have been a means to avoid some of the potential pitfalls associated with disclosure, it also came with complex effects, motivations, and implications.

#### 9.2.3.1 Risks of non-disclosure

One of the potential benefits of non-disclosure for practitioners is that they may be able to construct a socially desirable self-image through the concealment of mental illness (Kelly, 2000, in Farber, 2006, see section 2.7.3), and avoid being discredited through stigma and prejudice (Goffman, 1963). The current research found evidence to suggest that practitioners may avoid disclosure to escape negative judgement from colleagues and service-users, present an image of wellness, and adhere to constructs of professionalism. This ties in with suggestions from various authors that disclosure can lead to negative judgements from colleagues (Morgan & Laswon, 2015; Adame, 2011; Boyd et al, 2016). However, concealment of mental illness may perpetuate stigma and cultivate inaccurate views of mental health dichotomies between ‘unwell’ service-users and ‘well’ staff, and disclosure avoidance may strengthen the dichotomy between ‘unprofessional’ disclosing staff, and ‘professional’ non-disclosing staff.

Non-disclosure was cited by some service-user respondents, particularly those in the focus groups, as spoiling therapeutic relationships, causing distress, and leading to disagreeable perceptions of their practitioner, agreeing with previous literature on non-disclosure (see section 2.7.3) which suggests that that insufficient disclosure can elicit negative views of practitioners (Egan 1990, cited in Ashmore & Banks, 2001), and non-disclosure can cause distress (Evans & Barker, 2010) and damage therapeutic relationships (Gibson, 2012).

In survey responses, some service-users interpreted non-disclosure as a means to assert power and control over them (see section 6.5), and experienced such interactions as non-reciprocal and unfair. Practitioner survey respondents reported feeling it would be rude not to disclose in some circumstances, because some reciprocity is necessary for good relationships to be maintained (see section 6.4.3), and UK and Australian focus groups suggested this was the case,

with service-users expressing considerable anger and reporting disengagement due to the lack of reciprocal disclosure. Those practitioners who used non-disclosure to explore transference may interpret service-users' feelings in light of what they reveal about their relationships, however, as Stolorow (1997) suggests, reactions may not reveal anything about the service-user's psyche, but comprise normal reactions to unhelpful working and interpersonal practices.

One health care assistant felt that disclosure by peer workers appeared to be authentic and meaningful and that they would like to be able to disclose too (see section 7.4.1.2), and there were a few other indications that that non-disclosure can cause practitioners to feel less authentic. This supports Gough's (2011) and Morgan & Lawson's (2015) suggestion that non-disclosure may cause practitioners to feel dishonest or fraudulent.

Non-disclosure was frequently cited as a way of reducing risk to the practitioner throughout focus groups and the survey. However, as a strategy for risk reduction, non-disclosure may be limited because examples given in both surveys and focus groups suggested that in the absence of real information, service-users could, and did, invent damaging information about practitioners and used that to cause them distress and to make complaints about them, agreeing with Morgan & Lawson's (2015) suggestions that non-disclosure may encourage the development of fictitious accounts of practitioners' lives.

### ***9.2.3.2 Pressure against disclosure***

Real life examples of sharing (chapter 6) and the UK and Australian service-users focus group feedback (chapter 8) indicate that personal mental health lived experience is shared least often; hypothetical ratings (chapter 7) suggest it is the most helpful type of disclosure for service-users; half of practitioner respondents who gave their mental health status indicated they had personal experience of mental ill-health; three quarters of practitioners said they had shared some information about themselves with service-users; and practitioners did not cite irrelevance as a reason for not sharing personal mental health experiences. The prevalence of mental illness in the workforce may be higher than in the general population, and certainly in the current research those with mental health lived experience comprised 50% of practitioner respondents. There is much to encourage practitioner openness about mental illness, including national campaigns such as Time to Change (2017a, see section 1.3.4.3), localised efforts to recruit more mental health practitioners with lived experience into the mental health workforce (see section

1.4), increasing use of peer support (see section 1.3.3), and the positive experiences of sharing cited by most practitioners and service-users in this study who experienced sharing mental health information in real life (see section 6.2.3.1).

This suggests that something other than lack of relevance, lack of experience, or fundamental opposition to self-disclosure per se, deters practitioners from making mental health disclosures and encourages them to practice in what Repper and Carter (2010) refer to as traditional, linear, client/professional dichotomies. This places practitioners in a contradictory situation where they pursue actions to reduce stigma for clients but feel compelled to hide their own experiences (Otto et al, 2009; Curtis & Hodge 1994).

Practitioners felt that admission of illness might cause service-users to worry about them, and this was the case for some service-users who felt that knowledge of practitioner illness would cause concerns about their credibility, stability, and reliability. This exerted pressure on some practitioners not to disclose. However, there were competing views that disclosure could increase credibility; reduce stigma; demonstrate recovery; and be beneficial to service-users, practitioners, and their relationships with each other.

Although no direct examples were given of actual discrimination against practitioners by colleagues and managers, as suggested by Miles (1998), practitioners did report fear of being judged negatively by colleagues and managers in the UK and Australian practitioner focus groups, a finding that concurs with other research findings from Morgan & Lawson (2015), Boyd et al (2016), and Adame (2011). Practitioners also reported concerns about the threat of disciplinary action (UK practitioner focus group); and being instructed not to disclose during training (ibid). Other pressures that deterred disclosure included adherence to therapeutic models, as outlined in section 2.5 and 9.2.8 of this thesis, and the avoidance of various forms of risk which were cited throughout hypothetical responses to a wide range of disclosure types. Risk was explored in more depth in the UK and Australian practitioner focus groups. Risk included service-users using information against the practitioner, which could result in complaints and disciplinary procedures.

Focus group discussions in the UK indicated risk increased with practitioner authority, with doctors being at the top of the hierarchy. A clinician in the Australian focus group took this further to suggest that doctors may not only be concerned about their own disclosure and risk,

but pressure colleagues implicitly or explicitly to avoid disclosure too. Since doctors have high status and authority their views may have significant impact on how other professionals behave. Further, if the suggestion of Geppert & Taylor (2014) is correct, and the majority of psychiatrists would not disclose because of their psychoanalytic training and approach, this might combine with their authority status and position of influence to enable psychoanalytic conventions to have a disproportionate effect on other practitioners' use of disclosure. Quantitative findings support this view, since doctors rated disclosure of mental health as less helpful than any other type of practitioner rated it, regardless of the job role of the potential discloser. Similarly, regression analysis indicated that one of the factors associated with lower helpfulness ratings of personal mental health disclosure was being a doctor. Doctors, therefore, were not only concerned about disclosure by other doctors, but opposed to disclosure of mental health lived experience by any other type of practitioner too, even peer workers for whom disclosure is an integral aspect of their role.

One reason for non-disclosure, cited several times in the survey by practitioners and some service-users, was that disclosure is explicitly forbidden in professional codes of conduct, standards and ethics (see section 7.5.2). A review was undertaken of the major codes and guidance statements relevant to the job roles of practitioner respondents in the current research (nurses, doctors, psychologists, social workers, dietitians, occupational therapists, physiotherapists, psychotherapist, and counsellors). Of the 20 documents reviewed, 14 did not mention disclosure, and the 6 that did promoted good management of disclosure rather than condemning it, agreeing with feedback from a focus group of representatives of professional (registration) bodies (Morgan & Lawson, 2015) which indicated a propensity towards disclosure management, rather than avoidance. However, all 20 codes of conduct and ethics warned against boundary violations, and 16 made reference to the need for practitioners to maintain good personal mental health. It is feasible that these messages combine to: (a) give the impression that disclosure of personal mental health problems could indicate a lack of competence; (b) where disclosure is not mentioned, the emphasis on the maintenance of professional boundaries could be interpreted to implicitly include disclosure; and (c) where disclosure is mentioned, warnings about careful management of disclosure may convey an implicitly negative, risk-laden message that disclosure might best be avoided altogether.

Although, during their training, some practitioners in the Australian and UK focus groups felt they had received positive or neutral messages about using disclosure in their work, others said

they had been warned against it, agreeing with Boyd et al's (2016) empirical findings, and Kottsieper's (2009) account of personal experience. One Australian practitioner said they warn pre-qualifying practitioners against disclosure until they are qualified, to avoid criticism of their practice. However, there is little in the current research or in the literature about whether and how the topic of disclosure is dealt with during practitioner training.

Bottrill's (2010) study of trainee clinical psychologists suggested that disclosure is seen as a taboo subject, and while the current study endorses this view, there is no clear reason why this may be because the evidence seems contradictory: although there was some suggestion of pressure against disclosure, the incentives to disclose mental illness outlined in the opening paragraph of section 9.2.3.2 (above) appear to be stronger than the factors which oppose its use. Norm circles (Elder-Vass, 2012, see section 1.2.4.5) may offer an explanation for the continuation of practices that are perpetuated by false or inaccurate perceptions and minority pressure. The propagation of an anti-disclosure culture may not rely on majority pressure, but the perception, however misplaced, that negative judgment awaits practitioners if they disclose. It may be the case, for example, that no practitioner in a proximal norm circle, such as a professional team, holds anti-disclosure views. It may only be necessary for practitioners to believe that other team members might or do hold such views to influence conformity to an implicit, unwritten set of rules that do not, in fact, exist. It could also be the case, for example, that in such a team most or all members have lived experience of mental illness, and that all or most of them share this with service-users. However, if all or most members are concealing their lived experience and their use of disclosure, this may reinforce group members' perceptions of practitioner wellness and disclosure avoidance. The indication from this research is that practitioners are not sharing their lived experience of mental illness to any extent; one doctor (ID029) indicated they actively sought to conceal their illness from their colleagues (see section 7.4.1.1); and fear of negative judgement from colleagues was reported in both the survey and in focus groups. Hence, although some practitioners may be disclosing, they may not make this known, and feedback from Australian practitioners suggested that discussion of disclosure was as taboo as disclosure itself. Although strident anti-disclosure practitioners were in a minority in the current research, norm circle theory may explain why their impact is greater than their prevalence might suggest.

While there appears to be little demonization of disclosure in the research literature, and none in the professional codes of conduct or ethics, practitioners may abide by the rules that they

think exist. These perceptions could be passed on verbally, but may also arise from the lived reality of working in teams where disclosure and personal mental illness are taboo discussion subjects. This may also be underpinned and perpetuated by the active pursuance of dogma (Malloch & Porter-O'Grady, 2010), which is resistant to the development of new practices.

Non-disclosure may also create other imagined norm circles. In reality (the actual norm circle) many practitioners have experience of mental illness. Concealing mental health lived experience in the mental health workforce may cultivate perceptions of a simple and neat dichotomy between 'well practitioners' and the 'ill service-users', encourage the construction and perpetuation of an incorrect imaginary norm circle, and compound feelings of isolation and stigma among service-users. This is antithetical to outcomes that the mental health workforce, professional bodies, and campaigns are ostensibly trying to achieve. Pursuit of Freud's blank slate practice (see chapters 1 & 2) may be a minority pursuit, but in norm circle theory minority views, even non-existent views, may be enough to perpetuate practice.

### ***9.2.3.3 Unavoidable disclosure***

Service-users and practitioners gave examples of non-deliberate practitioner disclosures that were attributable to circumstances or visible signs, such as walking with a limp or visible pregnancy (see section 6.4.3), highlighting what Meissner (2002, P.854) refers to as the "false dichotomy" between disclosure and non-disclosure because full non-disclosure is difficult, if not impossible (see section 2.7.3). The current findings agree with previous literature which suggests that practitioners may be known by what they 'give off' rather than what they deliberately 'give' (Goffman, 1963; Silverman, 2001). In particular, examples were given of service-users learning about practitioners through photographs of family in offices (highlighted by Raines, 1996); visible pregnancy (Silverman, 2001; Hjalmarsson, 2005); and the ways in which practitioners projected themselves and conversed with service-users (Meissner, 2002; Renik, 1995). Although, in one Australian focus group, a service-user suggested that practitioner lived experience can be 'felt' even if they do not talk about it (see section 8.5.2), examples of non-deliberate, automatic, or unavoidable disclosure were generally not given in relation to personal mental health lived experiences. This may suggest that experience of mental illness is more concealable than other experiences and identities. However, Yarek's (2008) reflections on the difficulty of concealing personal mental health information from colleagues were echoed by one psychiatrist who said he did not attend a lived experience group because he may meet staff

members whom he is treating, suggesting that concealment is not necessarily straightforward or without consequence.

#### **9.2.4 Breaking the cycle of silence**

##### ***9.2.4.1 Guidelines and training***

Previous literature has suggested that there is little guidance to help practitioners make decisions about disclosure (see section 2.8; Ashmore & Banks, 2001; Bottrill, 2010; section 3.1; Morgan & Lawson, 2015), or that stresses the importance of good disclosure management (Gilbert & Stickley, 2012). This was echoed in the current research, with some practitioners reporting they do not have access to training, guidance, or permission to share, while others reported receiving negative, disclosure-detering messages in their professional training (see section 6.2.3.3 regarding the lack of guidance or consensus on disclosure; section 6.5 on the influence of psychotherapeutic training, nurse training, and concern about breaching codes of conduct; and section 7.4.1.1 concerning the belief that a code of ethics specifically stops psychiatrists disclosing).

##### ***9.2.4.2 Proactive agencies***

Several researchers stress the importance of organisational support for using lived experience in practice (Gilbert & Stickley, 2012; Marino et al, 2015; Morgan & Lawson, 2015), though several also suggest that practitioners feel they may face negative judgements if they reveal their experiences (Morgan & Lawson, 2015; Adame, 2011; Boyd et al, 2016). Organisational support could include giving permission for practitioners to share their lived experience, but it might also include proactively matching service-users with practitioners based on identity and experience. Few positive examples were given in the UK and Australia of organisations proactively matching practitioners and service-users based on their personal characteristics and needs. In the UK, the single example given involved linking service-users with external agencies based on their religious identity. In Australia there was an example of matching a practitioner with a service-user based on parenting experience, and Australian clinicians felt it was generally acceptable for substance use workers to share their experiences of substance use (see section 8.5.3). However, these examples appear to be in the minority, and several service-users in the survey and in the focus groups felt they either did not meet other people who shared their experiences, or if they

did it was through external voluntary sector organisations. This suggests that it may be beneficial for organisations to link service-users more consistently with a wider range of peer and non-peer support, either internally or in other organisations. While mental health lived experience appears to be at most valued, other identities, experiences and needs should be taken into account.

#### ***9.2.4.2 Stigma reduction and hope for recovery***

Lack of training and guidance, and the lack of overt permission by managers in mental health settings for practitioners to share their personal mental health lived experience, may undermine the efforts of high profile campaigns aimed at decreasing the stigma of talking about mental illness, such as Time to Change's Time to Talk campaign funded by the Department of Health (Time to Change, 2017a, 2017b). Lack of permission to share may also question the purpose of proactive efforts of mental health organisations to recruit practitioners with lived experience, if they feel they are not able to explicitly use this in their work (see section 1.4).

While sharing personal mental health lived experience could be especially powerful from qualified practitioners, several service-user and practitioner survey respondents cited fears that it might invalidate the practitioner, causing concern about their competence, reliability and potential relapse, agreeing with Mallow's (1998) non-empirical paper and several empirical papers that highlight practitioner concerns about negative judgement from colleagues (Morgan & Lawson, 2015; Adame, 2011; Boyd et al, 2016). This may constitute a valid reason for non-disclosure. However, since many practitioners do have lived experience, buying into what one Australian clinician termed the 'silence' of non-disclosure may create an unrealistic fantasy of a dichotomised world that perpetuates fears about the inescapability of mental illness, in which practitioners constitute a subset of a generally 'well' population and service-users are a service-accessing subset of an 'ill' population (see figure 9.1, below). An alternative world view may be promoted by ensuring that service-users do not feel as isolated and alone as many respondents to the current research reported (see figure 9.2). Further, as Mallow (1998) acknowledges, it is not necessary to avoid disclosure entirely, but to strike a balance so that concerns about relapse and capability are avoided.



Figure 9.1: Dichotomised view of practitioners and service-users

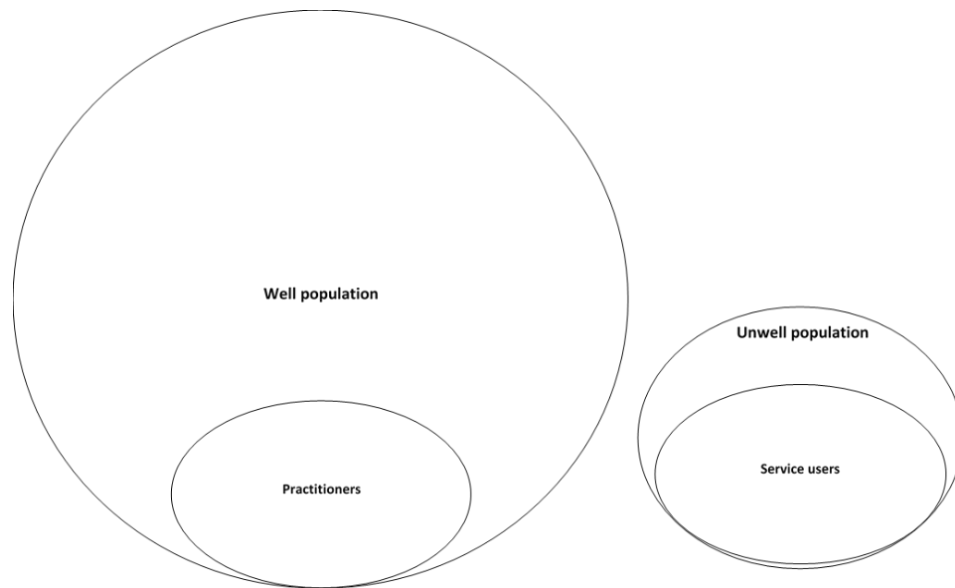
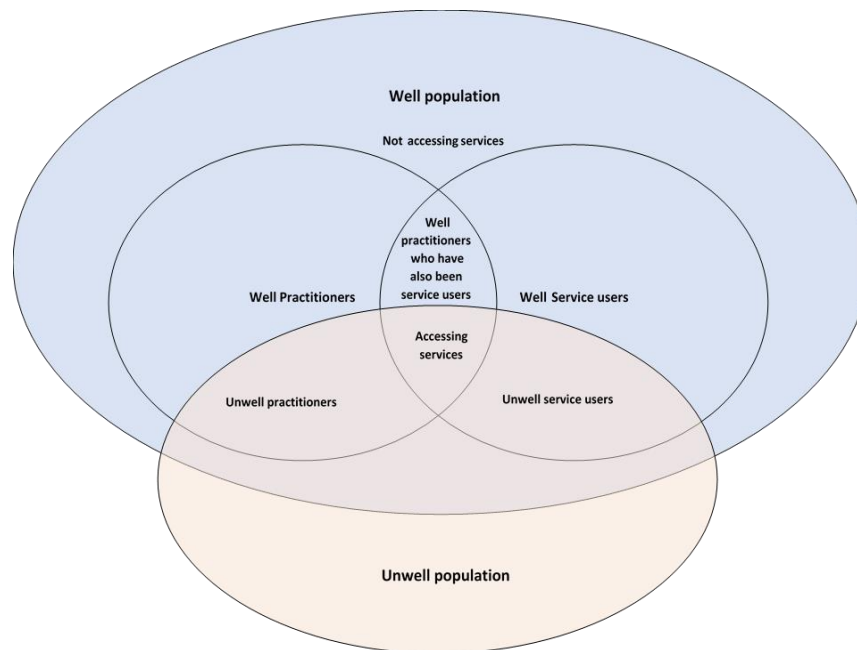


Figure 9.2 Integrated view of service-users and practitioners



Applying Ingleby's (2010) adaptation of Kelley's (1973,cited in Ingleby, 2010) theory of covariation to mental illness, prejudice may occur where the behaviours, illnesses or conditions of the affected person are: highly consistent, i.e. repeated or long-term; of low distinctiveness, i.e. they also exhibit other undesirable behaviours, such as absence from work, professional incompetence, or emotional instability; and of low consensus, i.e. most other people do not have a mental illness.

Viewed in this way, practitioner silence may perpetuate the service-users' views that practitioner (and their own) relapse is inevitable; that the practitioner (and perhaps themselves) will have other undesirable behaviours, such as instability and incompetence; and that service-users are a separate, isolated group of people who are somehow different to practitioners and the general public. Non-disclosure may help perpetuate the stigma and prejudice that the mental health workforce and policy makers are ostensibly supposed to tackle.

Haghighat (2001) suggests that anti-stigma campaigns operate at a cognitive level, and their success may be limited if action is not taken in other domains. Table 9.1 offers a potential framework for how sharing practitioners' lived experience of mental illness might contribute to Haghighat's suggested six levels of intervention (see section 1.3.4.4).

Table 9.1: Intervention at 6 levels

<b>Level</b>	<b>Haghighat's description (aimed at reducing stigma)</b>	<b>Suggested contribution of sharing lived experience to stigma reduction and recovery promotion</b>
Educational intervention	Cognitive level. Campaigns and awareness aimed at how people think.	Practitioner voices in mental health campaigns. At a local level, could include practitioner champions of sharing lived experience.
Affective intervention	Intervention aimed at exploring and changing how people feel about mental illness.	Enable practitioners to talk to each other and with service-users about their feelings and fears towards disclosure.
Legislative intervention	Intervention at legislative level, to change discriminatory laws, for example.	Endorsement of sharing lived experience at organisational, policy levels, including professional bodies.
Political intervention	Understanding the political system within which stigma operates, whereby some attributes are valued above others.	More cohesive, inclusive relationship between practitioners in different roles with each other and with service-users. Break down professional divisions about sharing lived experience (who can share, and who cannot). Breakdown unhelpful divisions between practitioners and service-users.
Linguistic intervention	Replacing negative language with positive terms.	Promote positive language about disclosure focused on management and proficiency, not risk.
Intellectual and cultural intervention	Developing new ways of conceptualising and valuing difference.	Challenging anti-disclosure ideology. Developing new models, training, guidance, and practice. Moving from consideration of whether to disclose, to how to disclose to best effect.

### 9.2.5 Disclosure and Intimacy

Practitioners appear to be reluctant to share more intimate aspects of their lives, and more willing to share less intimate information. Henretty & Levitt (2010, see section 2.6.2) suggest that disclosures at different levels of intimacy may be more or less helpful depending on the stage of the relationship. The development of the pre-research intimacy scale indicated a hierarchy of intimacy for the seven different types of hypothetical disclosure. In the current research, there were no correlations between ratings of helpfulness of different types of disclosure and their intimacy ratings. However, this does not necessarily refute Henretty and Levitt's findings because the stage of the relationship between the hypothetical disclosure and the person being disclosed to was not explored. Additionally, although no correlations were found between intimacy and helpfulness, personal mental health was the second most intimate disclosure subject, and was the least shared, while hobbies were rated least intimate and were shared most often. It may be the case that intimacy does not impact on perceptions of helpfulness, but does impact on what types of information are shared.

### 9.2.6 What and How to Disclose

The current research agrees with suggestions in previous literature that sharing past, resolved struggles can be helpful (Morgan & Lawson, 2015; Henretty & Levitt, 2010; Knox & Hill, 2003, see section 2.6.3). In the hypothetical survey questions, although some service-users felt that mental health disclosure could cause concern about practitioners' illness, weakness, credibility or reliability, agreeing with Gody (1996, see section 2.7.2), a greater number of respondents felt that credibility could be increased (7.2.3.1) especially in relation to mental health rather than other types of disclosure. Additionally, many real life examples of disclosure, which service-users found helpful, promoted recovery and coping mechanisms despite practitioners' past struggles, (see chapter 6). In the focus groups, the helpful nature of disclosing past struggles with mental illness was even more apparent (see chapter 8).

In the current study, some service-users were concerned that they may not be able to cope as well as the practitioner did, rendering disclosure unhelpful, agreeing with Dilts' (1997) suggestion that such disclosures could be disempowering where service-users are not able to overcome their problems in the same way that practitioners have. Disclosures of success alone may be received less favourably than disclosures that acknowledge struggle (Henretty et al,

2014), and disclosures of information without motivational statements may be ineffective in raising feelings of trust and expertise towards practitioners (Abramsky, 2013). In the current study, although motivational statements were not explicitly mentioned, real-life disclosures tended to be made with a purpose, promoted recovery and coping mechanisms, acknowledged difficulties, and were almost exclusively experienced as helpful.

Unlike previous literature, the current research gathered several examples of disclosures regarding mental health and mental health-related information that were current and unresolved, including sharing information about conditions or difficulties, such as phobias, difficulty sleeping, or being on anti-depressant medication. Disclosing past and resolved struggles, as well as current and unresolved struggles, appear to be helpful as long as they are managed in the right way, have a positive message and demonstrate recovery, coping, or living with a condition effectively.

Knox & Hill (2003) suggest that disclosure should be used infrequently, and also that it is used infrequently. This study agrees with these assertions; poor disclosure occurred where disclosers spoke too much about themselves, though this was only cited in relation to real-life disclosures that were not related to mental health (see section 6.4.3.2). Focus group attendees suggested it was not necessary to disclose often or a great deal to obtain a positive effect (chapter 8.5.1 & 8.5.10). In the real-life examples, service-users and practitioners frequently spoke about the need to limit disclosures as a mediating factor of success (see section 6.2.3.3). The almost exclusively positive nature of the real-life examples in this study suggest that practitioners are getting the frequency and amount disclosure right.

The current study did not measure the same items as Somers et al (2013), but general findings are in agreement. Somers et al suggest that positive therapy outcomes may be achieved where disclosures of psychological problems are similar in nature to those of the client. In the hypothetical questions, service-users tended to dislike disclosures of dissimilitude, and indicated disclosures were better where they were relevant to their situation. In real life examples, most disclosures appeared to be relevant and were experienced as helpful.

Feedback from the UK practitioner focus group suggested that disclosure can be particularly helpful in group therapy situations to enable group members to feel less reticent to disclose their own experiences, agreeing with Dixon et al's non-empirical literature review (2001).

