For Whose Benefit? Service User Involvement, Co-Production and Healthcare Quality Improvement

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Declaration

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I, the author, confirm that the thesis is my own work. I am aware of the University's Guidance on the Use of Unfair means (www.sheffield.ac.uk/ssid/unfair-means). This work has not been previously presented for an award at this, or any other, university.

Signed

Arbaz Kapadi
March 2023

Abstract

This thesis presents the results of an empirical study conducted to explore the role of service user groups in the clinical microsystems (CMS) approach to quality improvement (QI). Utilising a qualitative case study approach, the study followed three CMS teams located in respective community brain injury and mental health inpatient rehabilitation services over a nine-month period. The research sought to first examine how concepts of service user involvement, co-production and QI were constructed by different stakeholders before observing CMS QI meetings to examine how service user knowledge was utilised in practice. The research draws on interview, observational and documentary data to make sense of the various ambitions, conceptualisations and practical implications of involving service users in QI.

The research reports instability within the CMS processes of teams along with gaps in understanding of the different participatory approaches. Cross-referencing findings with QI theory, the instability of CMS teams reflected organisational constraints and relational deficits in the process of QI which subsequently require further attention. This includes prioritising psychological safety for stakeholders involved in QI work. Furthermore, the research observed marginal service user participation with service users having few entry points or resources for involvement, both of which are controlled by the professional. Applying the concept of epistemic injustice, the research links the limited role of service users to epistemically unjust mechanisms in the organisation and practices of QI. That is, certain forms of knowledge, language and expertise are preferred at the expense of others, and these often mirror the dominant hierarchical constructions within healthcare practice. This does little to shift the limited role of service users beyond that of passive sources of information, restricting the possibility of co-producing QI. The research argues more epistemically just QI practice should entail a level of epistemic humility, that requires critical reflection of the subconscious beliefs guiding action and the recognition of underlying power differentials. This may, then, further emphasise the need to prioritise the emotional and relational aspects of QI practice, which appears to lag behind a technical focus.

Acknowledgements

I would like to start this long list of thanks, conscious that it will be impossible to acknowledge everyone, by expressing my gratitude to an ever-patient supervisory team: Rachael Finn, Diane Burns and Damian Hodgson. I will be forever indebted to Rachael and Diane for selecting me to carry out this wonderful opportunity, and believing in me throughout, when, at times, I did not. I would also like to thank Damian for joining the team at the most uncertain and difficult of times, but whose wisdom and insight I have found immensely helpful. I can not thank you all enough for your time, support and kindness, and this is something I will cherish wherever the future carries me.

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I have been grateful for the support and encouragement from my siblings throughout this journey: Amjad, Insha, Azhar, Safa. The doctoral journey has also coincided with two beautiful additions to the family - Yusuf and Isa - and hopefully your favourite 'Chachu' will be able to spend more time with you now. To Mum and Dad, I would not have reached this point without your endless support, love and sacrifice over the years, so thank you.

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Acronyms

CMS	Clinical Microsystems
CQC	Care Quality Commission
DoH	Department of Health
NHS	National Health Service
NIHR	National Institute for Health Research
PDSA	Plan-Study-Do-Act
PPI	Patient and Public Involvement
QI	Quality Improvement
UK	United Kingdom
WHO	World Health Organisation

Terminology

Co-Production	'Co-'terminology, as will become evident, may be used interchangeably. The term co-production is predominantly used in this thesis owing to its broad utility as an 'umbrella' term for other 'co-' language.
Epistemic Injustice	"A specific form of injustice 'done to someone specifically in their capacity as a knower'" (Fricker, 2007 p.1). The capacity for someone to share knowledge with others or make sense of one's experiences in spaces where communication and dialogue takes place (epistemic practices) is undermined.
Quality Improvement	There is no single definition of QI. This thesis adopts the definition offered by Shah (2020 p.1): "QI is a systematic and applied approach to solving a complex issue, through testing and learning, measuring as you go, and deeply involving those closest to the issue in the improvement process".
Quality Improvement: Linked Aims	"QI is the combined and unceasing efforts of everyone - healthcare professionals, patients and their families, researchers, payers, planners and educators - to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development learning" (Batalden and Davidoff, 2007 p.2).
Service User	Whilst recognising that there are partial connotations, the term 'service user', owing to its broad descriptive utility, is used in this thesis to be inclusive of patients, customers, clients, consumers, carers and family members. Where cited authors or research participants use different terms in their accounts, words are kept in their original format.
Vulnerability	Conscious that vulnerability is ill-defined as a term and can be linked with damaging narratives, this thesis acknowledges the view of 'vulnerability' as being unable "to fully participate in the economic, social, political and cultural life of society" (French and Raman, 2021 p.778), and where "access to resources and opportunities may be limited in comparison to what one is expected to possess" (Brandsen, 2021 p.529).