### 9.2.7 Benefits of Disclosure

The current study agrees with Bottrill (2010), de Vos et al (2016), and Marino et al (2015) that disclosure of mental health experiences can improve therapeutic relationships. This study also supports findings from various authors that suggest disclosure can have a wide range of beneficial effects for recipients (see section 2.7), including: normalising conditions and behaviours (Glessner et al, 2012; Morgan & Lawson, 2015); demonstrating authenticity and congruence (Burks & Robbins, 2010); being reassuring (Knox & Hill, 2003); increasing client disclosure (Henretty & Levitt, 2010); and equalising power, demonstrating honesty and genuineness, validating service-users' experiences, and overcoming treatment impasses (Gorkin, 1987, cited in Maroda, 1999). In particular, service-user focus group feedback (see chapter 8) supports assertions from the empirical (de Vos et al, 2016; Marino et al, 2015; Morgan & Lawson, 2015) and non-empirical literature (Costin & Johnson, 2002; Burnell, 2001; Yarek, 2008) which suggests disclosure can offer hope for recovery, and may also mark turning points in recovery (Burnell, 2001; Yarek, 2008). Other findings in agreement with messages from the non-empirical literature were that mental health and other disclosures can help challenge service-users' beliefs that no-one understands them (Costin & Johnson, 2002), educate colleagues by providing insider perspectives on conditions (Yarek, 2008; Asad & Chreim, 2016), and that professional status and consumer status reinforce each other to provide greater credibility among service-users of practitioner knowledge (Schiff, 2004).

This study agrees with the findings of Henretty & Levitt's (2010) review suggesting self-disclosure is more beneficial than non-disclosure from the service-user's perspective. In the survey, more service-users (n=54) rated mental health disclosure as helpful than rated it unhelpful (n=37). The number of helpful ratings increases further if the majority of middle-ratings are amalgamated with helpful ratings, which seems reasonable since the positive/negative statement analysis given in section 7.2.2.1 indicated that most service-users who gave middle ratings thought disclosure was 'helpful if' mediating factors were taken into account, rather than 'unhelpful if.' Further, focus group feedback revealed that disclosure could be helpful, while non-disclosure could be damaging. The current study also found that: mental health disclosures gave rise to increased positive feelings towards practitioners and their perceived ability to understand service-users (see section 6.2.3.1); and mental health disclosure can increase client self-disclosure (see sections 6.2.3.1, and feedback from focus groups in chapter 8 indicating greater engagement with disclosing practitioners). Unlike Henretty & Levitt's (2010) findings,

apart from a couple of mentions, personality disorder was not cited to any extent by practitioners as a deterrent to sharing.

Armour's (2007) study found no effect between disclosure and non-disclosure groups on assessments of therapist empathy and credibility. In contrast, the current study found that service-users who rated hypothetical mental health disclosure as helpful felt it increased practitioner credibility and demonstrated empathy and understanding (see section 7.2.3.1). Real life examples of sharing also suggested that disclosure could help service-users to feel understood, increase perceptions of practitioner credibility, lead to better engagement, and promote recovery (see section 6.2.3.1). The contrast in findings is strongest in the examples of actual disclosures made in real practice situations, which were almost exclusively helpful, and which were least like Armour's analogue methodology. Hypothetical survey questions, although still non-analogue because they canvassed the views of actual service-users and actual practitioners (rather than proxy groups), were closer to analogue methodology because of their hypothetical nature, and these elicited more ambiguous messages and greater disparity of views than the real-life examples. The implication is that analogue methodology may not capture what happens in real life situations, and may generate misleading results. However, neither Armour's study nor the current study indicate any need for practitioners to hide their mental health lived experience on the grounds of credibility reduction, nor whether clients will seek therapy from someone with lived experience. In the focus groups, although some service-users indicated they would prefer to work with practitioners with lived experience (see section 8.5.1), no service-user said they would avoid practitioners without it.

### **9.2.8 Risks of Disclosure**

Despite the benefits, potential risks were also recorded by respondents, and these were similar to those identified in the existing literature. The current study highlighted practitioner concerns about making disclosures in the moment, knowing where to stop, risk, and self-protection, supporting Bottrill's (2010) empirical findings and extending these beyond psychotherapy roles to other mental health practitioners. Other authors including Audet (2011) and Barnett (1998) have considered practitioner fears regarding disclosure being a slippery slope, where one disclosure leads to more disclosures and boundary violations. Current research also highlighted these concerns (see section 8.5.7), as does professional guidance (Royal College of Psychiatrists, 2013a, see section 2.8.1). However, the Royal College of Psychiatrists guidance also emphasises

helpful aspects of disclosure, and advocates responsible disclosure and boundary management, rather than disclosure avoidance. There was nothing to suggest in the literature or the current research that boundary violations are inextricably linked to disclosure, indicating that this concern may either be an overstated fear, or that practitioners are sufficiently aware of potential boundary violations and take steps to avoid them. It is difficult to imagine that boundary violations, for example inappropriate relationships, could occur in the absence of sharing personal information, and it may be intuitive to think that excessive disclosure would lead to boundary violations. However, there doesn't seem to be any evidence to suggest a directly causative effect. In the research, a couple of examples were given of excessive disclosure, but there was no indication of boundary violation (see sections 6.4.2 & 6.4.3.2). Excessive disclosure may therefore indicate poor practice, rather than boundary violations.

Practitioners suggested in the hypothetical questions that mental health disclosure could burden service-users (see section 7.2.2.1), and both practitioners and service-users mentioned that disclosure of difficult or traumatic experiences could burden recipients (see section 7.2.1.2), agreeing with Kowalski, 1999 (cited in Farber, 2006). However, service-users did not mention this in relation to mental health disclosure in the hypothetical questions, nor in relation to real life examples of sharing personal mental health or mental health-related information. The only example service-users gave of disclosure being a burden was in relation to sharing physical health information.

In the general literature, Audet & Everall (2010) suggest that poorly executed disclosures may negatively shift the focus of interactions away from the service-user (see section 2.7.2), and may indicate lack of understanding and empathy where they are irrelevant or dissimilar to the service-user's experiences. The current research agrees with both of these positions, but not necessarily in relation to mental health disclosure. Shifting the focus could be either helpful, by taking the focus off the service-user and helping to lighten the mood of interactions, or unhelpful, by preventing the service-user from being the centre of focus. Focus shift was most associated with mental health disclosures (see section 7.3.11) by both service-users and practitioners, but this was in relation to hypothetical disclosure; in the real-life examples, focus shift was only reported in relation to sharing family circumstances, information about other clients, and hobbies. Service-users gave several examples of irrelevant real-life disclosures and disclosures that were dissimilar to their own experiences, which were taken to indicate practitioners' lack of understanding of their situation (see section 6.2.3.2, 6.3.3.2 and 6.4.3.2).

However, such effects were uncommon, and no more frequent for mental health than any other disclosure type.

Transference was cited as a reason for not disclosing by several practitioners. Transference is a term associated most with psychotherapy (see sections 1.3.4.5, 1.5.1, and 2.5), but in the current study transference concerns were mentioned by several nurses and a doctor in addition to psychotherapists. This suggests nurses may be influenced against disclosure by psychotherapeutic models, either in training or practice. However, several psychotherapists in the current study did share information about themselves with service users, indicating that disclosure is compatible with psychotherapeutic practice. In the general literature, Eagle (2000) and Hanly (1998) suggest that transference can be explored without withholding information, and Hoglend et al (2006) suggests examination of extratherapy relationships can be as effective as exploring transference.

Although the non-empirical (Schiff, 2004) and the empirical literature (Adame, 2011) suggest that disclosing personal mental health information can lead to discrimination and being discredited, the current study only highlighted these as fears in relation to hypothetical disclosure, while in real life disclosures appeared to go well. This does not mean that discrimination does not happen in real practice settings, but evidence in the current study suggested that disapproval was focused on the act of disclosure, rather than the existence of mental illness.

### **9.3 Validity checks**

Several validity checks have already been outlined in previous chapters. Service-users and practitioners both reported that practitioners shared hobbies more often than other types of disclosure. It was suggested in section 4.2.2 that low level, non-intimate disclosures might not be recalled by service-users, or might not be recognised as disclosure, because of their everyday, reciprocal, conversational nature. However, both service-users and practitioners reported that hobbies are shared most often, suggesting that hobbies and activities are recalled and recognised as disclosures, and their frequency is a real-world occurrence rather than a result of recall bias.



Disclosure studies have been criticised in the past because measures of disclosure recall do not match real life disclosure frequencies (Cozby, 1973; Chelune, 1975), perhaps due to social desirability bias (Burnard and Morrison, 1994). There is also a possibility that practitioners are unaware of what they disclose unintentionally (Gibson, 2012; Luft, 1969), while Haghghat (2001) suggests that negative, rare events may be associated with minority groups, perhaps suggesting that poor disclosures from people stigmatised by mental illness would be remembered more than positive, helpful disclosures. While such biases might be expected to operate differently for practitioners and service-users, they both reported real life examples of disclosure topics in the same order of frequency at a categorical level, and in a highly similar order at a sub-categorical level (see section 6.7). Section 6.7 also highlights that practitioners and service-users agreed that real life examples of disclosure were mostly helpful, while unhelpful disclosures were spread across disclosure categories and were generally not dramatic or particularly damaging. The frequency and pattern of positive, negative and mediating statements given in relation to hypothetical disclosures were also highly consistent for both service-users and practitioners across all seven disclosure subjects in relation to unhelpful, middle, and helpful disclosures (see section 7.6).

Quantitative and qualitative evidence also support one another. Service-users rated mental health disclosure as the most helpful type of disclosure, and in the qualitative coding this was the type of disclosure that had most positive and least negative statements associated with it (see section 7.5.1). Focus group feedback from service-users (chapter 8) also included personal testimonies of the power and positivity of mental health disclosure. Likewise, practitioners rated sharing hobbies as the most helpful type of hypothetical disclosure, shared it most often in real life, and in the qualitative coding sharing hobbies had the most positive and least negative statements associated with it.

A validity check was undertaken regarding the quotes included in chapters 6 & 7. It indicated a fair spread of quotes from practitioners and service-users. 102 quotes were included from 48 (43%) of the 111 service-user survey respondents. 120 quotes were included from 79 (39.50%) of the 200 practitioner respondents. Practitioner quotes were also analysed according to the job category of the respondent. This validity check indicated that both the number of practitioners quoted from each practitioner job category, and the number of quotes used from each job category (which might have differed because some practitioners might have been quoted more often than others), were broadly comparable to the proportion of practitioners

from each job category who responded to the survey. See Appendix 11 for further detail. This does not guarantee that quotes were an unbiased reflection of all participants, demographics and views, but it does indicate that this study's approach to data analysis and presentation sought to reflect a fair balance of respondent submissions.

However, there was a discrepancy between the number of practitioners who report they have shared something with service-users (three quarters), and the number of service-users who report that practitioners have shared something with them, which was less than half. One explanation for this was that service-users might not recognise disclosure of hobbies as disclosure because of its everyday, conversational nature. Practitioners share non-mental health related information most often, and although those validity checks described above indicate that practitioners and service-users may be recalling disclosures accurately, it may nevertheless be the case that some service-users do not recognise this type of sharing as disclosure, and hence did not think practitioners had ever shared anything with them even though, overall, they still report this type of sharing most often. It may also be the case that the make-up of practitioner populations are more stable than service-user populations, because practitioners are likely to remain in their roles for some time, while service-users may use services for shorter periods. Practitioners may have been looking back over a longer time frame and may have recalled instances of disclosure with different service-users from different points in time, while service-users may have been reflecting on a more limited time frame and in relation to fewer potential practitioner disclosers.

Taking various validity checks into account, it seems fair to conclude that there is much agreement between the different measures used in this study, and from the different types of respondent. This indicates that: (a) real life examples of disclosure given in the survey reflect what happened in real life, rather than biased inaccurate recollections; (b) coding was consistent enough to indicate that findings were valid; and (c) reporting of qualitative findings fairly reflects the diversity of respondents and views.

#### 9.4 Strengths

This study was non-analogue. It adds to the knowledge base about the use of lived experience in mental health settings by drawing on the reported experiences and views of current mental health practitioners and service-users in a statutory mental health setting. Validity checks indicate robustness of methods and findings.

Many of the empirical studies identified in the scoping review had a narrower focus than the current study, limiting their enquiry to subsections of the mental health workforce, such as therapists or psychologists, or taking place in non-statutory settings. Most were undertaken in the USA, and only a minority explored the UK context. This study is the largest on the topic of self-disclosure of personal mental health lived experience in the UK to date, canvassing the views of 111 statutory mental health service-users and 200 practitioners, and analysing almost 500 examples of practitioner disclosure. It agrees with many of the findings of previous studies, and extends their applicability to the UK and to a wide range of mental health practitioners in statutory settings. It also provides new insights into the different reflective thought processes of disclosing and non-disclosing practitioners that have hitherto not been identified.

This research explored self-revealing disclosures, and did not explore self-involving disclosure (see section 2.6.1). Although this research cannot make an argument about which is better, it adds to the literature suggesting self-revealing disclosures can be helpful and beneficial.

Hill & Knox (2002) suggest that previous literature on disclosure has been atheoretical. Although the current study did not test disclosure in relation to a particular theory, the consideration of norm circles (Elder-Vass, 2012) offers an opportunity to theorise how a tendency towards non-disclosure of mental health lived experience is perpetuated, and use this to direct further inquiry and practice development.

## 9.5 Limitations

This research was only conducted in one NHS mental health trust, and may not reflect the views of practitioners and service-users in other trusts.

Survey response rates were relatively low (see section 5.1), with only 8.3% of practitioners and 5.5% of service-users returning a survey, and respondents may not be representative of practitioners and service-users within the organisations, nor applicable to those in other organisations. It may also be the case that those respondents who completed a survey did so because of particular interest in the subject, for example being very pro- or very anti-disclosure, though it is not possible to surmise from the data which direction this might have influenced the results. It may also be the case that response bias influenced service-users and practitioners to report instances of disclosure and feelings towards disclosure in what they perceive to be socially desirable ways, though this was mitigated to some extent through the various validity checks undertaken.

There were insufficient numbers of respondents from some minority groups to enable robust testing of data based on demographic and other grouping variables. Hence, some findings are implicit and based on consistent statistical patterns rather than significance. However, much emphasis has been placed on statistically significant findings, and non-significant trends are reported with appropriate caveats.

The number of practitioners and service-users who took part in focus groups was also relatively small, and similar limitations apply as to the survey. However, there was an element of deliberate selection of focus group invitees by the researcher, to provide a balance of pro- and anti-disclosure attitudes, which may have mitigated this to some extent (see section 4.4.3).

Originally it was intended that Australian research activities would replicate those of the UK to offer a full, like-for-like comparison of results. Due to difficulties described in section 4.4.1 it was necessary to restrict activities to focus group discussion of disclosure and the UK findings. The Australian perspective has therefore not been fully investigated and may be a useful topic for further investigation.

## 9.6 Implications for Clinical Practice

Meeting with others who have shared a similar experience of mental illness was helpful for many service-users, and for some it was transformational. Conversely, little or no practitioner disclosure was unhelpful for many, and profoundly damaging for some. Peer support may provide the validation and connection that some individuals desire, but the availability and provision of peer support was inconsistent and, for some, disclosure by qualified practitioners could be more powerful because of their higher status and authority. In addition, sharing a wide range of non-mental health experiences and identities could also be helpful. In Australia, there was an example of a statutory mental health agency proactively matching a practitioner with a service-user based on parenting experience. In the UK, another example was given of putting a service-user in touch with an external organisation based on their religious affiliation. However, several respondents in the survey and in the focus groups felt they either did not meet other people who shared their experiences, or if they did it was through external voluntary sector organisations, often contacted through their own efforts rather than the agency. This suggests that there may be scope for organisations to link service-users more consistently with a wider range of peer and non-peer support, either internally or in other organisations. While mental health lived experience appears to be at the top of the list, other identities, experiences and needs should be considered.

The general guidance given in section 2.8 by Knox & Hill (2003) and Hill & Knox (2001) is supported by the current research, namely that before disclosing practitioners should think about who to, what, when, why, how, and the client's response. However, there is a good deal more detail that might be found in sections 6,7 and 8 of this thesis that might usefully be transformed into guidance materials in the future, particularly the work of Morgan and Lawson (2015) which has been validated by the current study.

There was some suggestion that not only disclosure, but discussion of disclosure, was a taboo subject in some settings (see sections 8.5.5 and 8.5.12). This was particularly evident in the Australian focus groups, but also in the UK focus groups. Since the current study suggests that most practitioners disclose some information about themselves, and the literature indicates that some level of disclosure or being known is inevitable, reflective practice and effective use of self-disclosure may be hampered by the lack of opportunity to share disclosure experiences. The current study also implies that disclosing practitioners may be more reflective than non-

disclosing practitioners (see chapter 7). It may therefore be beneficial for mental health organisations to encourage and support discussion and reflection in teams regarding current, past and future use of disclosure, and its potential positive and negative impact on service-users. This may be especially relevant for doctors, who may appreciate the helpfulness of sharing mental health lived experience less than other types of practitioner.

### **9.7 Implications for Future Research**

Some survey respondents and some focus group participants indicated that the topic of self-disclosure was considered in their pre-qualifying training. Some of this was pro-disclosure, and some was anti-disclosure. However, there was no general consensus, and there is little in the existing literature to indicate what messages about disclosure mental health practitioners receive in pre-qualifying training. Future research might usefully explore how disclosure is considered, or whether it is mentioned at all, in pre-qualifying training across the mental health workforce.

This current research did not attempt to measure outcomes. UK survey and focus group responses indicated a range of attitudinal reactions to disclosure and non-disclosure which might influence service satisfaction. As indicated in the Australian focus groups, sharing lived experience (or the lack of) appeared to influence engagement, which might feasibly influence clinical outcomes for some individuals. Measuring outcomes may be difficult, for the reasons outlined in section 4.2.1, and what counts as an outcome for practitioners, funders, agencies and service-users may differ. In light of this, the influence of disclosure on both quality of life and clinical outcomes may be relevant areas for future study. Since disclosure was reported by many service-users to reduce stigma and isolation, and increase hope for recovery, future research might explore whether receiving disclosures has a demonstrable impact on levels of self-stigma and hope for recovery.

Gough's (2011) study, and Morgan and Lawson (2015) suggest that concealing personal mental health lived experience is mentally unhealthy for practitioners. However, Gough's and Morgan & Lawson's samples were small and not representative of the mental health workforce. The current study did not explore this issue. Future research might usefully explore the impact of concealment on practitioner's mental health.

This study has suggested that training and guidance may be useful for practitioners to help them decide what, when, and how to share lived experience. If this were to be developed, it would be useful to measure whether this has an impact on clinical practice, confidence in using disclosure, and service-user satisfaction.

### **9.8 Implications for Policy**

National campaigns such as Time to Talk (Time to Change, 2017a & 2017b, see section 1.3.4.3) aim to reduce the stigma surrounding mental health by encouraging people to be more open about their lived experience of mental illness. The current study, however, indicates that practitioners may be reluctant to share their lived experience due to fear of negative judgment about their practice and capabilities, and that some service-users may hold stigmatising views of mental illness. Local agencies also make some efforts to recruit people with experience of mental illness into both peer and non-peer roles (see Appendix 1 and Appendix 2). The current study illustrated that some practitioners did share their experience of mental illness with service-users, but they appeared to be in the minority. In light of this, the efforts of national campaigns, local statutory agencies, and individual practitioners to reduce stigma and promote recovery may be limited, and potentially negated to some extent, by the reticence of staff to share, and be open about sharing, their personal mental health lived experience. A more comprehensive approach to sharing lived experience may be required, perhaps by adapting Haghghat's (2001) model of reducing stigma to tackle the issue at multiple levels. Not least, at a local level, more explicit permission may be needed by mental health trusts not only to recruit and value mental health lived experience in the workforce, but to explicitly endorse the use of self-disclosure of mental health and other identities and experiences to colleagues and service-users.

### **9.9 Postscript: Practitioner and Student Feedback on Dissemination, Training and Guidance**

The findings of this study have been shared with students on several social work courses, including a fast-track mental-health focused social work course. Part of several presentations and workshops has involved students rating the hypothetical disclosures from the original survey, and their quantitative responses have closely reflected the study's practitioner responses. Discussion with students also indicates a greater prevalence of helpful than unhelpful previous disclosures from their own experience either as a recipient or as a discloser.

Student responses might be expected to match practitioner responses because they are practitioners in the making. The fact that they did lends credibility to the findings of this research relating to practitioner ratings of hypothetical disclosures. Tentative guidance and training has been delivered based on the messages from this research, and feedback has indicated that this was helpful.

### **9.10 Conclusion**

The current study has facilitated a more focused consideration of the topic of mental health disclosure from the perspective of service-users and practitioners across a wide range of services in statutory settings. This has enabled conclusions to be drawn about what happens in real practice situations when practitioners disclose. The survey's hypothetical disclosure questions were slightly more detached from practice, because they required theoretical responses, and responses to these questions suggested mixed views of disclosure with a heavy emphasis on risk. These responses were at odds with the almost exclusively helpful real-life examples of sharing. This suggests either that fears about disclosure are inflated, or that practitioners generally mitigate potential negative effects by managing disclosure well. Whatever the case, there appears to be little justification for disclosure avoidance or negative judgment of practitioners who disclose. Disclosures tend to be helpful, and can be especially helpful and powerful when made by qualified practitioners. Further, it may be the case that the potentially helpful effects highlighted in the current study are underestimated. One service-user in a UK focus group (see section 8.3.3) initially expressed clear and certain views regarding the undesirability of practitioner disclosure, but changed their view when their negative preconceptions of disclosure were contradicted by the positive experiences of another service-user. It may be the case that some of the negative attitudes towards disclosure in the survey were likewise the result of inaccurate negative assumptions about disclosure in the absence of positive alternative evidence that could be gained by practitioners sharing their mental health lived experience more often. Quantitative and qualitative data from the hypothetical questions was validity checked, so the findings appear to be internally valid. Because this study agrees with much of the existing UK and international literature, attracted a relatively large number of UK research participants, and there was much agreement between UK and Australian participants, the findings of the current study may be applicable to other settings in the UK and internationally.



Helpfulness ratings suggest that compared to service-users, practitioners may underestimate the helpfulness of sharing lived experience of all types, including personal mental health lived experience. Practitioners shared personal mental health lived experience least often but it was rated as the most helpful type of disclosure by service-users. In particular, doctors appeared to rate disclosure as less helpful than other practitioners rated it, and this might be associated with greater concerns about risk. Since doctors are at the top of the professional hierarchy, non-disclosing doctors may contribute more than other practitioners to non-disclosing team cultures. There may be a need to increase understanding among doctors of the helpfulness of sharing personal mental health lived experience.

The difference between hypothetical disclosures and real-life examples of disclosure indicates that while real-life disclosures were almost simplistically helpful, a great deal of complex thought went into the process of practitioner disclosure, in which potential positive and negative effects were considered, and mediating strategies were employed to maximise benefit and minimise risk. This strategy was largely successful; disclosures were almost exclusively experienced as helpful, and there seems little evidence to justify discouragement of disclosure.

This study agrees with previous literature and research about self-disclosure in general which suggests that disclosure tends to have neutral or positive effects, and that negative effects, while they are reported, are relatively uncommon. Research literature that concentrates more specifically on the disclosure of personal mental health lived experience illustrates a similar pattern. Despite a wealth of evidence to suggest disclosure can be helpful, the efforts of national campaigns, and proactive policies of mental health organisations, there remains much controversy about disclosure, and practitioners experience implicit and explicit pressure to conceal their experiences. To maximise recovery, stigma reduction, and hope for service-users, practitioners should be given the permission and support they need to share personal mental health and other lived experience in their work. It may be especially powerful if such permission came from, and extended to, those at the top of the professional hierarchy, such as doctors.

# Appendices

## Appendix 1: Peer Support Job Description

## Leeds and York Partnerships NHS Foundation Trust

<b>Chapter 2 JOB TITLE</b>	Peer Support Worker Role
<b>Chapter 3 DEPARTMENT</b>	Adults and Older Peoples Pathway Teams- community settings
<b>Chapter 4 GRADE</b>	Band 3
<b>Chapter 5 REPORTS TO</b>	/Team Manager
<b>Chapter 6 SUPERVISED BY</b>	Direct line management from area Clinical lead supported by Recovery and Social Inclusion team providing professional supervision
<p>The trust board has endorsed the concept of recovery as central to the working of the Trust. Recovery is embedded in Trust values and means goals for the next year 2013/2014.</p> <p><b>1. JOB SUMMARY AND WORKLOAD MANAGEMENT</b></p> <p>As an integral and highly valued member of the multi-disciplinary team, the PSW will provide formalised peer support and practical assistance to people using our services in order for them to take control over their own lives and engage actively in their own unique recovery process.</p> <p>Through sharing the wisdom gained through personal ‘lived’ experience, peers are able to inspire hope in others and the belief that recovery is possible for all. Within a relationship of mutuality peers can facilitate and support information sharing to promote choice, self determination and opportunities for the fulfilment of socially valued roles with connection to local communities.</p> <p>There is an expectation that PSWs will be involved in the ongoing development of the peer roles in the Trust including running groups and contributing to the recovery education centre.</p>	

As a core member of the multi-disciplinary team, the PSW will work alongside an agreed number of service-users on a 1:1 basis and in groups. They will also have the opportunity to co-work with other colleagues.

Reporting directly to the Team leader/ward manager and under the professional supervision of the Peer support worker leads, the PSW will be responsible for the delivery of peer support interventions as agreed within the peer relationship and feeding into the CPA process.

The role of the Peer support worker is to deliver specific components of prescribed care packages under the direct supervision of Care Coordinators and Clinical Leads. The post holder will work in the community with clients who have complex needs, and will involve effective liaison with service-users, carers, and other professionals and agencies as required.

Car Driver preferred or the ability to travel around the local area using public transport is required.

#### **KEY RESPONSIBILITIES:**

1. *To establish a supportive and respectful relationship with service-users.*
2. *Help individuals identify their own achievable and meaningful recovery goals and collaboratively set recovery objectives*
3. *Drawing on your mutual resources as peers and utilising a range of recovery tools, techniques and experience.*
4. *Model personal responsibility, self awareness, self belief, self advocacy and hopefulness via appropriate and timely relating of own recovery story to inspire and instil confidence in peers.*
5. *Assist people to create their own crisis plans, well being plan, advance directive/decision statements. This list is neither exhaustive or prescriptive*
6. *Coach people to understand their own coping skills, self-help and self-management techniques within the peer relationship individually and in groups.*
7. *Support service-users to identify and overcome fears and challenges.*
8. *Facilitate access to community groups and networks that enable participation in community activities, in order to maximise opportunities and support opportunities for training and work.*

9. *Accompany service-users to appointments/meetings of their choice and perform a range of practical tasks, aligned to recovery goals.*
10. *Act as a positive role model showing professional and caring attitudes and behaviour towards other multidisciplinary team members, service-users and carers.*
11. *Have a focus on the rights of service-users at all times.*
12. *Ensure that the recovery goals of the peers you support are integrated into the Trusts CPA process and are reviewed on a regular basis, liaising closely with care co-ordinators as necessary.*
13. *Work in a way that acknowledges the personal, social, cultural and spiritual strengths and needs of the individual.*
14. *Uses own initiative, personal experience and job related training in deciding on the approach and interventions required when working with a service-user in delivering peer support.*
15. *Attend regular Team meeting and 1:1 supervision.*

**Other responsibilities:**

16. *Attend multi-disciplinary team meetings to promote the use of self-directed recovery tools. For example WRAP, Recovery Star, crisis plan etc*
17. *Attend clinical review meetings to feed back progress on recovery goals.*
18. *To raise awareness of recovery language with Trust staff by modelling positive strengths based, non discriminatory, non- jargon, non-medicalised language in all areas of work.*
19. *Support other members of the multi- disciplinary team in promoting a recovery orientated environment and in identifying recovery focused activities imparting information/education as required.*

**2. KNOWLEDGE, SKILLS AND EXPERIENCE REQUIRED**

- Experience of informal peer support with a range of service-users with mental health needs.
- Personal experience of using mental health services is required.
- Will show a good level of knowledge about community resources and how to help service-users access them.
- Ability to work on a one to one basis with clients in their own homes and / or community settings without constant, direct live supervision
- A good level of understanding of the recovery approach and its application to care packages
- Ability to respond well in a crisis situation, and understands the need to record/report such situations accurately to Care Coordinators or other senior staff within the team
- Demonstrates a good level of skill in all methods of communication
- Has an understanding of medication and side effects, also support people to explore options, ask questions and be better informed.
- Fully participates in clinical supervision and mandatory training as required
- **NVQ 3 in Care or recognisable equivalent / or the agreement to attend a relevant qualification**

### **3. COMMUNICATION AND WORKING RELATIONSHIPS**

- To have good verbal communication skills and an excellent understanding of how to build rapport with service-users, carers and others as required.
- Ability to work effectively in a multidisciplinary team, and to have a good understanding of individual's roles within the team
- Will understand the possible barriers in building a good, effective, professional yet peer driven and empathic relationship with service-users, and to be aware of strategies to help improve communications and relationships
- Will understand the importance of effective communication and liaison with other agencies and professionals.

- To maintain accurate records of client care, informing senior clinicians of any changes in the client's health or social care. To contribute to the evaluation of care plans by reporting observations accurately and regularly .
- To participate in multidisciplinary reviews and other clinical meetings to ensure effective communication and develop recovery approach to client care.

#### **4. PRINCIPLE DUTIES AND AREAS OF RESPONSIBILITY**

- To work independently with users and carers in their homes, towards a collaborative package of care provided through the CPA process. Participation in the delivery of CPA including attendance and contribution within the meeting and the subsequent care plan.
- To promote social inclusion for clients by facilitating and supporting access to a variety of community based opportunities including work, social groups, education, spiritual pursuits, leisure activities to ensure holistic well being.
- Liaising with the MDT to report any concerns
- Involvement in the process of effective safety planning including assessment, planning, intervention and ongoing monitoring of safety/risk factors.
- To actively support clients who may be experiencing crisis.
- To participate in multidisciplinary reviews and other clinical meetings to ensure effective communication and a recovery approach to service-users care.
- To participate in the induction and support of new staff and students from a variety of different professional backgrounds under the supervision of the Clinical lead
- Will actively participate in clinical audit processes.
- To comply with all Trust policies, practices and legislation as laid down by the Trust. To work within the guidelines of the Health and Safety policies.
- To at all times promote a positive image and the good reputation of the Trust
- To adhere to the Trust's Lone Worker policy

**5. DECISION MAKING AND ADVICE**

- To participate in decision making processes and carry out agreed plans of care
- To participate in regular individual and peer supervision
- To use initiative by referring appropriate issues in a timely manner to a Clinical lead

**6. INITIATING AND IMPLEMENTING CHANGE**

- Actively participate in the quality standards and audit processes.
- Actively participate in team discussions to contribute to service improvements and developments
- To be assertive in promoting new ideas for positive change within the team

**7. HEALTH, SAFETY & RISK MANAGEMENT**

- Will be required to inform the line manager of any safety issues that could affect the post holder or others in the workplace. Will be responsible for own health and safety and must co-operate with management at all times in achieving safer work processes and working environments, particularly where it can impact on others.
- Will be trained in the correct use of any equipment provided to improve safety and health within the Trust. Will be required to use equipment when necessary and as instructed; it will be the post holders responsibility to ensure that equipment is safe for use, and that any defects are reported immediately to the line manager.
- To participate in regular clinical supervision with senior clinicians and report any concerns as appropriate.
- To comply with the guidelines of the Health and Safety Policies operating within the Trust.
- Will Follow agreed safe working procedures and reporting incidents using the Trust's risk incident reporting system.



<p><b>8. TRAINING AND PERSONAL DEVELOPMENT</b></p> <ul style="list-style-type: none"> <li>- To participate in clinical supervision and personal development plans to develop knowledge and skills in relation to the post.</li> <li>- To take personal responsibility for ensuring own continuous development</li> <li>- To be willing to undertake all mandatory training</li> </ul>
<p><b>9. RESPECT FOR PATIENT CONFIDENTIALITY</b></p> <p>Will know and understand the Trust's protocols on confidentiality and adhere to these at all times.</p>
<p><b>10. EQUALITY AND DIVERSITY</b></p> <p>The post holder must co-operate with all the policies and procedures designed to ensure equality of employment. Service-users, carers and colleagues must be treated equally irrespective of gender, ethnic origin, age, disability, sexual orientation, religion etc.</p>
<p><b>11. SPECIAL WORKING CONDITIONS</b></p> <ul style="list-style-type: none"> <li>- Will be aware of risks involved driving in inner city areas and to take appropriate safety actions wherever required</li> <li>- To be aware of and to follow Trust policies when delivering medication to client's homes.</li> <li>- Will always consider possible high risk situations and the need to communicate these to other workers.</li> </ul>
<p><b>12. ADDITIONAL INFORMATION</b></p> <p>It is desirable that you have a basic level of understanding of how information technology works and be competent in using a mouse, a keyboard, e-mail, internet and the standard Windows computer package</p>

## PERSON SPECIFICATION

Organisation	LYPFT
Post	Peer Support Worker
Band	3
Department	Adult or Older Peoples Care Pathway(CMHT – HUBS)

	Essential Criteria	Desirable Criteria
Education Qualification	<p>Good Level of secondary education to GCSE level</p> <p>Completion of some form of recovery plan.</p> <ul style="list-style-type: none"> <li>• WRAP</li> <li>• Crisis Plan</li> <li>• Joint crisis plan</li> <li>• Advance decision</li> <li>• Advance statement</li> <li>• Recovery star</li> <li>• Outcomes star</li> <li>• My shared pathway</li> <li>• Coping with setbacks</li> </ul> <p>etc</p>	<p>Related Health or social Care qualification</p> <p>Willingness to undertake further training in line with development of peer support</p> <p>Level of education attainment to NVQ 3/ AS Level or equivalent</p> <p>Completion of own Plan</p>
Experience	<p>Lived experience of mental health problems</p> <p>Wide range of life experience to bring an enabling and positive view of opportunities for others</p> <p>Experience of being in a supportive and enabling role</p>	<p>Psychiatric hospital admission</p> <p>Experience of working in the public sector</p> <p>Experience of training, teaching, coaching/mentoring</p>

	<p>Experience of working in a team or a group environment</p> <p>Experience of using a range of self-management or recovery tools and techniques</p>	<p>Experience of working across different organisational boundaries</p>
<p>Skills / Abilities / Attributes</p>	<p>Excellent written, verbal and non-verbal communication skills</p> <p>Computer literate</p> <p>Willingness to learn the Trust's IT systems</p> <p>Able to relate to a wide range of people</p> <p>Professional in appearance and behaviour</p> <p>Able to managed conflict and to help others to do so</p> <p>Ability to maintain a healthy home/work life balance</p> <p>High level of self awareness-ability to critically appraise own performance</p> <p>Critical thinker</p> <p>Ability to share personal story of recovery in a professional manner</p> <p>Ability to assist people to develop recovery plans</p>	<p>Presentation skills</p> <p>Computer literate in software applications such as Microsoft Word, Excel, Internet Explorer, Outlook Express etc</p>

	<p>Ability and willingness to reflect on work practice and be open to constructive feedback</p> <p>Ability to manage stress and to plan and prioritise workload</p> <p>Ability to carry out practical tasks</p>	
Knowledge / Understanding	<p>Understanding and practical knowledge of recovery</p> <p>Understanding of the issues and concerns of people supported by mental health services</p> <p>Knowledge and commitment to service-users rights</p> <p>Understanding of the impact of stigma and discrimination</p> <p>Knowledge of Mental Health Legislation</p>	<p>Appreciation of the community resources within the geographical location of the post and key partners</p> <p>Understanding the CPA and the role of care co-ordinator and knowledge of Trust Policies and procedures</p> <p>Understanding of the service delivery goals of the care pathway</p> <p>Knowledge of local policies in respect of safeguarding children and the protection of vulnerable adults</p>
Personal Qualities	<p>Emotional Maturity/range of life experience</p> <p>Flexibility and Reliability</p>	

	<p>Energy/drive, enthusiasm and tenacity</p> <p>Patient, Non-judgemental, Respectful and Compassionate</p>	
<p>Other Requirements</p>	<p>Must be able to travel to a range of locations</p> <p>Ability to transport / accompany peers to appropriate appointments</p> <p>A willingness to work flexibly through prior arrangement as the needs of the job dictate including occasional unsocial hours and weekends</p>	



## Appendix 2: CPN Job Description

AFC approved 12.04.2012. Clustered with CAJE 0108 – CPN (Adult Services), Band 6.

South West London and St George's   
Mental Health NHS Trust

**PERSON SPECIFICATION**

Job Title: Band 6 CPN – Support and Recovery Team

	<b>ESSENTIAL</b>	<b>DESIRABLE</b>	<b>HOW TESTED</b>
<b>TRAINING &amp; QUALIFICATIONS</b>	<ul style="list-style-type: none"> <li>• RMN (current NMC registration)</li> <li>• Mentorship for Contemporary Practice</li> </ul>	<ul style="list-style-type: none"> <li>• Diploma/BSC in Community Nursing</li> <li>• Evidence of post registration training related to the provision of relevant psychosocial interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Application Form</li> <li>• Interview</li> <li>• References</li> <li>• Proof of qualifications and professional registration</li> </ul>
<b>EXPERIENCE</b>	<ul style="list-style-type: none"> <li>• Demonstrable experience of working with people who experience serious ongoing mental health problems in a variety of settings</li> <li>• Experience of working in a multidisciplinary team</li> <li>• Experience of assessing and managing crisis with those with a severe mental illness</li> <li>• Experience of providing thorough baseline mental health assessments and case formulation based on these</li> <li>• Experience of care co-ordination</li> </ul>	<ul style="list-style-type: none"> <li>• Experience of working community nursing</li> <li>• Experience of working in a CMHT or other community health setting</li> <li>• Experience of contributing to policy and procedure development and implementation</li> <li>• Experience of managing and supervising other staff</li> <li>• Experience of recruitment and selection of staff</li> <li>• Experience of managing and monitoring budgets</li> </ul>	<ul style="list-style-type: none"> <li>• Application Form</li> <li>• Interview</li> <li>• References</li> <li>• Assessment</li> </ul>
<b>KNOWLEDGE &amp; SKILLS</b>	<ul style="list-style-type: none"> <li>• Excellent written and oral communication skills</li> <li>• Skills in assessment, care planning and case management</li> <li>• Ability to assess clinical situations quickly and use initiative</li> <li>• Ability to interpret research and apply to practice</li> <li>• Knowledge of counseling skills, group skills, cognitive skills, behavioural skills</li> <li>• Knowledge of our business and how it supports patient care</li> <li>• Knowledge of psycho-social interventions</li> <li>• Good time management skills and ability to prioritise</li> <li>• Effective team worker</li> <li>• Good IT skills</li> <li>• Clinical supervision skills</li> <li>• Clear understanding of the Mental</li> </ul>	<ul style="list-style-type: none"> <li>• Skills in CBT, family work, coaching.</li> <li>• Research and audit skills</li> <li>• Group facilitation skills</li> <li>• Report writing skills</li> </ul>	<ul style="list-style-type: none"> <li>• Application Form</li> <li>• Interview</li> <li>• References</li> <li>• Assessment</li> </ul>

AFC approved 12.04.2012. Clustered with CAJE 0108 – CPN (Adult Services), Band 6.

	<p>Health Act, Children's Act and National Policy</p> <ul style="list-style-type: none"> <li>• Ability to work as an active member of the multidisciplinary team</li> <li>• Knowledge of recent initiatives in nursing</li> <li>• Understanding of safeguarding procedures</li> <li>• Understanding of stepped care model</li> <li>• Knowledge and application of Recovery principles</li> <li>• Ability to work in partnership with service users and carers in the planning and delivery of care</li> <li>• To be able to reflect and learn from experiences</li> <li>• Able to think analytically</li> <li>• Knowledge of our business and how it supports patient care</li> </ul>		
OTHER	<ul style="list-style-type: none"> <li>• An understanding and positive regard for the needs and rights of people with mental health problems and their carers</li> <li>• Ability to manage stress and work under pressure</li> <li>• Ability to work to ensure effective communication both within and outside the services</li> <li>• Ability to adapt to changing environments, needs and demands</li> <li>• Act as a positive role model, dynamic, motivated caring and supportive</li> <li>• Ability to work closely and form good working relationships with a wide range of people</li> <li>• Interested in further professional development</li> <li>• Car owner/driving license with no endorsements.</li> </ul>	<ul style="list-style-type: none"> <li>• Personal experience of mental health problems</li> </ul>	<ul style="list-style-type: none"> <li>• Interview</li> </ul>



## Appendix 3: Codes of Conduct, Standards and Ethics

Practitioner Job type	Relevant codes of conduct, standards and ethics	Mention of self-disclosure	Self-disclosure	Boundaries	Mental health
Nurse, midwife	The Code: Professional standards of practice and behaviour for nurses and midwives (Nursing and Midwifery Council, 2015)	Self-disclosure is addressed in paragraph 20.7 “20.7 make sure you do not express your personal beliefs (including political, religious or moral beliefs) to people in an inappropriate way” (p.15). It also indicates nurses should “20.9 maintain the level of health you need to carry out your professional role” (p.16). It states that nurses must “have clear professional boundaries at all times” (p.15).	Yes	Yes	Yes
Doctor (Consultant, doctor, psychiatrist)	Good Medical Practice (General Medical Council, 2013)	Paragraph 54 states “You must not express your personal beliefs (including political, religious and moral beliefs) to patients in ways that exploit their vulnerability or are likely to cause them distress” (p.18). Paragraph 53 states: “You must not use your professional position to pursue a sexual or improper emotional relationship with a patient or someone close to them.” Paragraph 28 states: “If you know or suspect that you have a serious condition that you could pass on to patients, or if your judgement or performance could be affected by a condition or its treatment, you must consult a suitably qualified colleague. You must follow their advice about any changes to your practice they consider necessary. You must not rely on your own assessment of the risk to patients.”	Yes	Yes	Yes
	Good Psychiatric Practice: Code of Ethics (Royal College of Psychiatrists, 2014)	Principle 2 (p.6) refers to boundary violations, but does not mention self-disclosure. Principle 10 states that psychiatrists have a duty to act where they detect ill-health or wellbeing in colleagues (p.17). Principle 12 places a duty on psychiatrists to tackle stigma and discrimination in employment, law, health and education services, to educate the public, and provide positive images of mental health in the media.	No	Yes	Yes

Practitioner Job type	Relevant codes of conduct, standards and ethics	Mention of self-disclosure	Self-disclosure	Boundaries	Mental health
	On professional boundaries (Royal College of Psychiatrists, 2013)	This good practice guidance leaflet, part of a series, states: “EXCESSIVE PERSONAL SELF-DISCLOSURE. As in personal relationships, in a professional setting personal disclosure typically has the effect of bringing the two parties closer together, whereas excessive disclosure radically changes the dynamic, so that the focus shifts from the patient to the professional. In almost every case of violations of sexual boundaries there are a series of steps taken on the way, always including a significant increase in self-disclosure by the clinician. Care needs to be given to the how and when of disclosures, and open discussion with colleagues and mentors is essential.”	Yes	Yes	No
	Recommendations for psychiatrists on spirituality and religion (Royal College of Psychiatrists, 2013)	Recommendation 3 states “Psychiatrists should not use their professional position for proselytising or undermining faith and should maintain appropriate professional boundaries in relation to self-disclosure of their own spirituality/religion” (p.10).	Yes	Yes	No
	Personal beliefs and medical practice (General Medical Council, 2013)	Section 30 states “If you disclose any personal information to a patient, including talking to a patient about personal beliefs, you must be very careful not to breach the professional boundary that exists between you” (p.5). Section 31 states “You may talk about your own personal beliefs only if a patient asks you directly about them, or indicates they would welcome such a discussion. You must not impose your beliefs and values on patients, or cause distress by the inappropriate or insensitive expression of them” (p. 6)	Yes	Yes	No
Psychologist	Code of Ethics and Conduct (British Psychological Society, 2009)	Sections 4.2 and 4.3 address relationships and boundaries (p.22-23). They do not mention self-disclosure. Section 2.4 addresses practitioner impairment.	No	Yes	Yes

<b>Practitioner Job type</b>	<b>Relevant codes of conduct, standards and ethics</b>	<b>Mention of self-disclosure</b>	<b>Self-disclosure</b>	<b>Boundaries</b>	<b>Mental health</b>
	Standards of Proficiency – Practitioner Psychologists (Health and Care Professions Council, 2015)	Section 3.1 states registrant practitioner psychologists must “understand the need to maintain high standards of personal and professional conduct” (p.7). Section 11.5 states in relation to counselling psychologists only “be able to critically reflect on the use of self in the therapeutic process” (p. 12).	Yes	Yes	Yes
	Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	See * below	No	Yes	Yes
Social Worker	Code of Ethics for Social Workers (British Association of Social Workers 2012)	States “Social workers should establish appropriate boundaries in their relationships with service-users and colleagues...” (section 2.3, p.10). Principle 1 states social workers should “build and maintain professional relationships” (p.12).	No	Yes	No
	Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	See * below	No	Yes	Yes
	Standards of Proficiency – Social Workers in England (Health and Care Professions Council, 2017)	Section 3.1 states social workers must “understand the need to maintain high standards of personal and professional conduct” (p.8). Section 3.4 states social workers must “be able to establish and maintain personal and professional boundaries” (p.7). Section 9.1 states social workers must “understand the need to build and sustain professional relationships with service-users” (p.10). Section 3.2 address the need for social workers to maintain their own health and wellbeing.	No	Yes	Yes

<b>Practitioner Job type</b>	<b>Relevant codes of conduct, standards and ethics</b>	<b>Mention of self-disclosure</b>	<b>Self-disclosure</b>	<b>Boundaries</b>	<b>Mental health</b>
Dietitian	Standards of Proficiency – Dietitians (Health and Care Professions Council, 2013)	Section 3.1 states dietitians must “understand the need to maintain high standards of personal and professional conduct” (p.8). Section 2 addresses boundaries. Section 3 addresses fitness to practice including health.	No	Yes	Yes
	Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	See * below	No	Yes	Yes
Occupational therapist	Standards of Proficiency – Occupational Therapists (Health and Care Professions Council, 2013)	Section 3.1 states occupational therapists must “understand the need to maintain high standards of personal and professional conduct” (p.7). Section 2 addresses boundaries. Section 3 addresses fitness to practice including health.	No	Yes	Yes
	Code of Ethics and Professional Conduct (Royal College of Occupational Therapists, 2015)	Section 4.6.4 states “You should avoid entering into a close personal relationship with a current service-user. You are responsible for maintaining an appropriate professional relationship. If there is a risk that the professional boundary may be broken, this should be disclosed and discussed with your manager” (p.29). Section 4.7 addresses fitness to practice, health, and impairment of judgement.	No	Yes	Yes
	Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	See * below	No	Yes	Yes

<b>Practitioner Job type</b>	<b>Relevant codes of conduct, standards and ethics</b>	<b>Mention of self-disclosure</b>	<b>Self-disclosure</b>	<b>Boundaries</b>	<b>Mental health</b>
Physiotherapist	Standards of Proficiency – Physiotherapists (Health and Care Professions Council, 2013)	Section 3.1 states physiotherapists must “understand the need to maintain high standards of personal and professional conduct” (p.7). Section 2 addresses boundaries. Section 3 addresses fitness to practice including health.	No	Yes	Yes
	Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	See * below	No	Yes	Yes
Psychotherapist Counsellor	Ethical Framework for Good Practice in Counselling (British Association of Counsellors and Psychotherapists, 2016)	Sections 31-38 (p.8-9) deal with boundaries and relationships. Transgressions include inappropriate and multiple relationships, but not self-disclosure except separating personal profiles from professional profiles on social media. Sections 18 & 75 (pages 6 & 13) address the need to maintain mental health.	No	Yes	Yes
	* Standards of Conduct, Performance and Ethics (Health and Care Professions Council, 2016)	Section 1.7, under the title “Maintain appropriate boundaries” the standards state “You must keep your relationships with service-users and carers Professional” (p.5). Section 2.7 states “You must use all forms of communication appropriately and responsibly, including social media and networking websites” (p.6). Section 6.3 states “6.3 You must make changes to how you practise, or stop practising, if your physical or mental health may affect your performance or judgement, or put others at risk for any other reason” (p.8).	No	Yes	Yes

## Appendix 4: Survey Comparison

Practitioner survey	Service-user survey
<p>1. In your current or previous roles have you ever shared something about yourself or your experiences with a service-user?</p> <p>For example, your religion, your physical or mental health (or that of others), your sexual orientation, your religion, your family circumstances, difficult or traumatic life experiences, your hobbies or out of work activities, or other things about yourself or your life.</p> <p>YES <input type="checkbox"/></p> <p>NO <input type="checkbox"/></p> <p><b>If YES</b>, automatically take to the next question (a), below, then question 2. If NO go to (b) then question 2.</p>	<p>1. Has a mental health practitioner (for example, a social worker, doctor, nurse, or support worker) ever shared something with you about themselves or their experiences?</p> <p>For example, their religion, their physical or mental health (or that of others), their sexual orientation, their religion, their family circumstances, difficult or traumatic life experiences, their hobbies or out of work activities, or other things about themselves or their life.</p> <p>YES <input type="checkbox"/></p> <p>NO <input type="checkbox"/></p> <p>If Yes, automatically continue to the next question (a) below then proceed to (b). If NO, proceed to (b) then question 2.</p>
<p>a) What kinds of things did you share?</p> <p>For example, your religion, your physical or mental health (or that of others), your sexual orientation, your family circumstances, difficult or traumatic life experiences, your hobbies or out of work activities or other things about yourself or your life.</p> <p>Please give up to three examples, saying what was disclosed, why you shared this, and what was helpful or unhelpful about it.</p> <p>Example 1. What was shared? Please give a specific example from your own experience.</p> <p>(free text box, unlimited)</p> <p>Why did you share this?</p> <p>(free text box, unlimited)</p>	<p>b) What kinds of things did they share with you?</p> <p>For example, their religion, their physical or mental health (or that of others), their sexual orientation, their family circumstances, difficult or traumatic life experiences, their hobbies or out of work activities or other things about themselves or their life.</p> <p>Please give up to three examples, saying what was disclosed, why you think they shared this with you, and what was helpful or unhelpful about it.</p> <p>Example 1. What was shared?</p> <p>(free text box, unlimited online; limited on hard copy)</p> <p>Why do you think they shared this?</p> <p>(free text box, unlimited online; limited on hard copy)</p>









<p><b>Further information and Involvement</b></p> <p>The responses that you have given will be added to others, and analysed by the researchers.</p> <p>Focus Groups will be held separately with practitioners and with service-users to discuss the topics that have been raised.</p> <p>The results of the study may be made available in reports, and may be published.</p> <p>A small group of practitioners and service-users will get together after the research has been completed, to produce some training and guidance for staff about sharing lived experience.</p> <p>If you would like to be involved or kept up to date on progress, please indicate below, and leave your contact details. This information will be kept separately from your responses and will not be used to identify you in any way.</p> <p><input type="checkbox"/> I would like to be contacted with further information about taking part in a focus group.</p> <p><input type="checkbox"/> I would like to be kept up to date with reports and publications about this research.</p> <p><input type="checkbox"/> I would like to receive further information about how I can get involved with the production of training and guidance, after the research has been completed.</p>	<p><b>Further information and Involvement</b></p> <p>The responses that you have given will be added to others, and analysed by the researchers.</p> <p>Meetings (focus groups) will be held separately with practitioners and with service-users to discuss the topics that have been raised.</p> <p>The results of the study may be made available in reports, and may be published.</p> <p>A small group of practitioners and service-users will get together after the research has been completed, to produce some training and guidance for staff about sharing lived experience.</p> <p>If you would like to be involved or kept up to date on progress, please indicate below, and leave your contact details. This information will be kept separately from your responses and will not be used to identify you in any way.</p> <p><input type="checkbox"/> I would like to be contacted with further information about taking part in a focus group.</p> <p><input type="checkbox"/> I would like to be kept up to date with reports and publications about this research.</p> <p><input type="checkbox"/> I would like to receive further information about how I can get involved with the production of training and guidance, after the research has been completed.</p>
<p>My contact details are: (Please leave blank if you do not wish to be contacted).</p>	<p>My contact details are: (Please leave blank if you do not wish to be contacted).</p>
<p>I would like to submit my responses. <b>Submit.</b> <b>Thank you for submitting your responses.</b></p>	<p>I would like to submit my responses. <b>Submit.</b> <b>Thank you for submitting your responses.</b> (online version only)</p>

**Participant Information Sheet: Service-user Survey**

**Study title:** Sharing Lived Experience in Mental Health Interventions

**What is this research about and what difference will it make?**

The University of York and Leeds & York Partnership NHS Foundation Trust are working together to find out what you think about “sharing lived experience.” Sharing lived experience is where a person tells another person something about their life or their experiences.

This survey asks whether you find it helpful or unhelpful to know different things about the people who work with you, for example, doctors, nurses, and social workers. A similar survey is also being undertaken with the people who work at Leeds & York Partnership NHS Foundation Trust.

When we have completed the study we will look at what people have said and produce a report that will go to the Trust. We will also put together some training and guidance for Trust staff. The report, training, and guidance will help workers at the Trust think about what information they share about themselves with the people they support.

**Why have I been contacted?**

Many service-users from across Leeds and York Partnership NHS Foundation Trust have been selected, by chance, to take part in this survey.

**What will you do with my answers?**

The answers you give in this survey will be looked at along with other people’s responses. We might use some of the things you say when we write reports about the research, and some of these reports may be published on the internet, in journals, or in other reports. We will make sure that the things you say are not used to identify you in any way.

You can get updates about the research, and what happens afterwards, by visiting:

[www.jonnylovellblog.wordpress.com](http://www.jonnylovellblog.wordpress.com)

**Is my information confidential?**

You do not have to give any contact details. If you supply contact details, we can let you know what happened as a result of the research, and we may also invite you to come and discuss what you think about sharing lived experience as part of a small group, to help us to understand the things people have said in the surveys.

We will not share your contact details with anyone else, unless you tell us that you or someone else is at risk of harm. If that happened, we might need to pass the information on to appropriate agencies. We would always try to discuss this with you first.

**How will taking part in this research benefit me? And are there any risks?**

There might not be a direct benefit to you for taking part in this research, but your contribution might help to improve the way mental health workers think about sharing their

own experiences with service-users. There are minimal risks involved in taking part in this study.

**Who has approved this research?**

All research in the NHS has to go through a procedure to ensure that it is honest and safe for the people who take part. This is referred to as ethical approval. This research has ethical approval from the NHS (North West Research Ethics Committee), and has Research and Development approval from Leeds and York Partnership NHS Foundation Trust.

**How can I complain or get further information?**

If you encounter a problem with taking part in this research, or if you have a complaint or query, you can contact the Chief Investigator, Jonny Lovell, in the following ways:

By email: [jl1155@york.ac.uk](mailto:jl1155@york.ac.uk)

In writing: Jonny Lovell, at the address given below.

**What do I do next?**

You can take part by sending this completed survey back in the envelope provided. You do not need a stamp. Or, if you prefer to complete this survey on-line, please visit:

<http://bit.ly/sharemyexperience>

Please only complete one survey, either on-line or by post, but not both.

If you want to fill out the survey on-line but do not have access to a computer, you might want to visit a library where computer access is available.

The survey should take 15-20 minutes to complete. You do not have to answer any questions that you do not want to, but please complete all sections if you are happy to do so.

**What if I need help to complete this form?**

If you need help to complete the form, please discuss it with the person who you receive support from at Leeds and York Partnership NHS Foundation Trust. Alternatively, you can contact Alison O'Connell at Leeds & York Partnership NHS Foundation Trust on **0113 3056759** and appropriate support will be identified.

**Do I have to take part, and what if I want to withdraw from the research?**

Taking part in this survey is entirely voluntary. If you do take part, and if you give contact details in your survey, then we will be able to delete your responses if you change your mind, as long as we have not already begun analysis. If you have not left contact details, or if we have already analysed your answers and added them to the others, then we will not be able to remove your responses.

**Thank you!**

Jonny Lovell, PhD Student & Chief Investigator  
International Centre for Mental Health Social Research  
Department of Social Policy and Social Work, University of York  
Heslington, York, YO10 5DD

Email: [jl1155@york.ac.uk](mailto:jl1155@york.ac.uk)

Blog: [www.jonnylovellblog.wordpress.com](http://www.jonnylovellblog.wordpress.com)

**Survey Consent Form – Service-users**

If you wish to take part in the survey, please tick the box below to indicate that you understand the information you have received, and that you wish to take part.

I have read and understood the information supplied about this survey.

I understand that I do not have to take part, and how I can withdraw if I change my mind.

I understand that information given will be kept confidential, and I agree for quotations to be used anonymously in any publications that arise from this study.

I agree to take part in the survey.

You do not need to sign or date this form.

## The Survey

### About you

The information we ask about you will not be used to identify you in any way. It will be used so that we can see if there are differences in the way that different people think about sharing lived experience. You do not have to answer any of these questions if you do not wish to.

#### Age

How old are you in years?

Prefer not to say

#### Gender

Male

Female

Transgender

Intersex

Other

Prefer not to say

#### Sexual Orientation

Straight

Gay

Lesbian

Bisexual

Other

Prefer not to say

#### Ethnicity

White (English, Welsh, Scottish, Northern Irish, Irish, British, Gypsy or Irish Traveller, other white background)

Mixed / Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed / Multiple ethnic background)

Asian / Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)

Black / African / Caribbean / Black British (African, Caribbean, Any other Black / African Caribbean background)

Other ethnic group

#### Physical disability (including long-term physical health conditions)

I have a disability

I do not have a disability

Prefer not to say

#### Religion

I am religious

I am not religious

Prefer not to say

### Survey Questions

1. **Has a mental health practitioner (for example, a social worker, doctor, nurse, or support worker) ever shared something with you about themselves or their experiences?**

For example, their religion, their physical or mental health (or that of others), their sexual orientation, their religion, their family circumstances, difficult or traumatic life experiences, their hobbies or out of work activities, or other things about themselves or their life.

YES

NO

- c) What kinds of things did they share with you?

For example, their religion, their physical or mental health (or that of others), their sexual orientation, their family circumstances, difficult or traumatic life experiences, their hobbies or out of work activities or other things about themselves or their life.

Please give up to three examples, saying what was disclosed, why you think they shared this with you, and what was helpful or unhelpful about it.

Example 1. What was shared?
Why do you think they shared this?
In what ways was sharing this helpful or unhelpful?
What type of practitioner shared this information with you? (for example, nurse, social worker, doctor, support worker etc.)

Example 2. What was shared?
Why do you think they shared this?
In what ways was sharing this helpful or unhelpful?
What type of practitioner shared this information with you? (for example, nurse, social worker, doctor, support worker etc.)

Example 3. What was shared?
Why do you think they shared this?
In what ways was sharing this helpful or unhelpful?
What type of practitioner shared this information with you? (for example, nurse, social worker, doctor, support worker etc.)

d) Why do you think practitioners choose not to share information about themselves when working with service-users?

**2) How helpful or unhelpful do you think it would be for a practitioner to share the following kinds of experience and information about themselves with a service-user?**

(For example, a doctor, nurse, social worker, psychologist, occupational therapist etc.)  
Please rate each type of shared information, with 1 being most unhelpful, and 5 being most helpful. Tick or circle your choice.

a) Their personal mental health lived experience (i.e. their own mental health, rather than the mental health of someone they know)

1	2	3	4	5
○	○	○	○	○
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?



b) The mental health lived experience of their close family member or friend

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

c) Their religion

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

d) Their physical health (including any health conditions or physical disabilities)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

e) Difficult or traumatic life experiences they have experienced

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

f) Their hobbies and out of work experiences (for example, where they went on holiday)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

g) Their sexual orientation

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

In what ways do you feel sharing this information would be helpful or unhelpful?

**3) How helpful or unhelpful do you think it would be for the following practitioners to share information about their own mental health experiences or conditions with service-users?**

You don't need to have worked with these practitioners to say what you think. If you would prefer not to answer, or do not have any views on any of these questions, please leave blank.

Please rate each type of disclosure, with 1 being most unhelpful, and 5 being most helpful, by ticking or circling your choice.

**a) Nurse**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**b) Social Worker**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**c) Counsellor**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**d) Psychologist or psychotherapist**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**e) Occupational Therapist or Physiotherapist**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**f) Doctor**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**g) Peer support worker or mentor**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhelpful			Helpful	

**h) Health care support workers or assistants**

1	2	3	4	5
○	○	○	○	○
Unhelpful			Helpful	

**i) Non-clinical staff** (for example, administrators, cleaners, catering staff etc.)

1	2	3	4	5
○	○	○	○	○
Unhelpful			Helpful	

If you thought disclosure was more helpful or less helpful for different practitioner roles, please use this space to explain why (which roles, and why disclosure may be more or less helpful in those roles).

Please use this space to make any other comments about this survey or sharing lived experience.

**Further information and Involvement**

The responses that you have given will be added to others, and analysed by the researchers.

Meetings (focus groups) will be held separately with practitioners and with service-users to discuss the topics that have been raised.

The results of the study may be made available in reports, and may be published.

A small group of practitioners and service-users will get together after the research has been completed, to produce some training and guidance for staff about sharing lived experience.

If you would like to be involved or kept up to date on progress, please indicate below, and leave your contact details. This information will be kept separately from your responses and will not be used to identify you in any way.

I would like to be contacted with further information about taking part in a focus group.

I would like to be kept up to date with reports and publications about this research.

I would like to receive further information about how I can get involved with the production of training and guidance, after the research has been completed.

My contact details are:

(Please leave blank if you do not wish to be contacted).

**Appendix 6: Intimacy Measurement Scale Survey****How personal are different subjects of self-disclosure? Developing a measurement scale.****Information and Consent to Take Part****What is this research about and what difference will it make?**

Self-disclosure is where people share things about themselves with other people. This could include our likes and dislikes, what we think about someone's behaviour, our experiences, or our identity.

People might feel differently about sharing different things with different people. For example, you may be more inclined to share things with a friend than your employer.

I am about to undertake a study on what mental health professionals think about disclosing information about themselves to service-users. Professionals may include community workers, doctors, social workers, nurses, psychiatrists, occupational therapists, psychologists, and peer mentors, among others. Disclosure in this study refers to personal experiences and identities.

The study is primarily about how helpful or unhelpful mental health professionals think self-disclosure is. However, when I look at the responses, it would be useful to see whether mental health professionals think differently according to how *personal* the information is.

Several other studies have graded disclosures according to how personal the information being shared is. However, some research suggests views change over time, so it may be the case that people nowadays are more open about themselves, and see information about themselves as less personal than they would have done in the past. Since there are no studies that have rated disclosures according to how personal they are in the UK, in recent years, with the professionals that the current study is engaging with, it is necessary to construct a new scale.

**What will I be asked to do?**

You will be asked to complete a questionnaire and asked to rate how personal different kinds of information are. It will take less than five minutes.

**What will you do with the information I give and is my information confidential?**

Your ratings will be pooled with the ratings given by other participants, to create an average score for each disclosure item.

It will be necessary to report some general demographics of who took part, for example age, gender, and ethnicity. This information will be used for general analysis purposes, and to establish the limits of the measurement tool. Information will not be used in ways that could potentially identify participants. No names or contact details are collected unless you wish to be entered into the £20 Amazon voucher draw instead of receiving a £5 payment for completing the survey. Names and contact details will be kept securely.

If you want to know what happens with the research in general, you can check the blog for updates:

[Jonnylovellblog.wordpress.com](http://Jonnylovellblog.wordpress.com)

**How will taking part in this research benefit me?**

You may not directly benefit from taking part in this research. However, you may gain some insight into how social research is carried out, which may be useful for your current and future studies. You will gain a brief introduction to the contentious issue of self-disclosure, which may be useful to you, as this is an important issue across a range of health and social care settings.

**Who has approved this research?**

The research has received ethical approval from the NHS Research Ethics Committee (North West Research Ethics Committee) and permission to proceed has been received from the University of York (Social Policy and Social Work Ethics Committee).

**How can I complain or get further information?**

You can contact the Chief Investigator, Jonny Lovell, in the following ways:

By email: [jl1155@york.ac.uk](mailto:jl1155@york.ac.uk)

In writing: Jonny Lovell, PhD Student  
International Centre for Mental Health Social Research  
Department of Social Policy and Social Work  
University of York, Heslington, York  
YO10 5DD

**What if I want to withdraw from the research?**

It will not be possible to withdraw once your on-line questionnaire has been submitted, but you will be asked at the end of the questionnaire whether you wish to submit your answers, and you will have the opportunity to decline.

**Do I get paid?**

The first 20 participants will be paid £5 for completing this survey. If you are not one of the first 20 participants, or if you wish to be entered into the draw for a £20 Amazon gift voucher instead, please leave your contact details on the form. One participant will be selected at random to receive a £20 Amazon gift voucher.

**Consent**

If you want to take part, please tick the box below to indicate that you understand the information you have received, and that you wish to take part. Please sign and date this form.

I have read the information supplied about this research, and I consent to taking part in it.

Sign:

Date:

Print name:

**Demographic Information**

The following information will be used for general analysis and will not be used to identify you in any way.

**Job status**

Please tick the job role that most closely matches yours

- Practitioner in a job related to health and social care
- Student on a course related to health and social care
- Prefer not to say

**Area of health and social care worked in**

- Mental health
- Not mental health
- Prefer not to say

**Job type**

- Nursing
- Social Work
- Counsellor, psychiatrist, psychotherapist
- Occupational therapy
- Doctor



Peer support worker or mentor

Other, please state:

Prefer not to say

**Age**

**How old are you in years?**

Prefer not to say

**Gender**

Male

Female

Transgender

Intersex

Other

Prefer not to say

**Sexual Orientation**

- Straight**
- Gay**
- Lesbian**
- Bisexual**
- Other**
- Prefer not to say**

**Ethnicity**

- White (English, Welsh, Scottish, Northern Irish, Irish, British, Gypsy or Irish Traveller, other white background)**
- Mixed / Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed / Multiple ethnic background)**
- Asian / Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)**
- Black / African / Caribbean / Black British (African, Caribbean, Any other Black / African / Caribbean background)**
- Other ethnic group**

**Disability**

I have a disability

I do not have a disability

Prefer not to say

**Religion**

I am religious

I am not religious

Prefer not to say

### How to complete the Questionnaire

1. Rate the following potential disclosures according to how *personal* you think they would be if a practitioner shared them with a service-user in a work setting.
2. Do not think about whether practitioners should or should not share these items of information, just rate how personal you think they are.
3. Do not think about what type practitioner might share these items. Think in general terms. Practitioners might be anyone employed in health and social care roles.
4. Don't spend too long thinking about your answers. Just indicate how personal you think the disclosure is, on a 1 to 5 scale where:

1 = Not personal

5 = Highly personal

**a) The practitioner's personal mental health lived experience (i.e. the practitioner's own mental health, rather than the mental health of someone they know)**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal				Highly personal

**b) The practitioner's sexual orientation**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal				Highly personal

**c) The practitioner's religion**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal				Highly personal

**d) The practitioner's family circumstances or experiences (for example, whether they are married or have children)**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal			Highly personal	

**e) The practitioner's physical health (including any health conditions)**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal			Highly personal	

**f) The practitioner's previous difficult or traumatic life experiences**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal			Highly personal	

**g) The practitioner's hobbies and out of work experiences (for example, their interests, or where they went on holiday)**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal			Highly personal	

**h) The mental health lived experience of the practitioner's close family member or a friend**

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not personal			Highly personal	

**Thank you for completing this survey.**

## The Survey (Practitioner Demographics)

### About you

The information we ask about you will not be used to identify you in any way. It will be used so that we can see if there are differences in the way that different people think about sharing lived experience. You do not have to answer any of these questions if you do not wish to.

### Job type

Please indicate the job title closest to yours:

- Nurse
- Doctor
- Consultant
- Social Worker
- Health care support worker
- Health care assistant
- Clinical psychologist
- Psychotherapist
- Counsellor
- Physiotherapist
- Occupational therapist
- Peer support worker or mentor

Other, please state

Prefer not to say

**Age**

**How old are you in years?**

Prefer not to say

**Gender**

Male

Female

Transgender

Intersex

Other

Prefer not to say

**Sexual Orientation**

Straight

Gay

Lesbian

Bisexual

Other

Prefer not to say

#### **Ethnicity**

White (English, Welsh, Scottish, Northern Irish, Irish, British, Gypsy or Irish Traveller, other white background)

Mixed / Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed / Multiple ethnic background)

Asian / Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)

Black / African / Caribbean / Black British (African, Caribbean, Any other Black / African / Caribbean background)

Other ethnic group

#### **Physical disability (including long-term physical health conditions)**

I have a disability

I do not have a disability

Prefer not to say



**Religion** I am religious I am not religious Prefer not to say

Do you have direct contact with service-users?

(Direct contact means in a clinical role, rather than an administrative role).

 Yes No Prefer not to say

Do you provide clinical supervision for staff who have direct contact with service-users?

(Direct contact means in a clinical role, rather than an administrative role).

 Yes No Prefer not to say

**Have you personally experienced a previous or current mental health issue or condition that is significant or problematic for you?**

 Yes No Prefer not to say

**Do you have a partner or close family member who has experienced a significant or problematic mental health issue or condition?**

Yes

No

Prefer not to say

## Appendix 7: Service-user Survey Sampling Breakdown

Referral To Team Name	Sample	Population
CMHT WNW LOCALITY	447	3115
OPS - MEMORY SERVICE	350	2437
CMHT ENE LOCALITY	225	1570
CMHT SSE LOCALITY	168	1168
IAPT	143	996
PSYCHOLOGY & THERAPIES	121	846
LAU - LEEDS ADDICTION UNIT	113	789
CF - CHRONIC FATIGUE / M E	48	337
LP - LIAISON PSYCHIATRY	45	312
GI - GENDER IDENTITY	42	293
EX - ASPIRE	42	291
CARE HOME TEAM	41	289
AS - ASSERTIVE OUTREACH	24	168
PM - PSYCHOSEXUAL MEDICINE	22	150
OPS-YOUNG PEOPLE WITH DEMENTIA	21	143
PD - PERSONALITY DISORDER	18	122
AS - ADHD NEW ASSESSMENT	16	108
FS LDS- FORENSIC COMM	13	92
ED - YCED	12	82
OPS - PHYSIOTHERAPY	11	80
PN - PERINATAL	9	63
OPS - LIAISON PSYCHIATRY	8	59
CB - C B T	8	55
LEEDS AUTISM DIAGNOSTIC SERVIC	8	53
AS - HEALTHY LIVING SERVICE	7	51
FS LDS- FORENSIC PSYCHOLOGY	6	44
ACUTE LIAISON PSYCHIATRY TEAM.	5	36
PS - PATHWAY DEVELOPM'T SERV.	5	35
AS - ADULT DIETETICS SERVICE	5	33
OP - DIETETICS	3	18
OPS - I/P ACUTE (MH)	3	16
AS - BI-POLAR DISORDER	3	12
AS - LOCKED REHABILITATION WD5	3	11
FS LDS- FORENSIC I/P WARD 3	3	9
PY - PSYCHO-ONCOLOGY	3	9
AS - ADULT PHYSIOTHERAPY SER:	3	6
PC - PALLIATIVE CARE TEAM	3	7
FS YORK - FORENSIC COMMUNITY	3	5
CW - CITYWIDE TREATMENT SER:	3	5
SPA / SPUR	3	5
FS YORK - FORENSIC INPATIENTS	3	3
FS YORK - FORENSIC PSYCHOLOGY	3	3
FS LDS-FORENSIC I/P WD2 WOMEN	3	3
FS LDS-FORENSIC I/P WD 2 A&T	3	3
AS - PSYCHOLOGICAL THERAPIES	1	1
<b>TOTAL</b>	<b>2029</b>	<b>13,933</b>

## Appendix 8: Research Promotional Leaflet

## Sharing Lived Experience?

Leeds and York Partnership NHS Foundation Trust and the University of York are undertaking research into sharing lived experience.

**Is it helpful or unhelpful for practitioners to share their own experiences with service users?**

We are selecting a random sample of service users and practitioners to receive surveys, so not everyone will be contacted. But if you are, please consider taking part.

**Everyone has an opinion, and we want to hear YOURS!**

Whoever you are, whatever your experience:

**Service Users      Practitioners**

**Any job role**

**All kinds of lived experience  
not just mental health**

## What do YOU think?

**Your responses will be invaluable, and may help with the development of training and guidance on sharing lived experience for practitioners.**

**This research has ethical approval from the NHS and Research Governance  
Approval from Leeds and York Partnership NHS Foundation Trust**

## Appendix 9: Desktop & Bulletin Research Publicity

### Desktop publicity

#### To share or not to share?

There are different opinions among professionals about whether it is useful or beneficial for them to share their lived experience with clients despite the growing national agenda supporting recruitment of Peer workers.

Leeds and York Partnership NHS Foundation Trust and the International Centre for Mental Health Social Research (Department of Social Policy and Social Work, University of York) are currently undertaking research into the use of self-disclosure by professionals in mental health settings: what do practitioners think about self-disclosure, and what do service-users think?

You or someone you are supporting may receive a survey to complete as part of an anonymised study. We would be grateful for your support in carrying out this important piece of research.

For further information please contact the Chief Investigator, Jonny Lovell by email: [jl1155@york.ac.uk](mailto:jl1155@york.ac.uk)

Or visit the research blog, where updates are regularly posted: [www.jonnylovellblog.wordpress.com](http://www.jonnylovellblog.wordpress.com)

### Communications Bulletin

#### Sharing Lived Experience in Mental Health Interventions

When research was undertaken in 2013 into social workers' attitudes towards self-disclosure, a question was included about mental health. Would practitioners think it was acceptable or unacceptable for professionals to share their experiences with a client of having received counselling, or having been bereaved? These questions caught the eye of a mental health practitioner in Leeds and York Partnership NHS Foundation Trust, who wanted to further explore practitioners' thoughts about sharing lived experience with clients.

This topic has become the focus of a new piece of research, which is being undertaken by Jonny Lovell at the University of York, as part of a PhD in Social Policy and Social Work, which commenced in October 2013.

#### About this research

Leeds and York Partnership NHS Foundation Trust and the International Centre for Mental Health Social Research (Department of Social Policy and Social Work, University of York) are currently undertaking research into the use of self-disclosure by professionals in mental health settings:

What do practitioners think about self-disclosure, and what do service-users think?

Lived Experience:

Up to 1 in 4 people have experienced mental illness at some point in their lives so it is likely that lived-experience is prevalent to some extent across the workforce.

**To share or not to share?**

There are different opinions among professionals about whether it is useful or beneficial for them to share their lived experience with clients despite the growing national agenda in recruiting specific roles such as Peer Support Workers to the NHS workforce.

**Guidance and Training:**

There is little guidance and training available on the subject of self-disclosure to help practitioners make decisions about what they share, when, and for what purpose.

It is anticipated that this research will lead to the development of guidance and training on self-disclosure that may help practitioners to think about disclosure in more depth, so they can decide how they do, or do not, use it in their work.

A sample of service-users and staff from across LYPFT will receive a survey to complete over the next few weeks. Your input and views are invaluable to the success of the research.

For further information please contact the Chief Investigator, Jonny Lovell by email:

[jl1155@york.ac.uk](mailto:jl1155@york.ac.uk)

Or visit the research blog, where updates are regularly posted:

[www.jonnylovellblog.wordpress.com](http://www.jonnylovellblog.wordpress.com)

**Appendix 10: Proportional Illustrations of Positive, Negative & Mediating Factors**

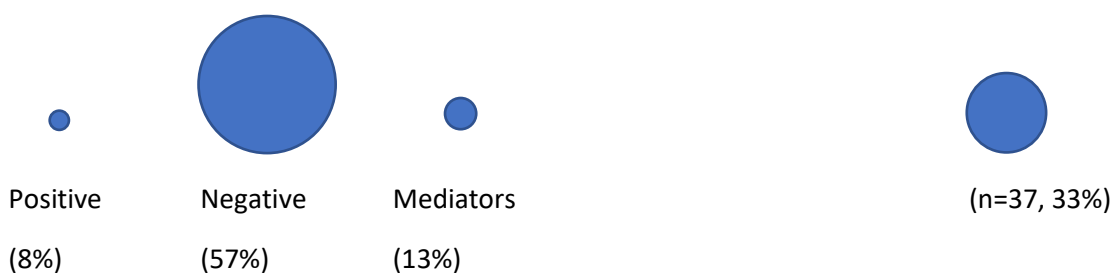
**Circles**

**Method to calculate area:** number of respondents taken as area of each circle; diameter of circle calculated in excel using pi to 9 decimal places; diameter of circle specified in word to 2 decimal places, in millimetres. N = number of respondents who gave this rating, with the % of total possible respondents shown afterwards. Each circle represents the proportion of respondents who said something positive or negative, or mentioned a mediating factor, as a percentage of the number of people who gave that rating to that question (not as a percentage of the total number of possible respondents). Combined percentages may sum to more or less than 100%, because (a) some respondents did not give a written explanation for their rating; (b) some statements were neither positive, negative, nor mediator; and (c) a single response might contain a combination of positive, negative and mediating factors.

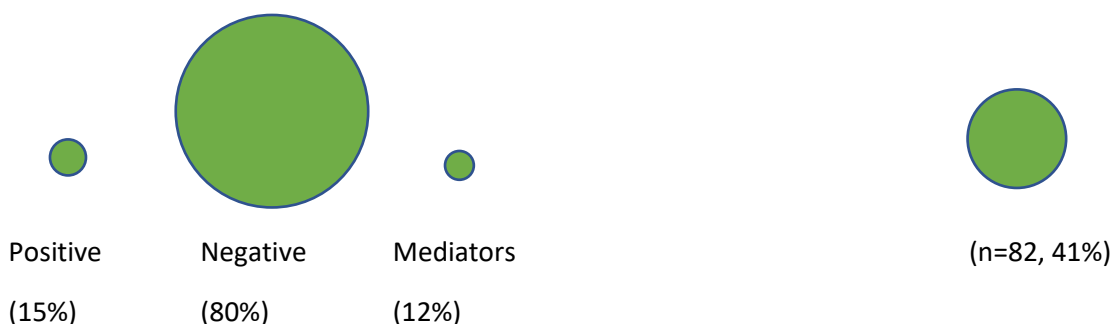
**Mental health ratings of 1 or 2, unhelpful**

**Total respondents who gave this rating as percentage of all possible respondents**

Service-user (n=37, 33%)

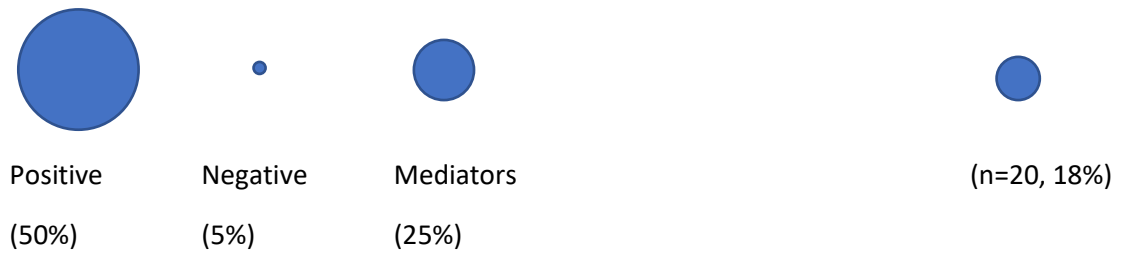


Practitioner (n=82, 41%)

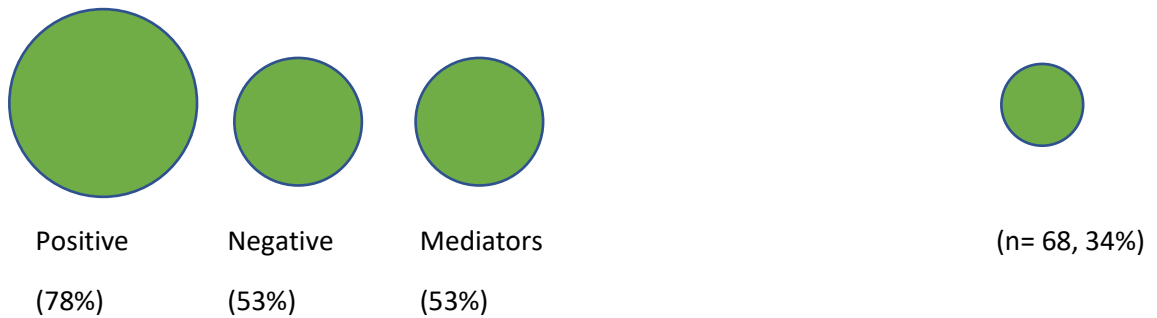


**Mental health ratings of 3, middle ratings**

Service-user (n=20, 18%)

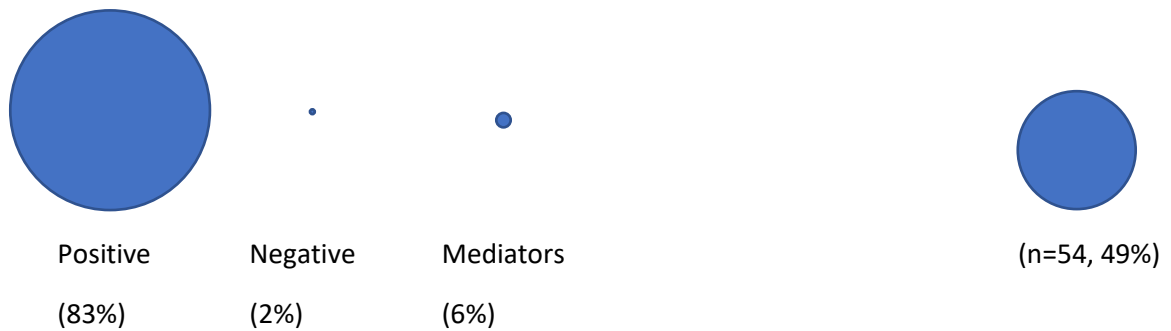


Practitioner (n= 68, 34%)

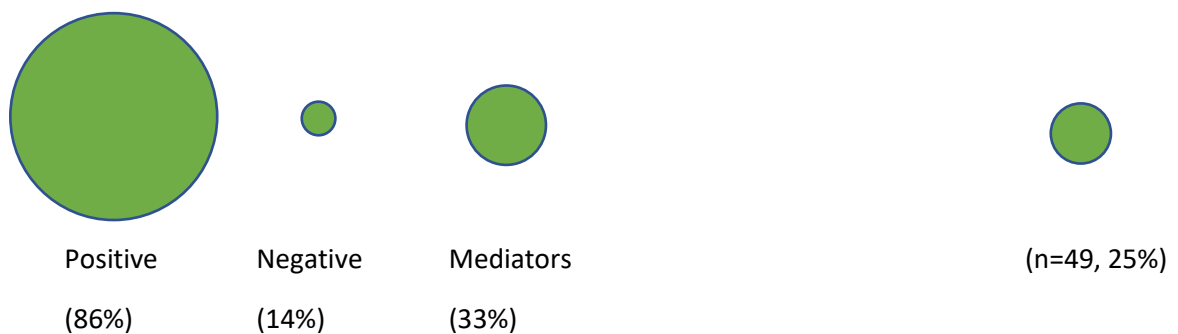


**Mental health ratings of 4 or 5, helpful ratings**

Service-user (n=54, 49%)



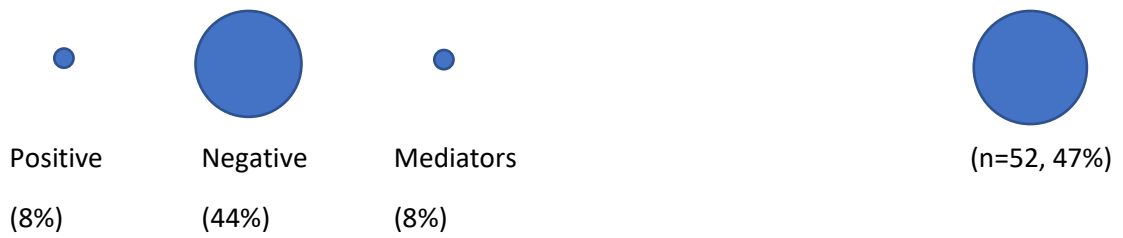
Practitioner (n=49, 25%)



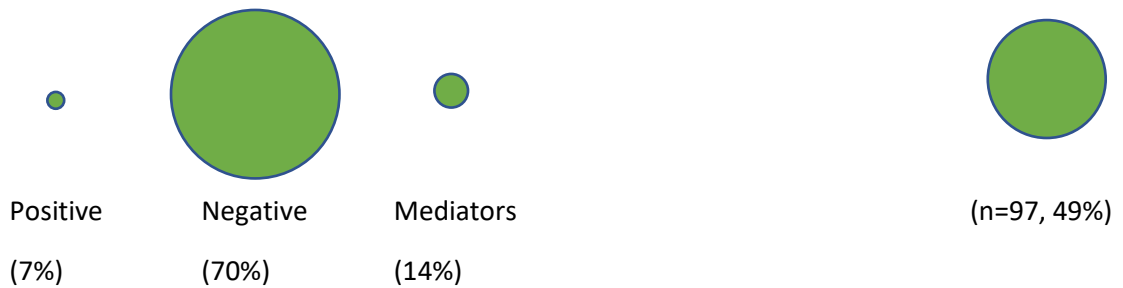


**Difficult or Traumatic Experiences 1 or 2, unhelpful ratings**

Service-user (n=52, 47%)

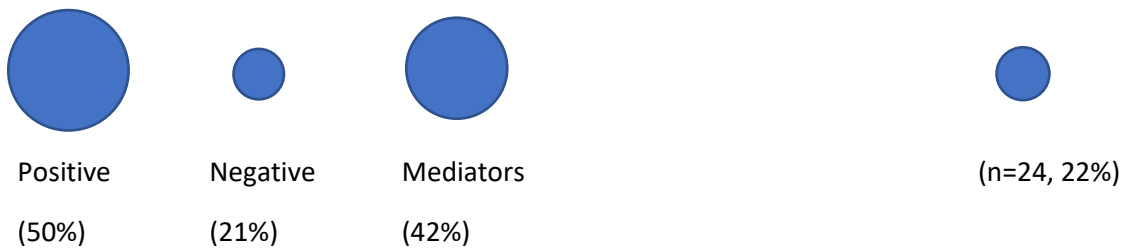


Practitioner (n=97, 49%)

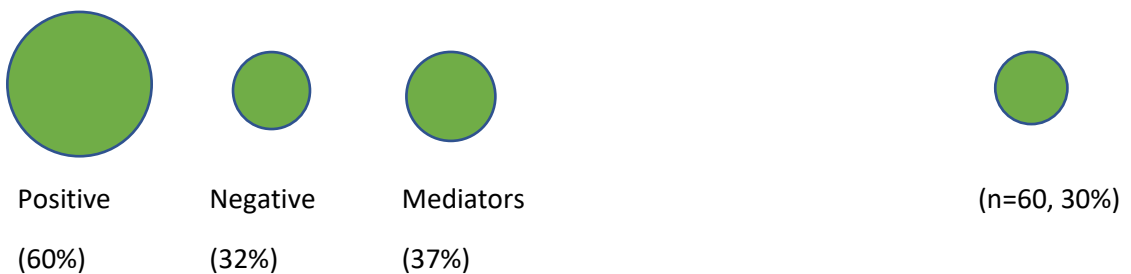


**Difficult or Traumatic Experiences 3, middle ratings**

Service-user (n=24, 22%)

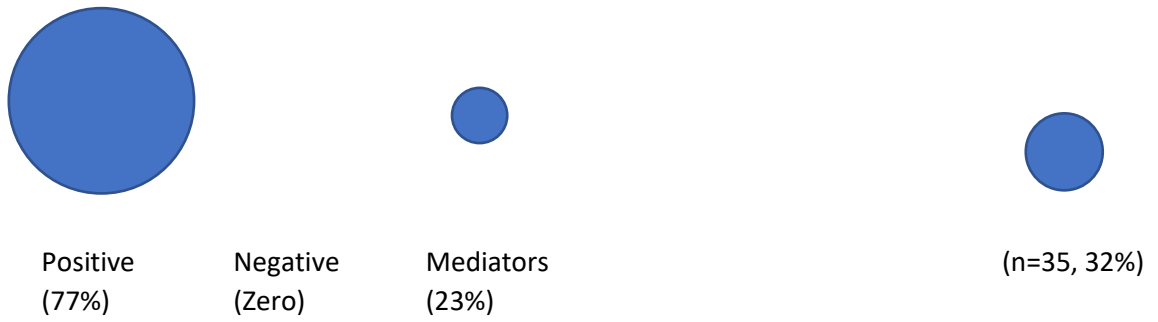


Practitioner (n=60, 30%)

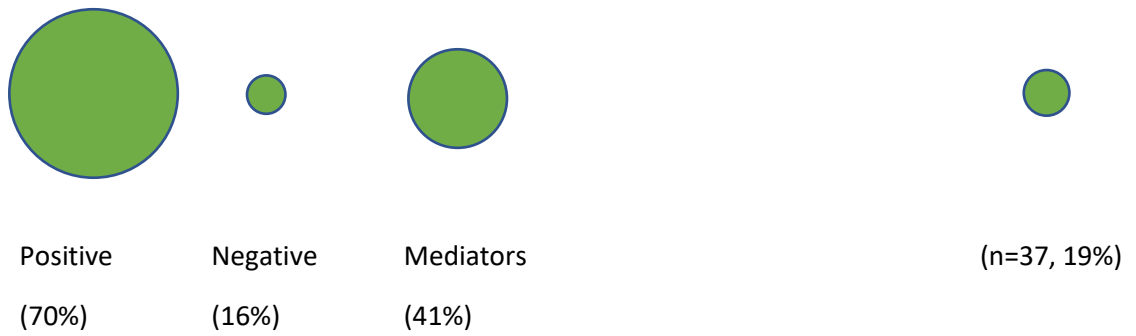


**Difficult or Traumatic Experiences 4 or 5, helpful ratings**

Service-user (n=35, 32%)

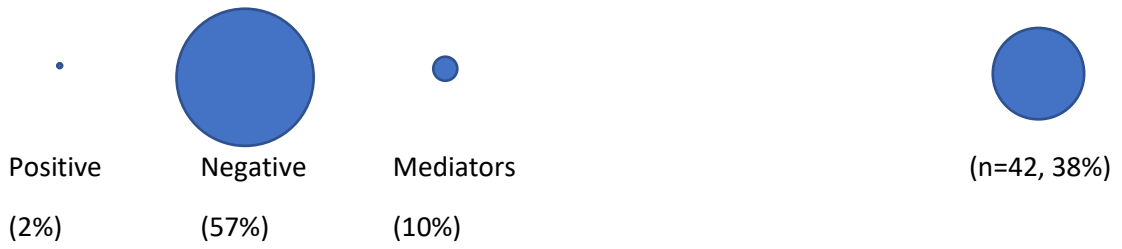


Practitioner (n=37, 19%)

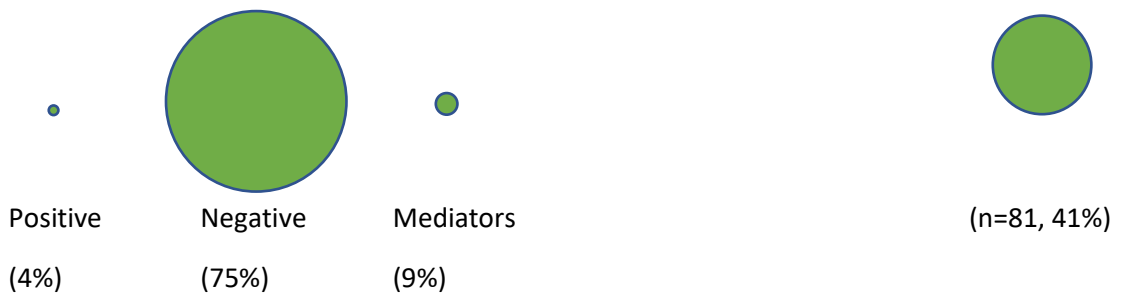


**Mental Health of Family Member or Friend 1 or 2, unhelpful ratings**

Service-user (n=42, 38%)

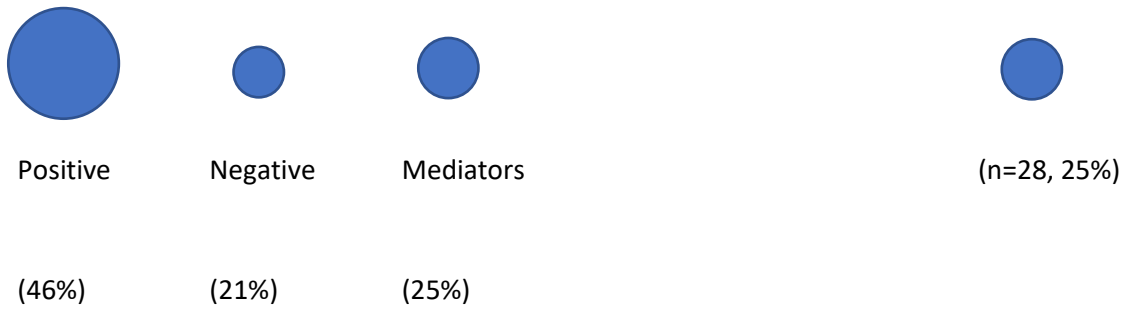


Practitioner (n=81, 41%)

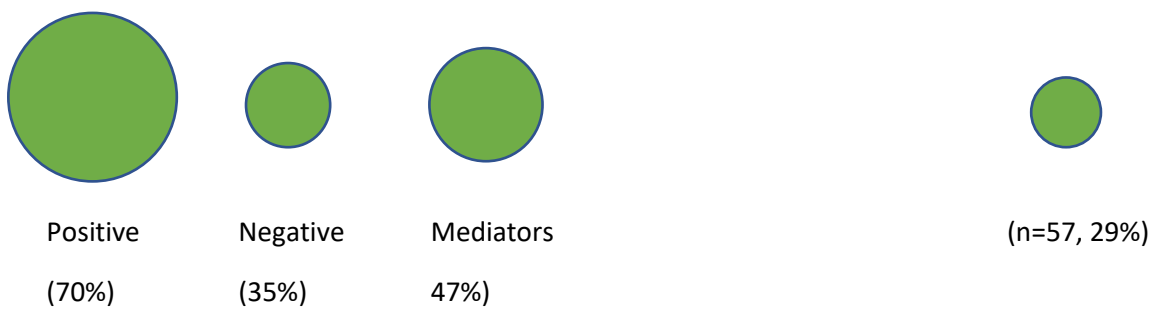


**Mental Health of Family Member or Friend 3, middle ratings**

Service-user (n=28, 25%)

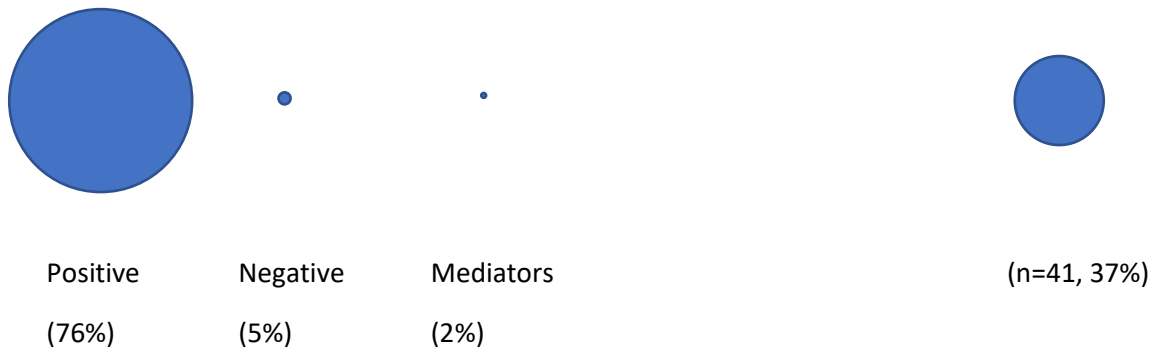


Practitioner (n=57, 29%)

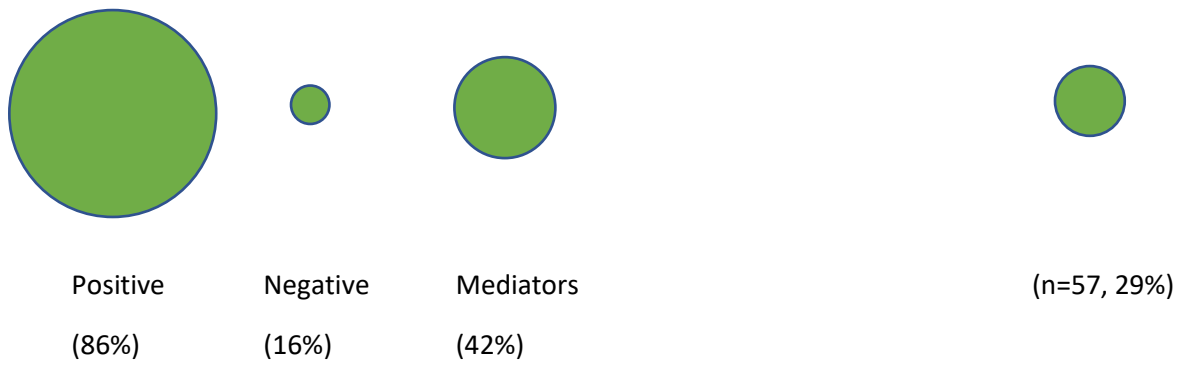


**Mental Health of Family Member or Friend 4 or 5, helpful ratings**

Service-user (n=41, 37%)

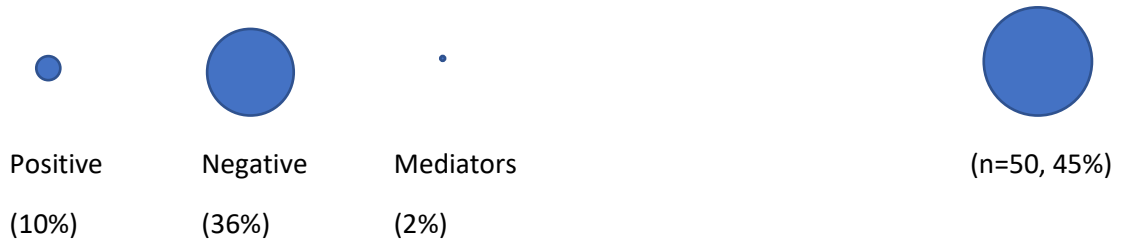


Practitioner (n=57, 29%)

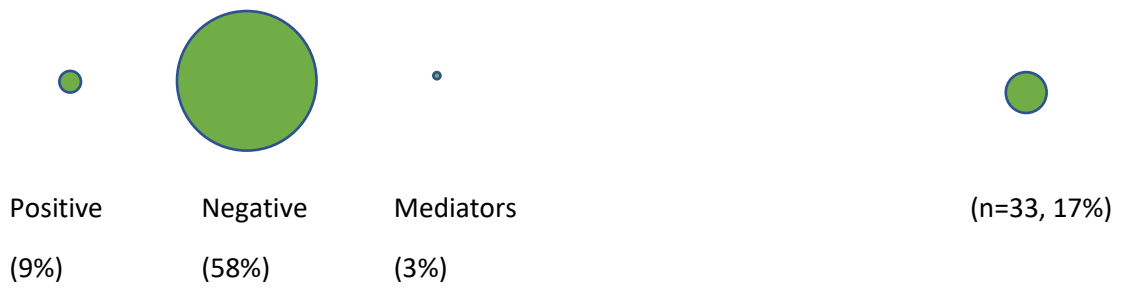


**Hobbies and out of work experiences 1 or 2, unhelpful ratings**

Service-user (n=50, 45%)

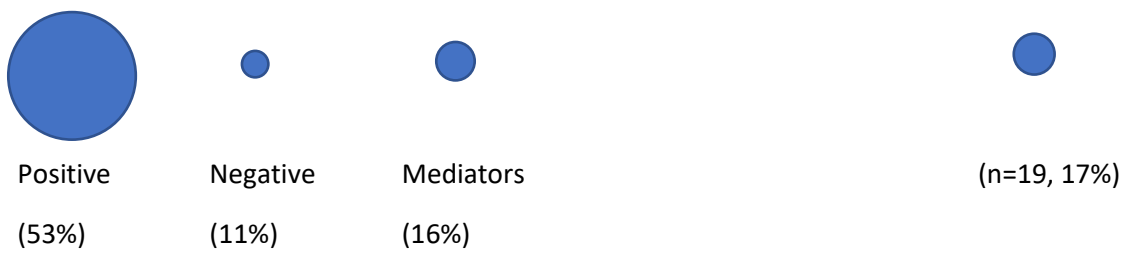


Practitioner (n=33, 17%)

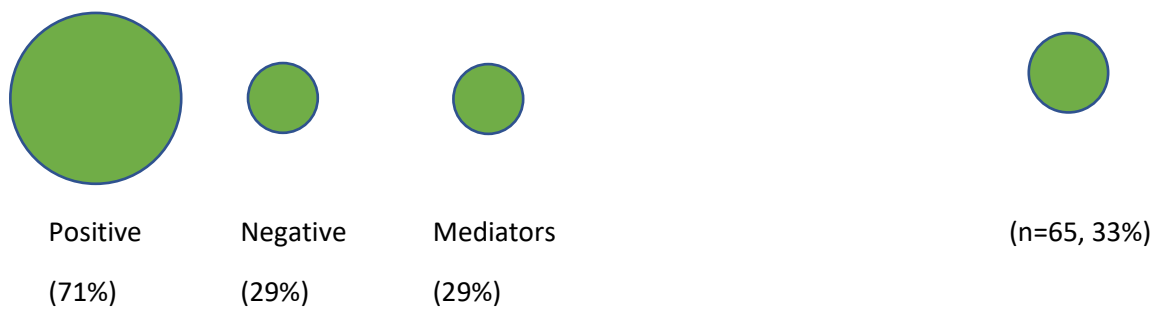


**Hobbies and out of work experiences 3, middle ratings**

Service-user (n=19, 17%)

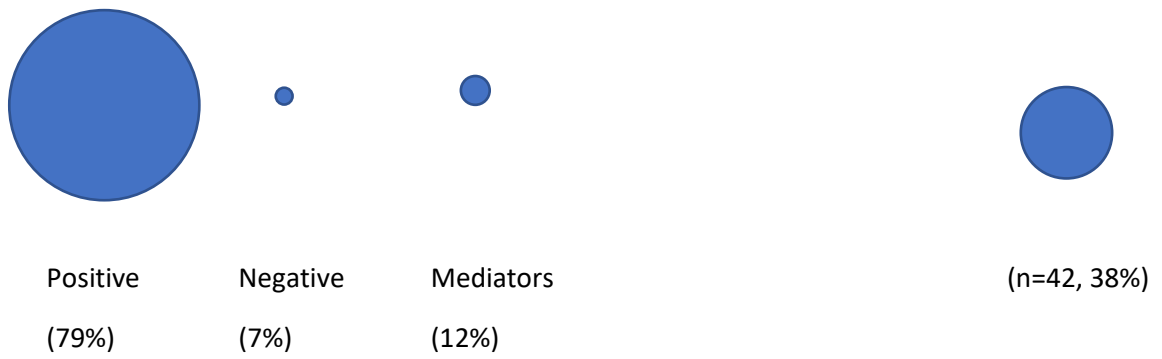


Practitioner (n=65, 33%)

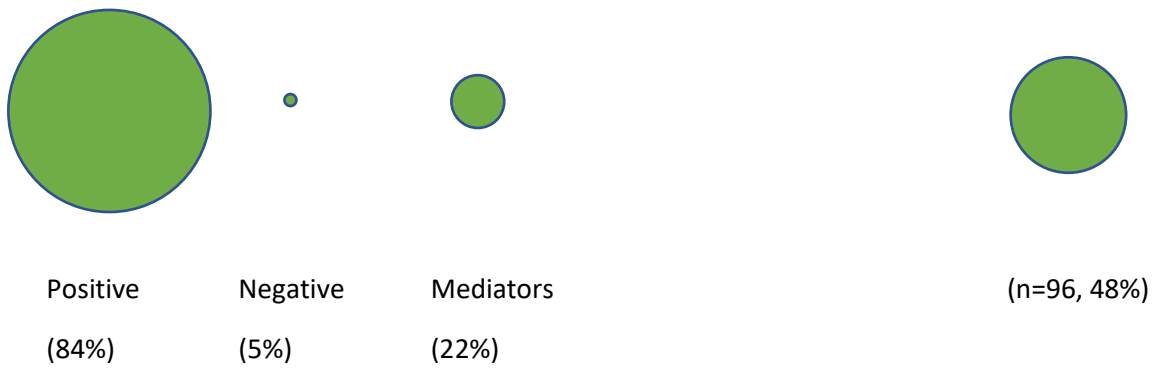


**Hobbies and out of work experiences 4 or 5, helpful ratings**

Service-user (n=42, 38%)

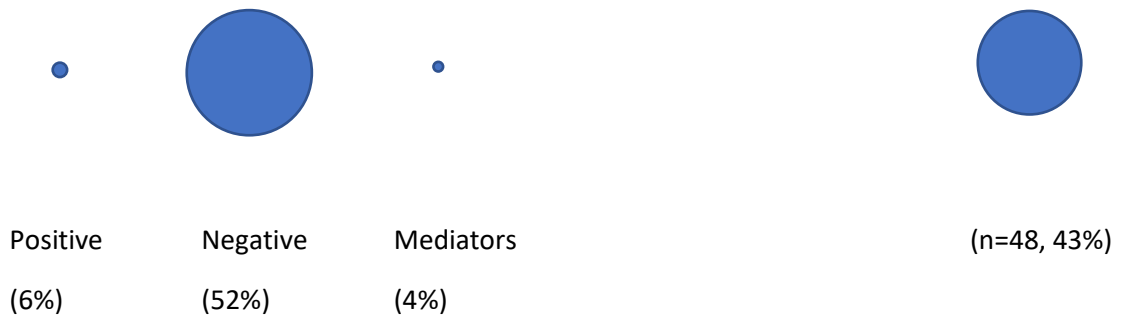


Practitioner (n=96, 48%)

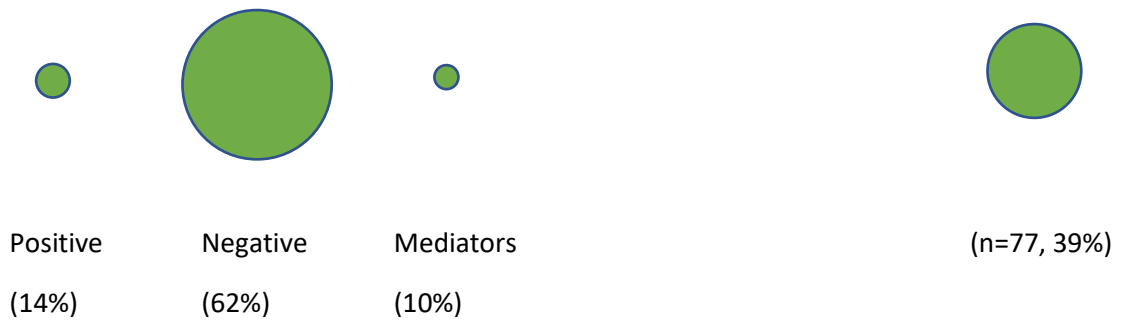


**Physical health 1 or 2, unhelpful ratings**

Service-user (n=48, 43%)

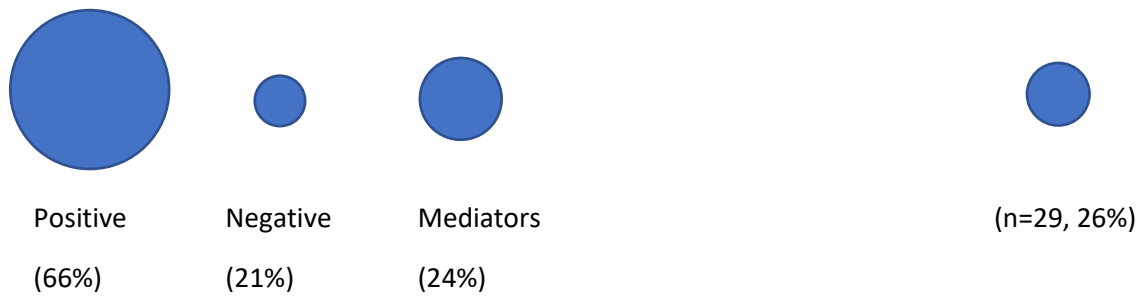


Practitioner (n=77, 39%)

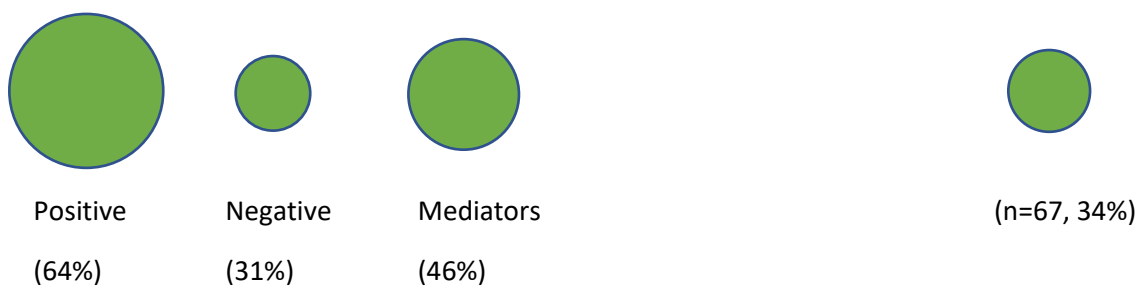


**Physical health 3, middle ratings**

Service-user (n=29, 26%)

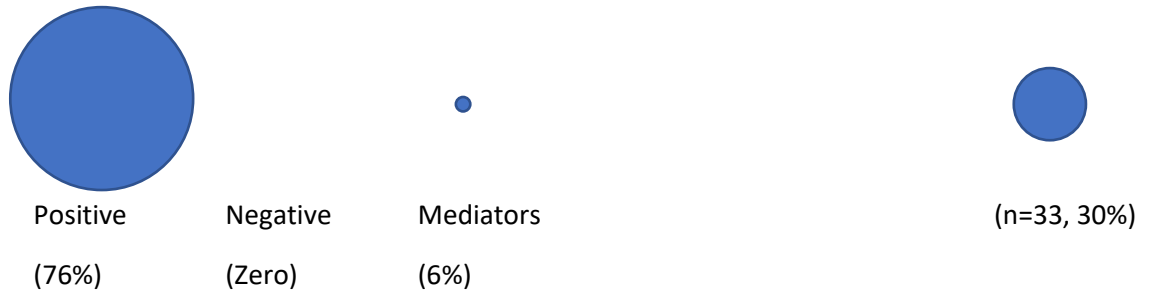


Practitioner (n=67, 34%)

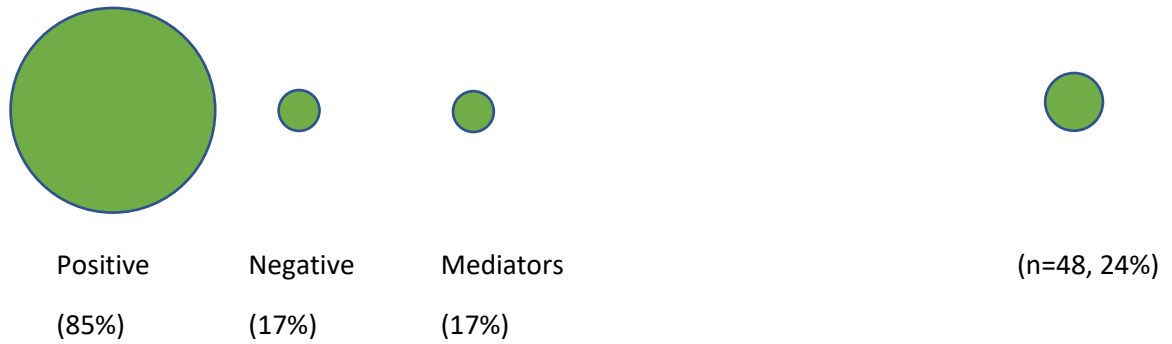


**Physical health 4 or 5, helpful ratings**

Service-user (n=33, 30%)



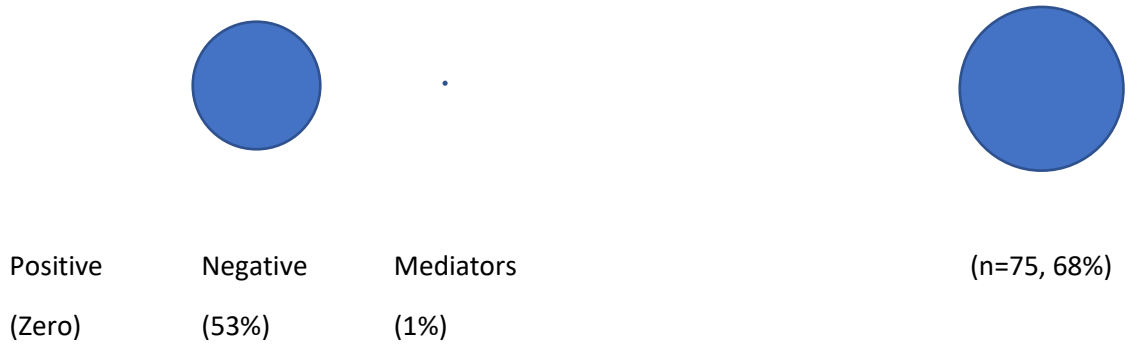
Practitioner (n=48, 24%)



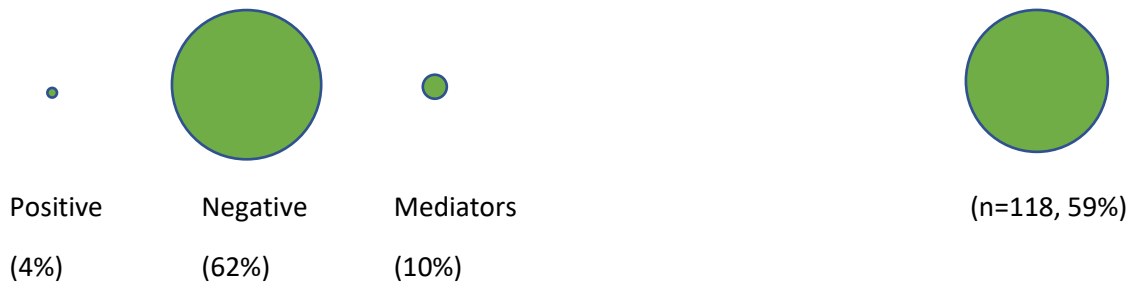


**Sexual orientation 1 or 2, unhelpful ratings**

Service-user (n=75, 68%)

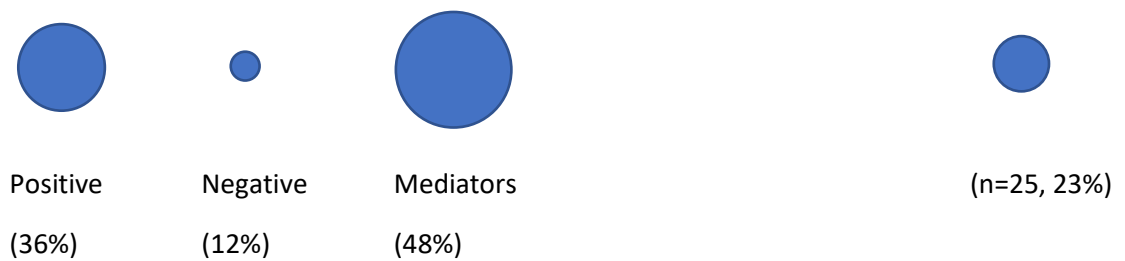


Practitioner (n=118, 59%)

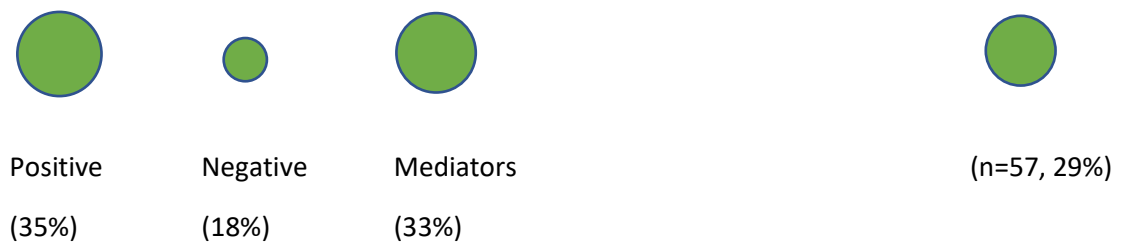


**Sexual orientation 3, middle ratings**

Service-user (n=25, 23%)



Practitioner (n=57, 29%)



**Sexual orientation 4 or 5, helpful ratings**

Service-user (n=11, 10%)



Positive  
(55%)

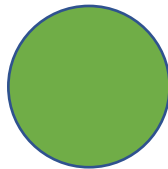
Negative  
(Zero)

Mediators  
(Zero)



(n=11, 10%)

Practitioner (n=12, 6%)



Positive  
(67%)



Negative  
(17%)



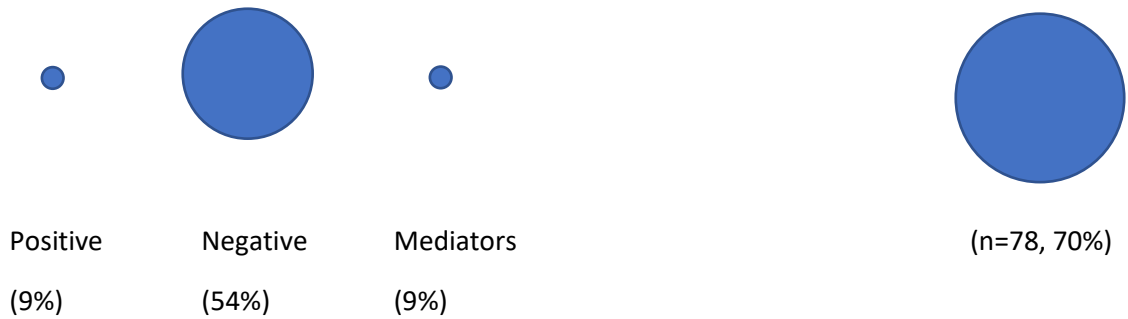
Mediators  
(33%)



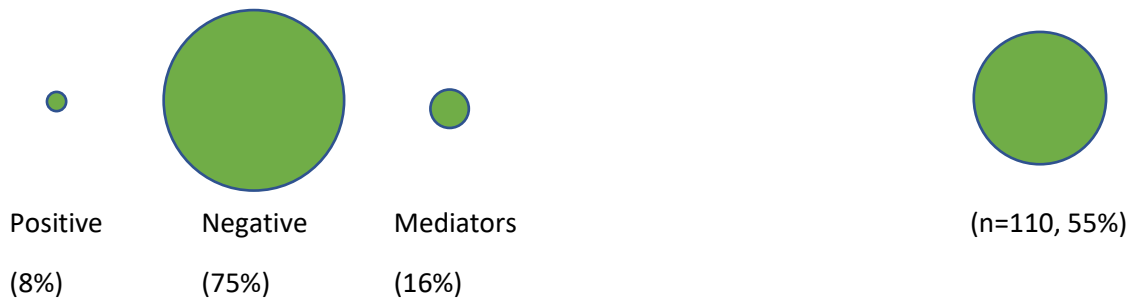
(n=12, 6%)

**Religion 1 or 2, unhelpful ratings**

Service-user (n=78, 70%)

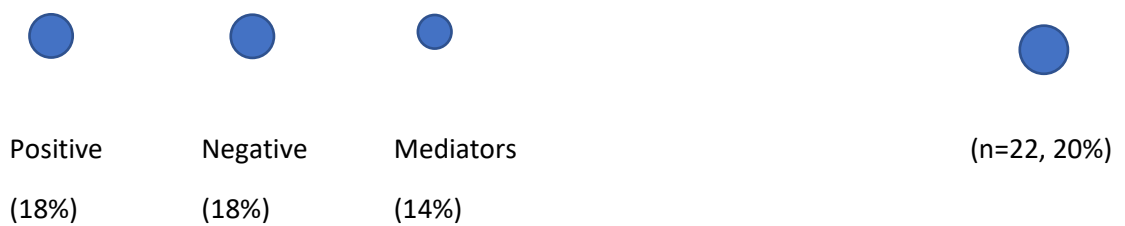


Practitioner (n=110, 55%)

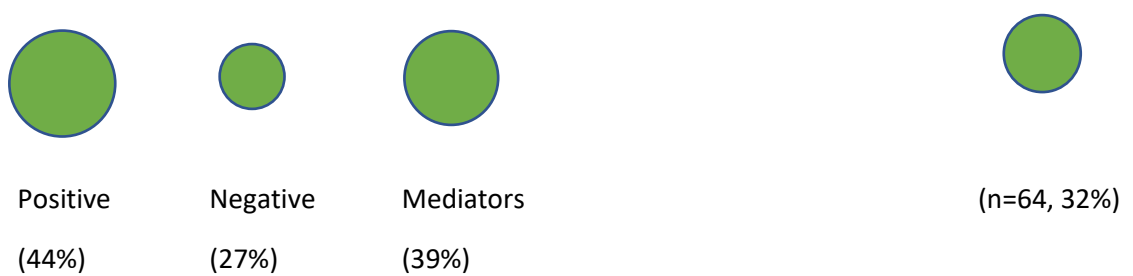


**Religion 3, middle ratings**

Service-user (n=22, 20%)

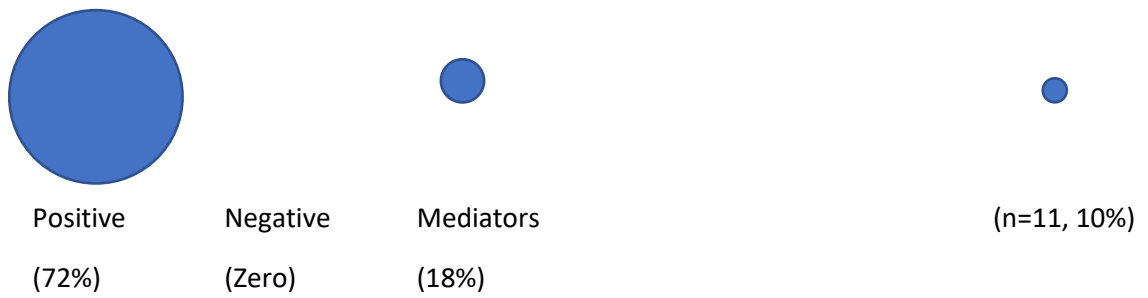


Practitioner (n=64, 32%)

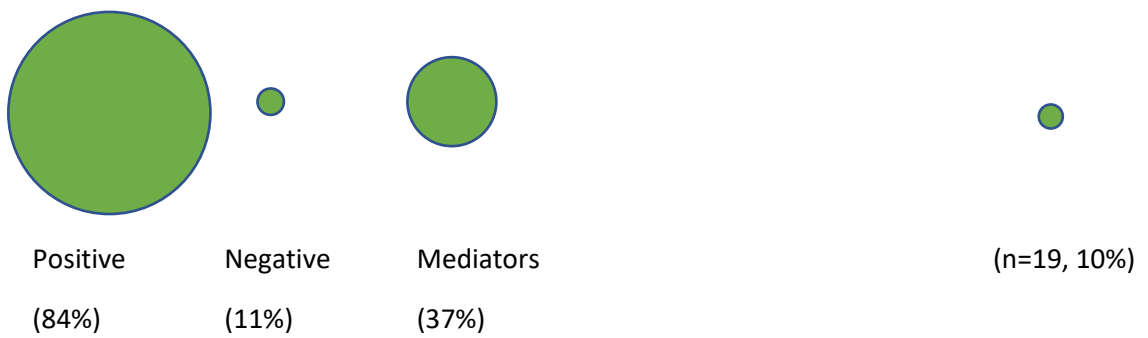


**Religion 4 or 5, helpful ratings**

Service-user (n=11, 10%)



Practitioner (n=19, 10%)

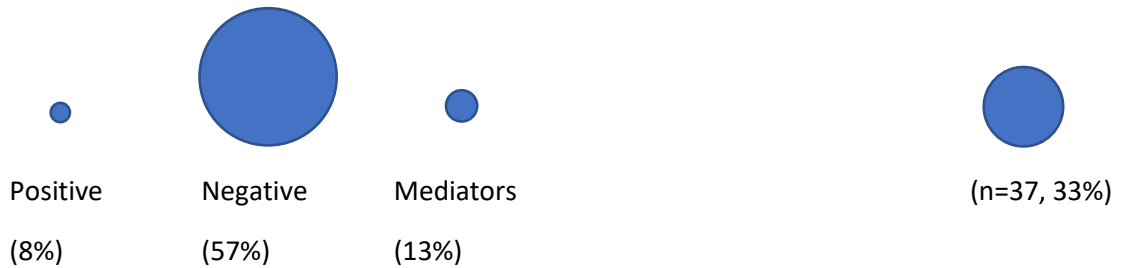


**Circles organised by rating**

**Mental health ratings of 1 or 2, unhelpful**

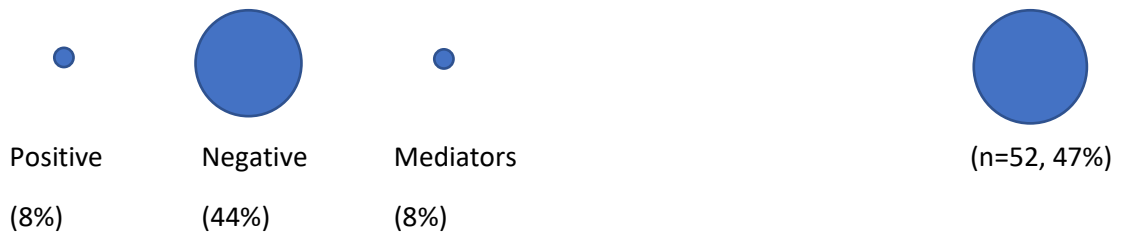
**Total respondents who gave this rating as percentage of all possible respondents**

Service-user (n=37, 33%)



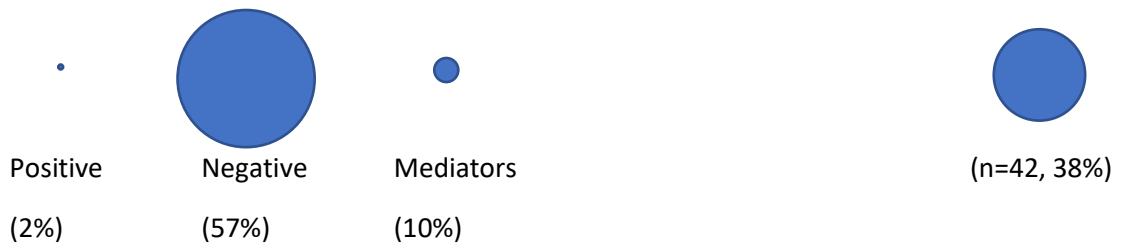
**Difficult or Traumatic Experiences 1 or 2, unhelpful ratings**

Service-user (n=52, 47%)



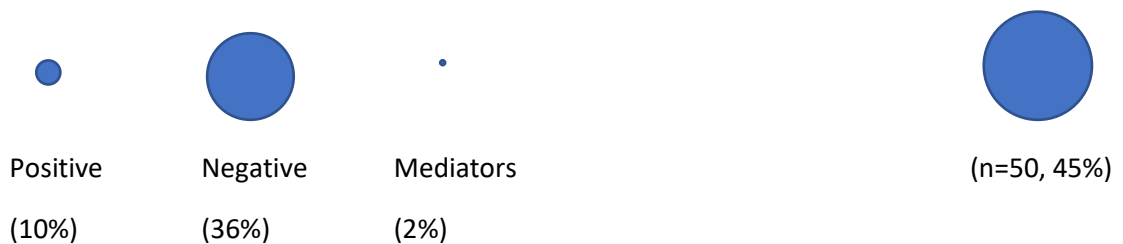
**Mental Health of Family Member or Friend 1 or 2, unhelpful ratings**

Service-user (n=42, 38%)



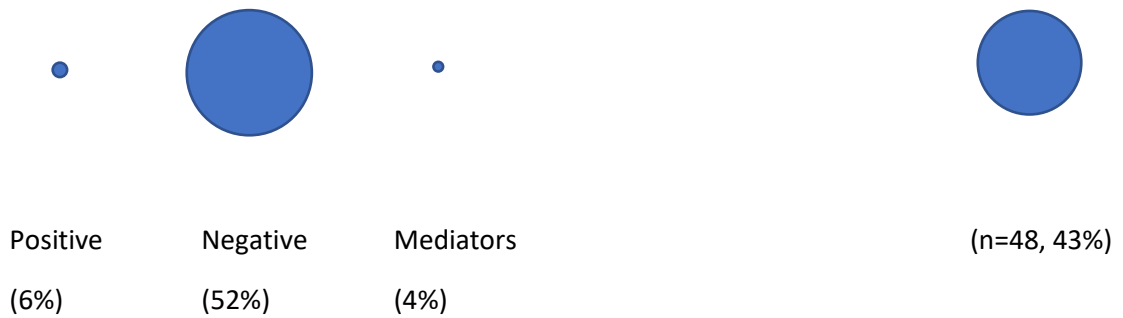
**Hobbies and out of work experiences 1 or 2, unhelpful ratings**

Service-user (n=50, 45%)



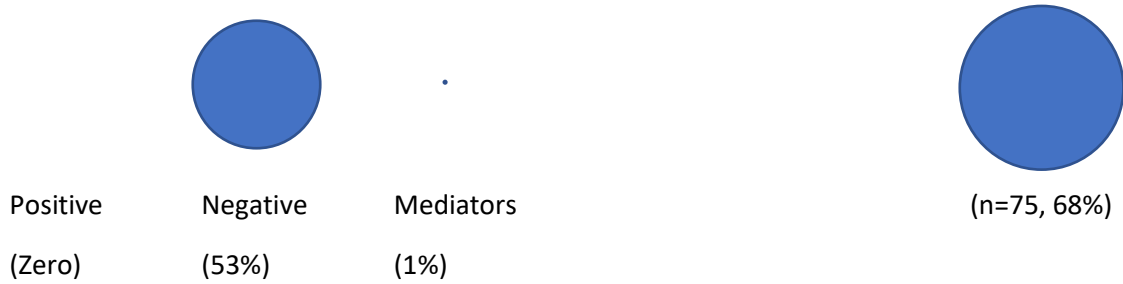
**Physical health 1 or 2, unhelpful ratings**

Service-user (n=48, 43%)



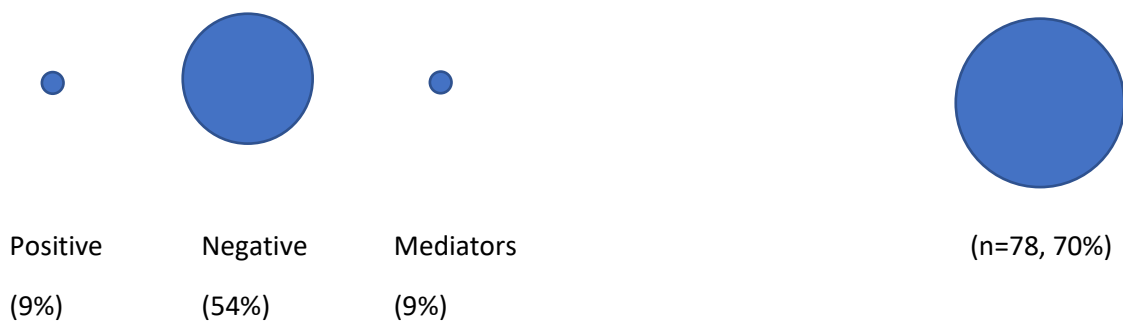
**Sexual orientation 1 or 2, unhelpful ratings**

Service-user (n=75, 68%)



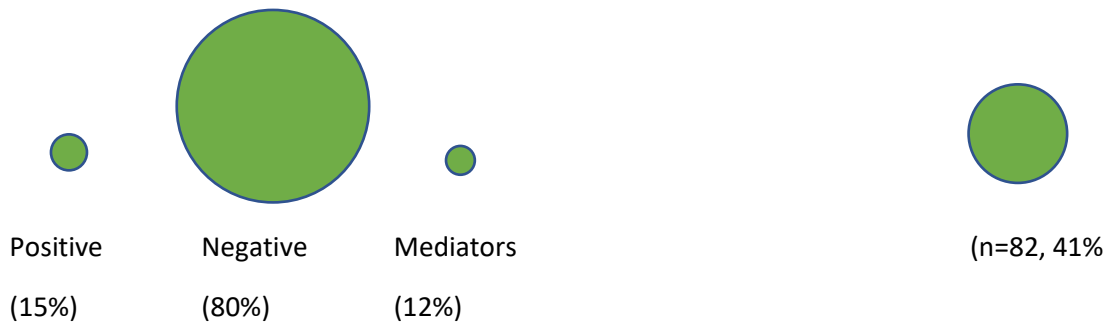
**Religion 1 or 2, unhelpful ratings**

Service-user (n=78, 70%)



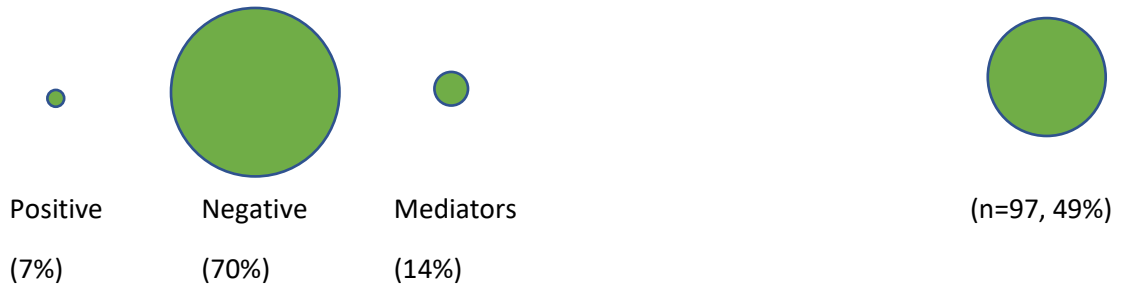
**Mental health ratings of 1 or 2, unhelpful**

Practitioner (n=82, 41%)



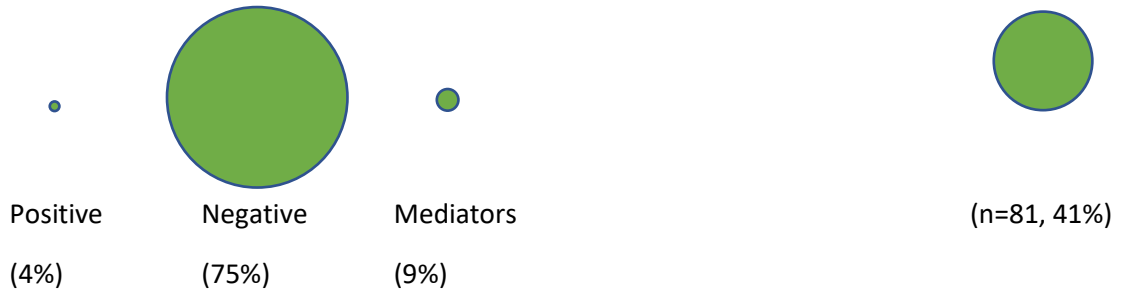
**Difficult or Traumatic Experiences 1 or 2, unhelpful ratings**

Practitioner (n=97, 49%)



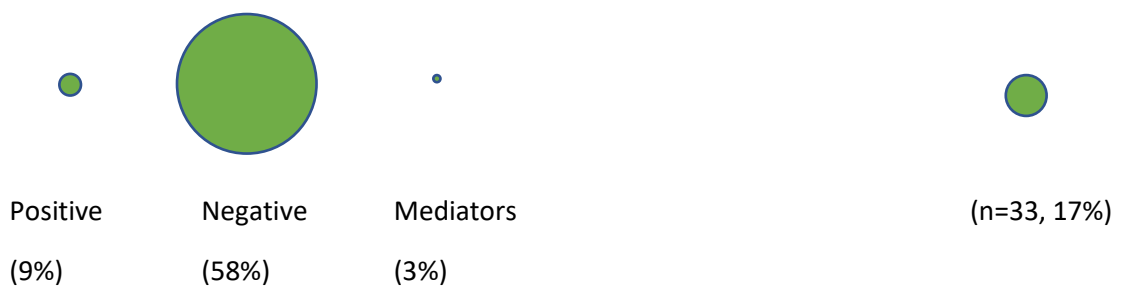
**Mental Health of Family Member or Friend 1 or 2, unhelpful ratings**

Practitioner (n=81, 41%)



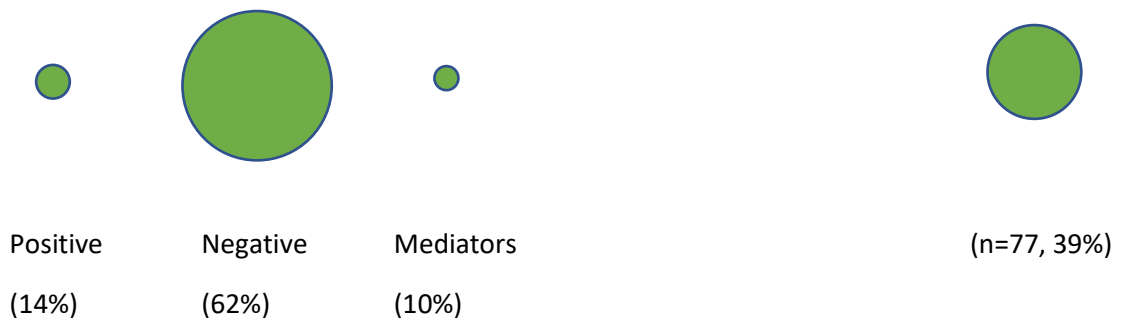
**Hobbies and out of work experiences 1 or 2, unhelpful ratings**

Practitioner (n=33, 17%)



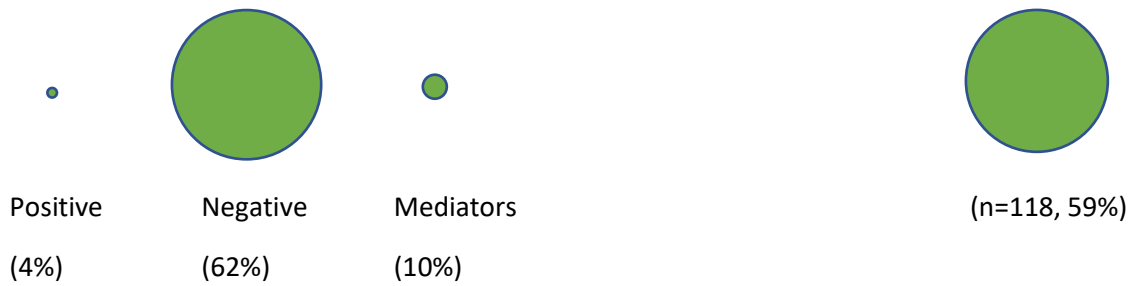
**Physical health 1 or 2, unhelpful ratings**

Practitioner (n=77, 39%)



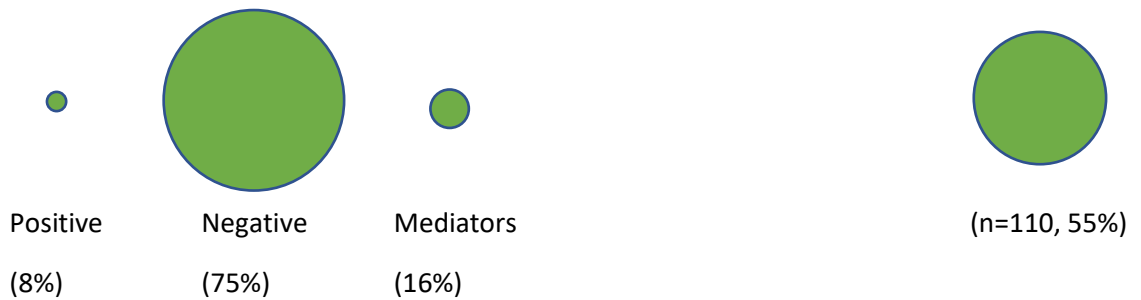
**Sexual orientation 1 or 2, unhelpful ratings**

Practitioner (n=118, 59%)



**Religion 1 or 2, unhelpful ratings**

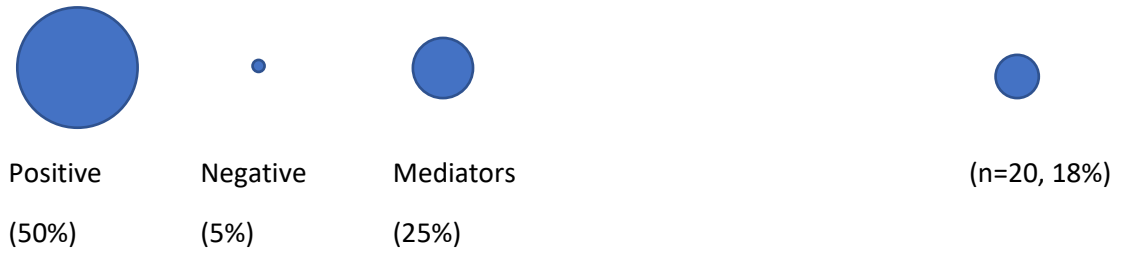
Practitioner (n=110, 55%)





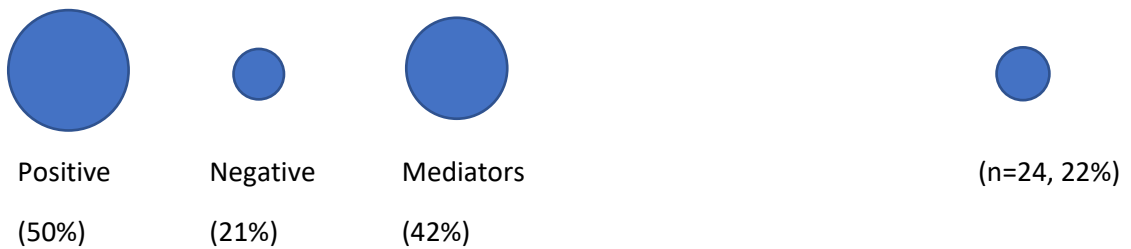
**Mental health ratings of 3, middle ratings**

Service-user (n=20, 18%)



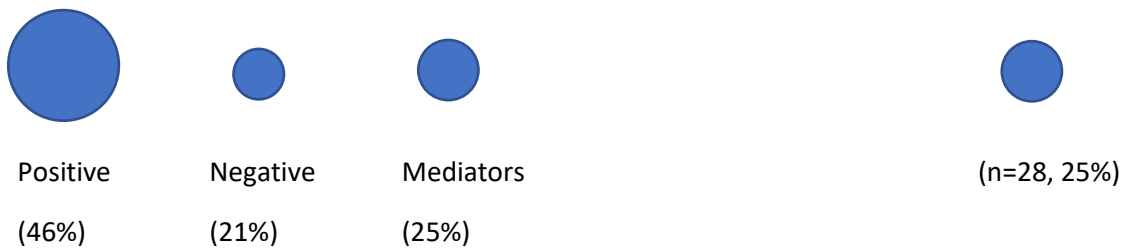
**Difficult or Traumatic Experiences 3, middle ratings**

Service-user (n=24, 22%)



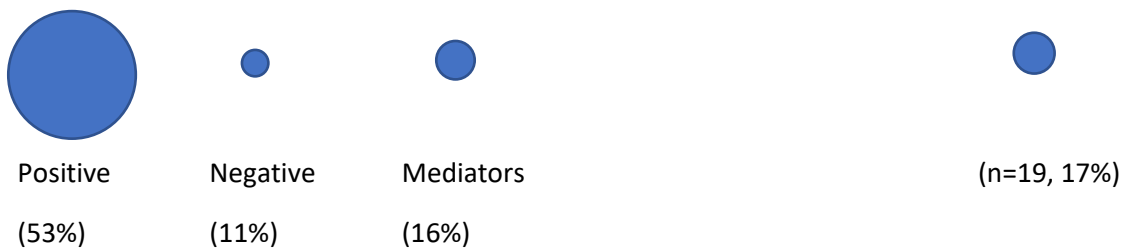
**Mental Health of Family Member or Friend 3, middle ratings**

Service-user (n=28, 25%)



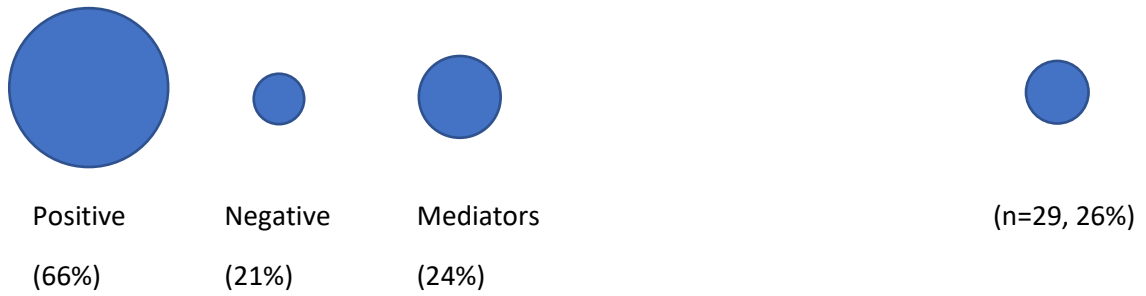
**Hobbies and out of work experiences 3, middle ratings**

Service-user (n=19, 17%)



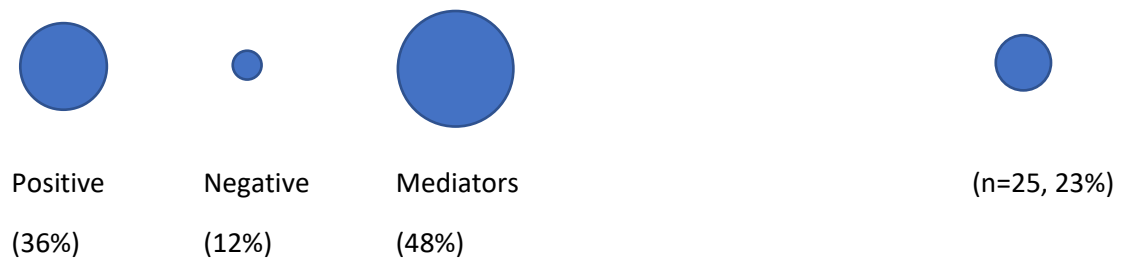
**Physical health 3, middle ratings**

Service-user (n=29, 26%)



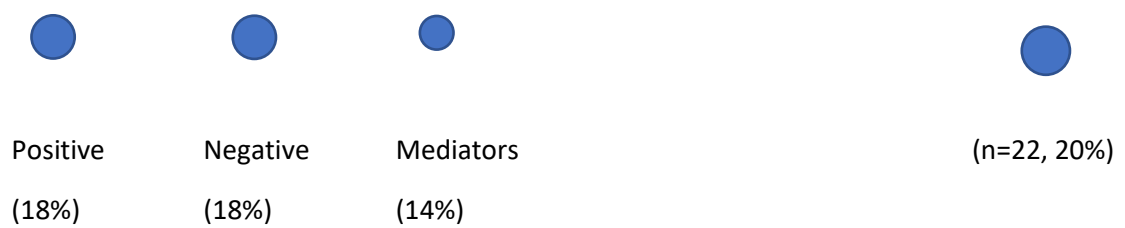
**Sexual orientation 3, middle ratings**

Service-user (n=25, 23%)



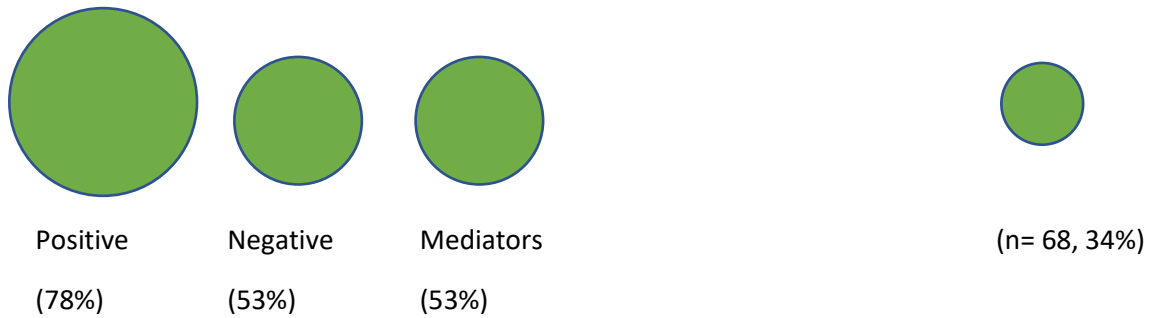
**Religion 3, middle ratings**

Service-user (n=22, 20%)



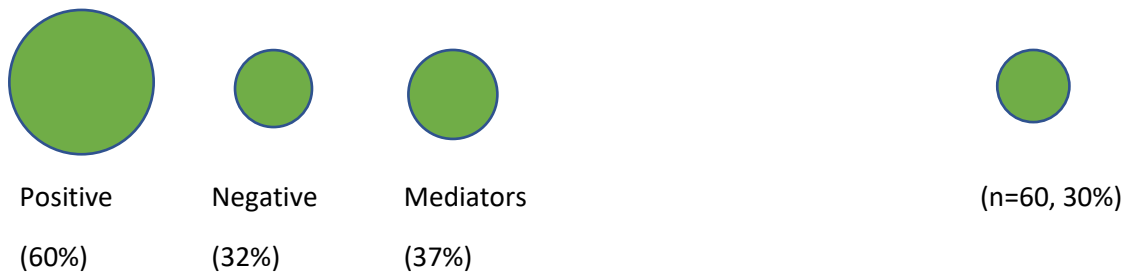
**Mental health ratings of 3, middle ratings**

Practitioner (n= 68, 34%)



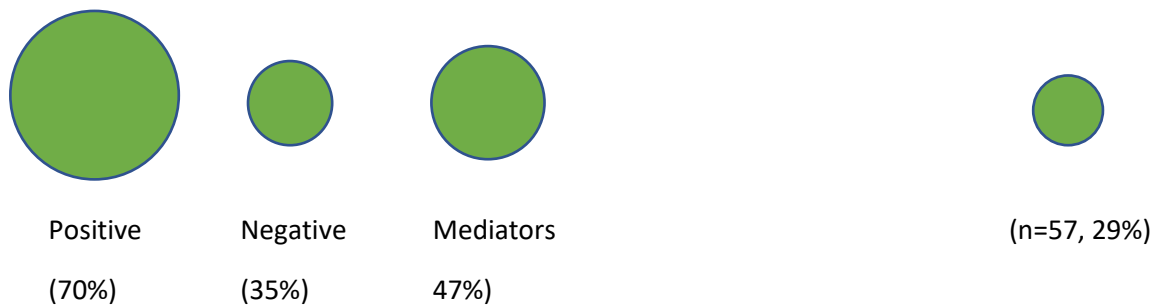
**Difficult or Traumatic Experiences 3, middle ratings**

Practitioner (n=60, 30%)



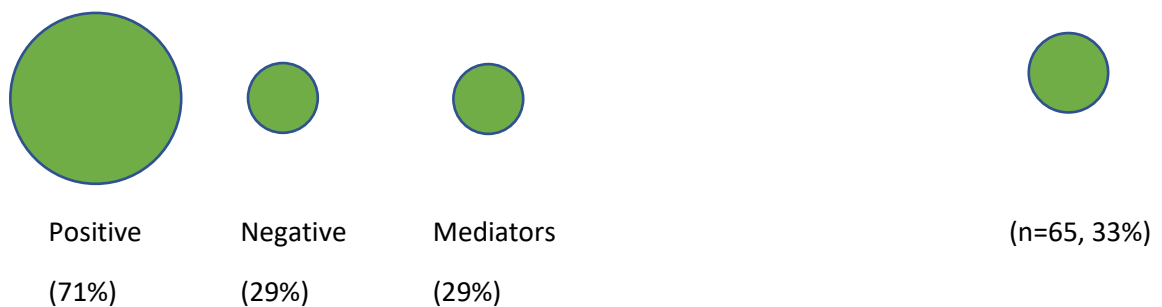
**Mental Health of Family Member or Friend 3, middle ratings**

Practitioner (n=57, 29%)



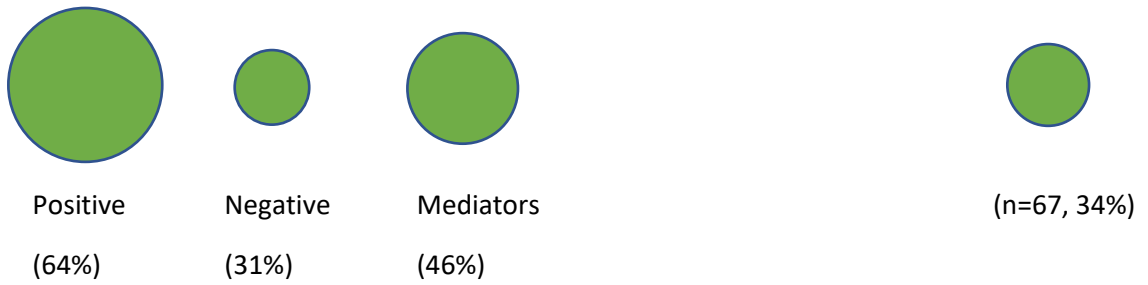
**Hobbies and out of work experiences 3, middle ratings**

Practitioner (n=65, 33%)



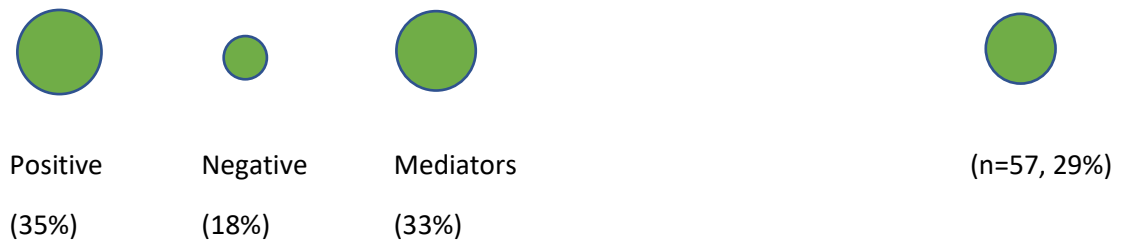
**Physical health 3, middle ratings**

Practitioner (n=67, 34%)



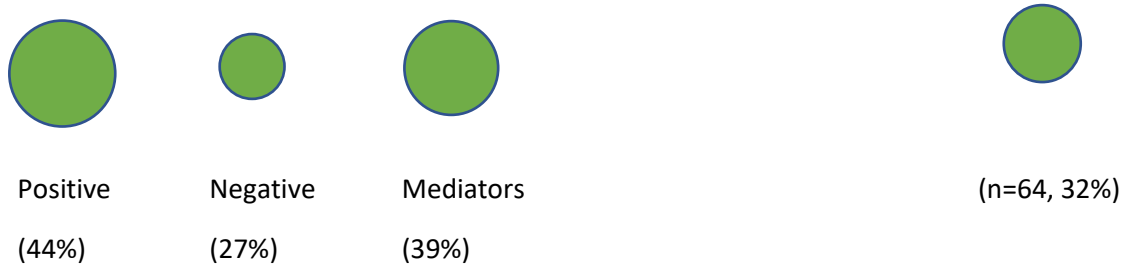
**Sexual orientation 3, middle ratings**

Practitioner (n=57, 29%)



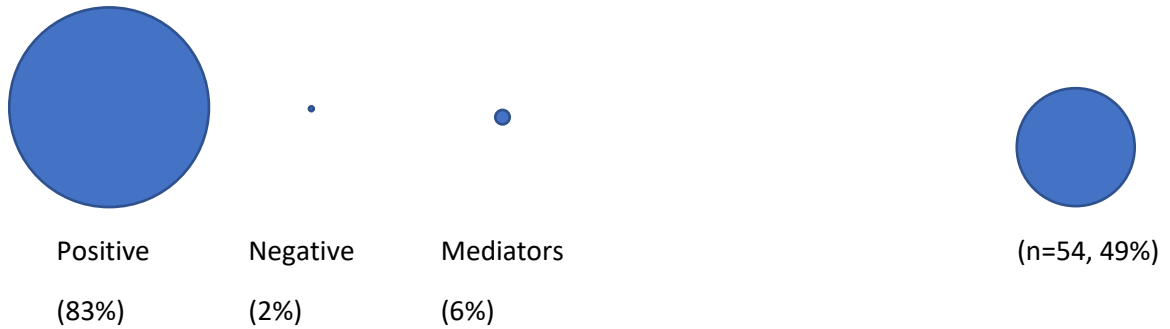
**Religion 3, middle ratings**

Practitioner (n=64, 32%)



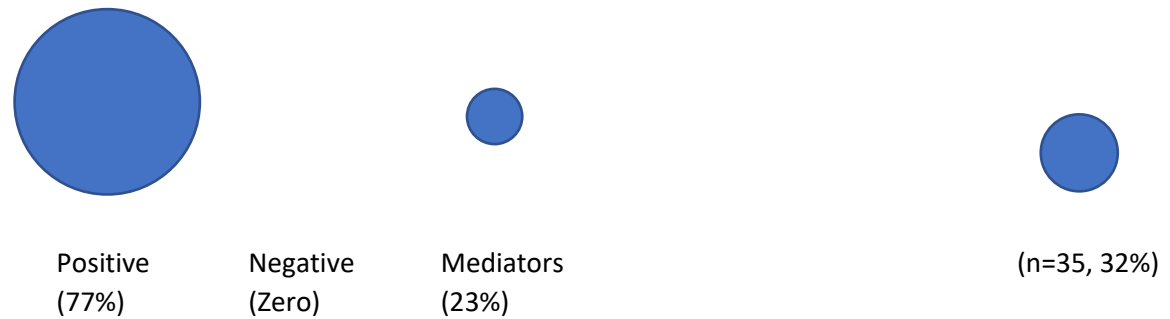
**Mental health ratings of 4 or 5, helpful ratings**

Service-user (n=54, 49%)



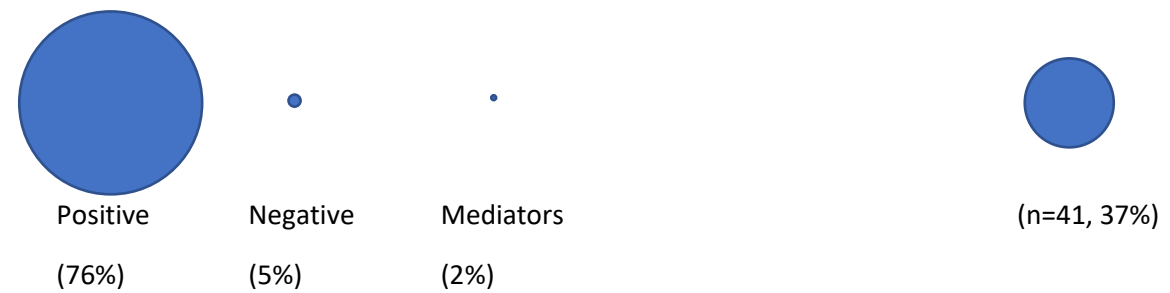
**Difficult or Traumatic Experiences 4 or 5, helpful ratings**

Service-user (n=35, 32%)



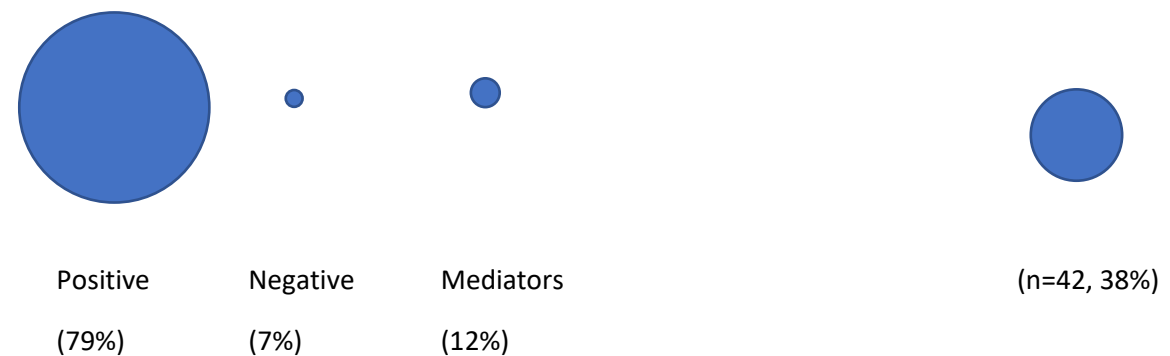
**Mental Health of Family Member or Friend 4 or 5, helpful ratings**

Service-user (n=41, 37%)



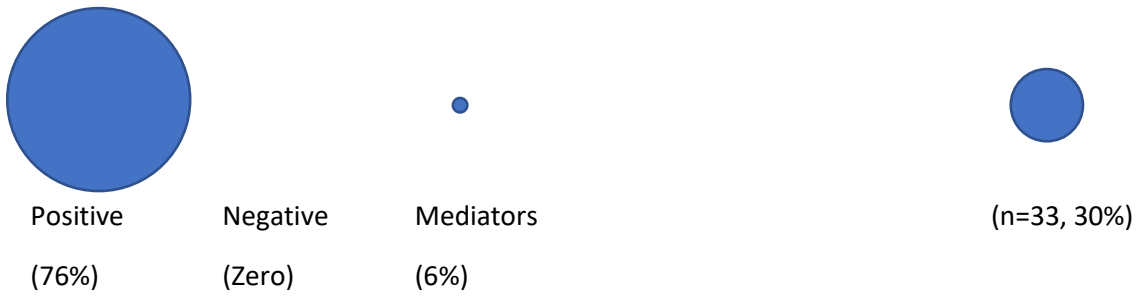
**Hobbies and out of work experiences 4 or 5, helpful ratings**

Service-user (n=42, 38%)



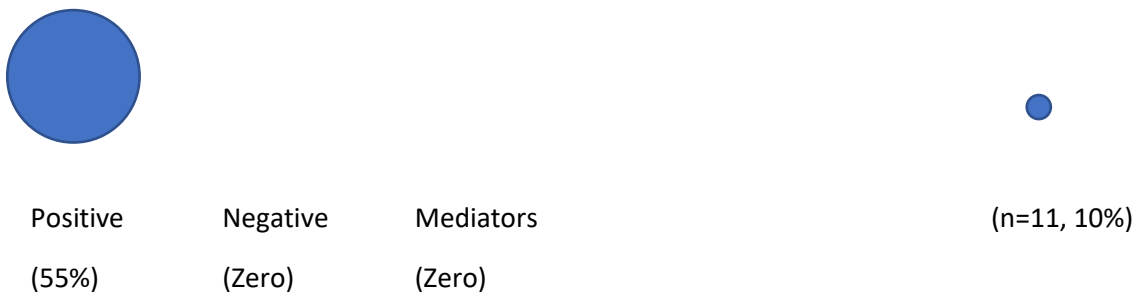
**Physical health 4 or 5, helpful ratings**

Service-user (n=33, 30%)



**Sexual orientation 4 or 5, helpful ratings**

Service-user (n=11, 10%)



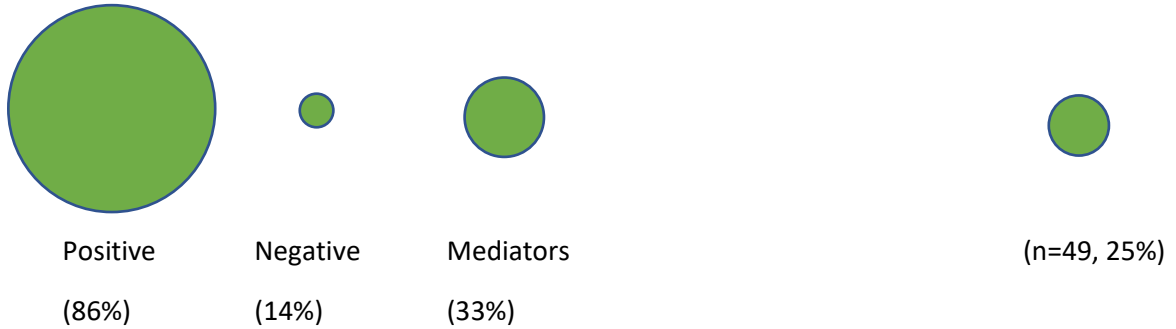
**Religion 4 or 5, helpful ratings**

Service-user (n=11, 10%)



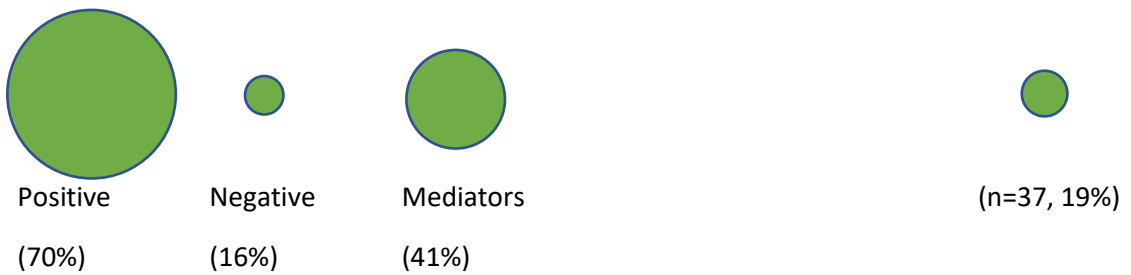
**Mental health ratings of 4 or 5, helpful ratings**

Practitioner (n=49, 25%)



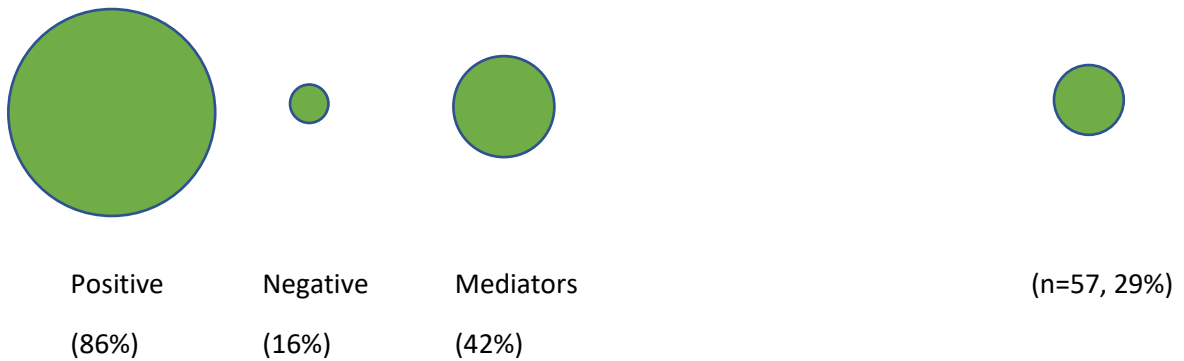
**Difficult or Traumatic Experiences 4 or 5, helpful ratings**

Practitioner (n=37, 19%)



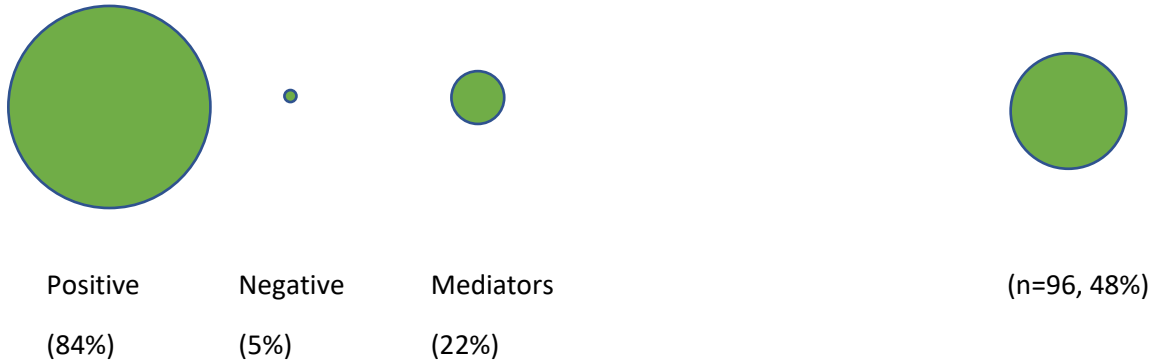
**Mental Health of Family Member or Friend 4 or 5, helpful ratings**

Practitioner (n=57, 29%)



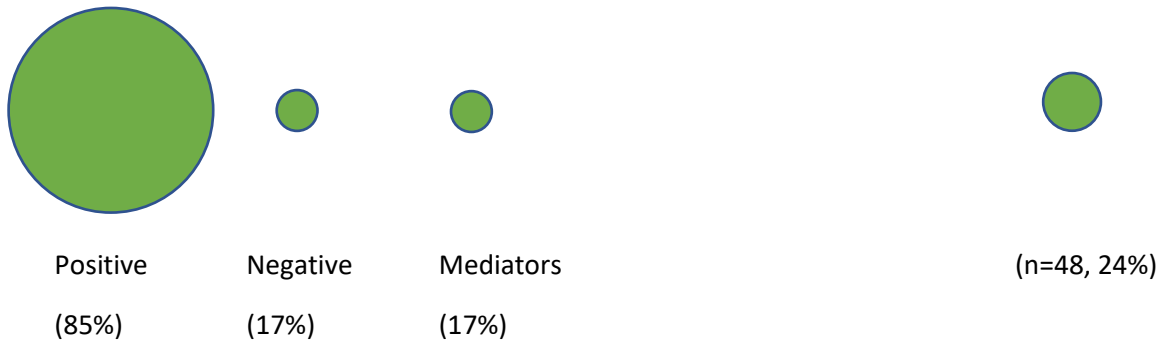
**Hobbies and out of work experiences 4 or 5, helpful ratings**

Practitioner (n=96, 48%)



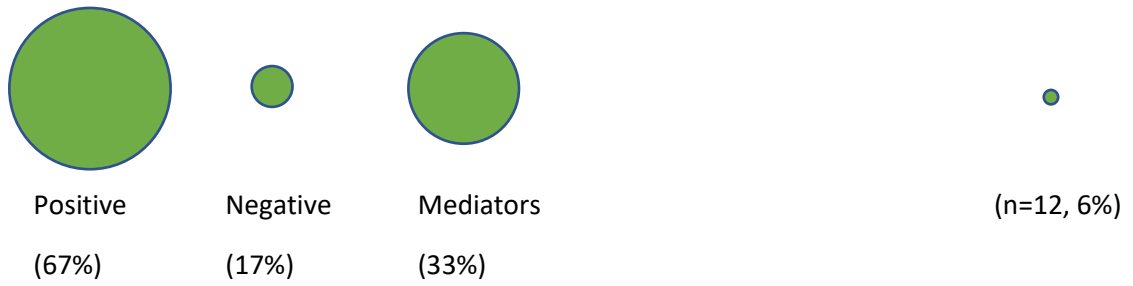
**Physical health 4 or 5, helpful ratings**

Practitioner (n=48, 24%)



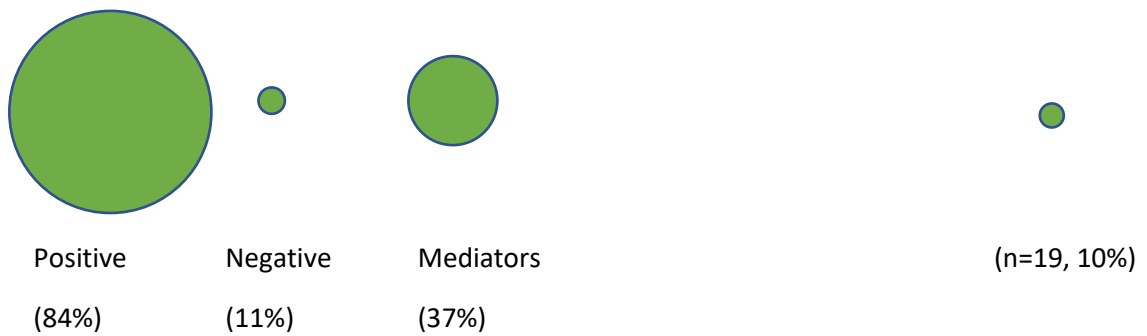
**Sexual orientation 4 or 5, helpful ratings**

Practitioner (n=12, 6%)



**Religion 4 or 5, helpful ratings**

Practitioner (n=19, 10%)





## Appendix 11: Validity Check of Quotations Used

Survey practitioner respondent job type	Number of survey respondents from each job category n=200 (%)	Number of respondents quoted from job group (chapters 6&7) n=79 (%)	Number of quotes used per job group n=120 (%)
Nurses & nursing assistants (Nurse, nursing assistant, drug liaison midwife)	75 (37.5)	28 (35.44).	37 (30.83)
Support workers various types (Carers support worker, health care assistant, health care support worker, outreach worker, senior support worker, therapy support worker, user involvement worker, peer support worker or mentor)	40 (20)	18 (22.78)	24 (20.00)
Allied professionals (Social worker, dietitian, occupational therapist , physiotherapist)	29 (14.5)	13 (16.46)	21 (17.50)
Doctors (Consultant, doctor, psychiatrist)	23 (11.5)	10 (12.66)	15 (12.50)
Therapist, psychologist, counsellor (CBT therapist, Clinical psychologist, counsellor, forensic psychologist, psychological wellbeing practitioner, psychotherapist)	22 (11)	9 (11.39)	22 (18.33)
Various uncategorised (Adult safeguarding lead, associate practitioner, deputy support manager, manager, mandatory trainer/advisor, operational manager, specialist practitioner, trade union rep)	9 (4.5)	1 (1.27)	1 (0.83)

## Appendix 12: Literature Review Quality Appraisal

<b>Author</b>	<b>Clear Aims</b>	<b>Transparent</b>	<b>Accurate</b>	<b>Purpose</b>	<b>Generalisable</b>	<b>Peer review</b>	<b>Impact factor of journal</b>	<b>Overall Quality Score</b> High/med/low
Empirical articles	Was the aim of the study clear?	Is the methodology clear? how subjects were chosen; methods and justifications for measurement; the use of statistical tests; and the hypotheses being tested	Does the research represent what people/literature said? Bias Reliability Validity (are there any attempts to eliminate bias, or cross-check results)	Was the research or approach fit for purpose? Design of research, i.e. focus group, interview etc.	Can the results be generalised to a larger population? May not be appropriate to generalise if this was not the purpose.	Was the research/ journal peer reviewed?		
Abramsky	High	High	High	Medium	Low	No	N/A	Medium
Armour	High	High	Medium	Low	Low	No	N/A	Medium
Bottrill et al	High	High	High	High	Low	Yes	1.6	medium
Cabral et al	High	High	High	High	Medium	Yes	1.15	High
Henretty & Levitt	High	High	Medium	High	High	Yes	7.18	High
Gough	Medium	Low	Low	Low	Low	Yes	0.63	Low
Somers et al	High	High	High	Low	Low	Yes	0.731	Medium
Davidson et al	Medium	Medium	Medium	Medium	Medium	Yes	3.25	Medium

<b>Author</b>	<b>Clear focus</b>	<b>Arguments evidenced</b> <b>Balanced view</b>	<b>Author credibility, experience, authority</b>	<b>Fit for purpose/audience</b>	<b>Generalisable</b>	<b>Peer reviewed</b>	<b>Impact factor of journal</b>	<b>Overall Quality Score High/med/low</b>
Non-empirical								
Anonymous	Medium	Low	Medium	Medium	Low	Yes	1.23	Low
Burnell	Medium	Low	Medium	Medium	Low	Yes	0.17	Low
Costin	Medium	Medium	Medium	Medium	Low	Yes	N/S	Medium
Curtis & Hodge	Low	Low	Medium	Medium	Low	Yes	1.16	Low
Miles	High	Low	High	Medium	Low	Yes	30	Low
Jacobs & Nye	Medium	Low	Medium	Medium	Low	Yes	N/S	Low
Kottsieper	Medium	Medium	High	Medium	Low	Yes	0.36	Medium
Mallow	Medium	Medium	Medium	Medium	Low	Yes	1.87	Medium
Nealy	Low	Low	Medium	Medium	Low	Yes	0.25	Low
Otto et al	Medium	Low	Medium	Medium	Low	Yes	0.429	Low
Dixon et al	High	High	High	High	Low	Yes	1.99	High
Schiff	Medium	Medium	Medium	Medium	Low	Yes	0.718	Medium
Yarek	Medium	Low	Medium	Medium	Low	Yes	None	Low

<b>Author</b>	<b>Clear focus</b>	<b>Arguments evidenced</b> <b>Balanced view</b>	<b>Author credibility, experience, authority</b>	<b>Fit for purpose/audience</b>	<b>Generalisable</b>	<b>Peer reviewed</b>	<b>Impact factor of journal</b>	<b>Overall Quality Score High/med/low</b>
Empirical, repeat review 2017								
Adame	Medium	Medium	Medium	Medium	Low	Yes	0.46	Medium
Asad & Chreim	High	Medium	High	High	Low	Yes	1.154	Medium
Boyd et al	High	High	High	High	Medium	Yes	1.692	High
de Vos et al	High	Medium	High	Medium	Low	Yes	1.116	Medium
Geppert & Taylor	High	High	High	High	Medium	Yes	N/A (book)	High
Gilbert & Stickle	Low	Low	High	Low	Low	Yes	0.28	Low
Marino et al	High	Medium	Medium	High	Medium	Yes	1.037	Medium
Morgan & Lawson	High	N/A	High	High	N/A	Yes	0.31	N/A

Appendix 13: Coding Illustration

Question 1

Name	Sources	References
Question 1	2	3304
Examples of items shared	2	1565
Type of practitioner who shared	2	1357
What ways helpful or unhelpful	1	19
Why item shared	2	363
Question 1b - why practitioners do not share	2	440

Coded Nodes

Name	Sources	References
Alternatives to SLE	2	91
Benefits and dangers of not sharing	2	26
Effects of disclosure	2	6
How SLE should be done	2	17
Impacts, Implications and Considerations of SLE	3	4920
Miscellaneous	3	167
Planning and Managing Disclosure	2	804
Positive or negative	3	3196
Services, conditions, contexts	2	141
Why practitioners should not share	2	71

Nodes

Look for
Search In
Practitioners 1 or 2
Fir

- Code Nodes
- Focus Group
- Focus Group Broad Nodes
- Job role queries
- Job role question new nodes
- New query codes
- Nodes for Hypothetical Questions
  - Practitioners 1 or 2
  - Practitioners 3
  - Practitioners 4 or 5
- Service users
  - Service users 1 or 2
  - Service users 3
  - Service users 4 or 5

**Practitioners 1 or 2**

Name	Sources	References
P Difficult or Traumatic 1 or 2	1	75
P Hobbies etc. 1 or 2	1	19
P MH of family or friend 1 or 2	1	63
P Pers MH 1 or 2	1	70
P Physical Health 1 or 2	1	55
P religion 1 or 2	1	90
P sexual orientation 1 or 2	1	87

Appendix 14: Positive, Negative and Mediating Factors by Hypothetical Disclosure Question &amp; List of Mediating Factors

Mental Health Rating	Theme	Service-user Personal Mental Health (%)	Practitioner Personal Mental Health (%)	Service-user Difficult or Traumatic Experiences (%)	Practitioner Difficult or Traumatic Experiences (%)	Service-user Mental Health of Family Member or Friend (%)	Practitioner Mental Health of Family Member or Friend (%)
1 or 2	Number of respondents	37 (33%)	82 (41%)	52 (47%)	97 (49%)	42 (38%)	81 (41%)
	Positive	3 (8%)	12 (15%)	4 (8%)	7 (7%)	1 (2%)	3 (4%)
	Negative	21 (57%)	66 (80%)	23 (44%)	68 (70%)	24 (57%)	61 (75%)
	Mediators	5 (13%)	10 (12%)	4 (8%)	14 (14%)	4 (10%)	7 (9%)
3	Number of respondents	20 (18%)	68 (34%)	24 (22%)	60 (30%)	28 (25%)	57 (29%)
	Positive	10 (50%)	53 (78%)	12 (50%)	36 (60%)	13 (46%)	40 (70%)
	Negative	1 (5%)	36 (53%)	5 (21%)	19 (32%)	6 (21%)	20 (35%)
	Mediators	5 (25%)	36 (53%)	10 (42%)	22 (37%)	7 (25%)	27 (47%)
4 or 5	Number of respondents	54 (49%)	49 (25%)	35 (32%)	37 (19%)	41 (37%)	57 (29%)
	Positive	45 (83%)	42 (86%)	27 (77%)	26 (70%)	31 (76%)	49 (86%)
	Negative	1 (2%)	7 (14%)	0 (0%)	6 (16%)	2 (5%)	9 (16%)
	Mediators	3 (6%)	16 (33%)	8 (23%)	15 (41%)	1 (2%)	24 (42%)

Rating	Theme	Service-user Hobbies and out of work experiences	Practitioner Hobbies and out of work experiences	Service- user Physical Health	Practitioner Physical Health	Service-user Sexual Orientation	Practitioner Sexual Orientation	Service- user Religion	Practitioner Religion
<b>1 or 2</b>	<b>Number of respondents</b>	<b>50 (45%)</b>	<b>33 (17%)</b>	<b>48 (43%)</b>	<b>77 (39%)</b>	<b>75 (68%)</b>	<b>118 (59%)</b>	<b>78 (70%)</b>	<b>110 (55%)</b>
	<b>Positive</b>	<b>5 (10%)</b>	<b>3 (9%)</b>	<b>3 (6%)</b>	<b>11 (14%)</b>	<b>0 (0%)</b>	<b>5 (4%)</b>	<b>7 (9%)</b>	<b>9 (8%)</b>
	<b>Negative</b>	<b>18 (36%)</b>	<b>19 (58%)</b>	<b>25 (52%)</b>	<b>48 (62%)</b>	<b>40 (53%)</b>	<b>73 (62%)</b>	<b>42 (54%)</b>	<b>83 (75%)</b>
	<b>Mediators</b>	<b>1 (2%)</b>	<b>1 (3%)</b>	<b>2 (4%)</b>	<b>8 (10%)</b>	<b>1 (1%)</b>	<b>12 (10%)</b>	<b>7 (9%)</b>	<b>18 (16%)</b>
<b>3</b>	<b>Number of respondents</b>	<b>19 (17%)</b>	<b>65 (33%)</b>	<b>29 (26%)</b>	<b>67 (34%)</b>	<b>25 (23%)</b>	<b>57 (29%)</b>	<b>22 (20%)</b>	<b>64 (32%)</b>
	<b>Positive</b>	<b>10 (53%)</b>	<b>46 (71%)</b>	<b>19 (66%)</b>	<b>43 (64%)</b>	<b>9 (36%)</b>	<b>20 (35%)</b>	<b>4 (18%)</b>	<b>28 (44%)</b>
	<b>Negative</b>	<b>2 (11%)</b>	<b>19 (29%)</b>	<b>6 (21%)</b>	<b>21 (31%)</b>	<b>3 (12%)</b>	<b>10 (18%)</b>	<b>4 (18%)</b>	<b>17 (27%)</b>
	<b>Mediators</b>	<b>3 (16%)</b>	<b>19 (29%)</b>	<b>10 (34%)</b>	<b>31 (46%)</b>	<b>12 (48%)</b>	<b>19 (33%)</b>	<b>3 (14%)</b>	<b>25 (39%)</b>
<b>4 or 5</b>	<b>Number of respondents</b>	<b>42 (38%)</b>	<b>96 (48%)</b>	<b>33 (30%)</b>	<b>48 (24%)</b>	<b>11 (10%)</b>	<b>12 (6%)</b>	<b>11 (10%)</b>	<b>19 (10%)</b>
	<b>Positive</b>	<b>33 (79%)</b>	<b>81 (84%)</b>	<b>25 (76%)</b>	<b>41 (85%)</b>	<b>6 (55%)</b>	<b>8 (67%)</b>	<b>8 (72%)</b>	<b>16 (84%)</b>
	<b>Negative</b>	<b>3 (7%)</b>	<b>5 (5%)</b>	<b>0 (0%)</b>	<b>8 (17%)</b>	<b>0 (0%)</b>	<b>2 (17%)</b>	<b>0 (0%)</b>	<b>2 (11%)</b>
	<b>Mediators</b>	<b>5 (12%)</b>	<b>21 (22%)</b>	<b>2 (6%)</b>	<b>8 (17%)</b>	<b>0 (0%)</b>	<b>4 (33%)</b>	<b>2 (18%)</b>	<b>7 (37%)</b>

<b>List of mediator headings</b>
Consent and confidentiality
Context, Situation, Individual
Emotive impact
Likely outcome
Motivation for sharing
Practitioner dynamics
Relevance
Service-user dynamics
Setting, intervention or illness type



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