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CHAPTER 1

Introduction

> "My answer to the critical *what* question is simply that citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future" (Arnstein, 1969 p.216)

The organisation, delivery and financing of public services over the past several decades has changed noticeably, recasting the role of the service user in the uptake of public services. Today, involving the public is an important policy ideal, whereby the public are being allocated greater powers and responsibilities in the management and delivery of public services (Fotaki, 2011; Fledderus et al., 2014; Brandsen et al., 2018). The service user now, certainly an ambition, is seen as an 'active citizen' with rights and responsibilities that allows them to shape the very services they use (Martin, 2010; Voorberg et al., 2014). This role expansion has been none more so evident than within the healthcare sphere, where substantial developments have been observed globally (Abelson et al., 2010; NHS, 2014; WHO, 2016; Komporozos-Athanasiou et al., 2018).

Over the last decade or so, calls for the co-production of healthcare services have intensified with these approaches described as the "new participatory Zeitgeist – the spirit of our times" (Palmer et al., 2019 p.247). In the UK, the NHS has been urged to become more responsive to service user needs and wishes, partly borne from the findings of several high-profile documented failings in care e.g. The Mid Staffordshire NHS Foundation Trust Inquiry. The ensuing public outcry has had profound impact on healthcare policy with an expectation that healthcare systems seek new ways of delivering healthcare (Butler and Greenhalgh, 2011; Martin and Dixon-Woods, 2014; Boaz et al., 2016). The NHS Constitution (2021) (section 1, para. 4) states the following:

> "The NHS aspires to put patients at the heart of everything it does. NHS services must reflect, and should be coordinated around and tailored to, the needs and

> preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment"

The drive to involve service users in the design and delivery of services coincides with a renewed commitment by healthcare organisations to improve the quality of care (Berwick, 2016; Ham et al., 2016). One particular response has seen healthcare systems adopting quality improvement (QI) methodologies, tools and principles (Burgess and Radnor, 2013; Dixon-Woods and Martin, 2016; Alderwick et al., 2017). Traced back to the rationale of production quality control, QI attempts to bridge the gap between current practice and best possible practice through interrogating the best possible research evidence (Batalden and Davidoff, 2007; Bergman et al., 2015; Williams and Caley, 2020). Clinical microsystems (CMS) is one such approach to QI. Underpinned by systems theory and complexity science, CMS improvement engages frontline healthcare teams in a structured process of continuous and iterative learning (Nelson et al., 2007). Through this process, CMS teams critically evaluate their practices, focusing on supporting structures and relationships, before developing and testing solutions that may improve the quality of care. Locock (2003 p.54) explains how QI challenges the "organisational treadmill" by looking to move beyond established and taken-for-granted practices. There is no single definition of QI. This thesis adopts the definition offered by Shah (2020 p.1): "QI is a systematic and applied approach to solving a complex issue, through testing and learning, measuring as you go, and deeply involving those closest to the issue in the improvement process". The systematic application of QI methods and tools to redesign care practices represents new territory for healthcare organisations. The broader, linked aims of QI can be described as the following:

> "QI is the combined and unceasing efforts of everyone - *healthcare professionals, patients and their families, researchers, payers, planners and educators* - to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)" (Batalden and Davidoff, 2007 p.2)

Given the narrative around understanding value and the policy drive towards involving service users in the design and delivery of services, calls for participatory spaces of QI to be co-produced and co-designed are unsurprising (Bate and Robert, 2006; Renedo et al., 2015; Robert et al., 2015; Boaz et al., 2016; Ham et al., 2016; Batalden, 2018). Subsequently, healthcare organisations are responsible for facilitating the transition of service users from 'users and choosers' to 'makers and shapers' in QI (Cornwall and Gaventa, 2000 p.50). Justifications for involving service users in QI are offered with technocratic and democratic rationales (Martin, 2008a). A technocratic rationale identifies the uniqueness of service users' experiential knowledge as crucial in driving improvement. Under a democratic rationale, the involvement of service users represents fair and ethical practice with service users having the right to be involved in research that may impact on their health status or the health services they receive (Verschuere et al., 2018). In practice, technocratic and democratic goals simultaneously drive the ambition for increased service user involvement. The involvement of service users in QI represents a recent development (Batalden et al., 2018; Gustavsson et al., 2022). QI has traditionally been undertaken as a highly specialised professional activity with a broader focus on service design rather than individual care (Luxford et al., 2011; Gremyr et al., 2021). If service users are to be meaningfully involved in QI, focusing on the space of QI, and addressing issues of power and responsibility are necessary (Robert et al., 2015; Gustavsson et al., 2016; Williams and Caley, 2020).

The following sections of this introductory chapter continue to establish the research context and lay out the focus and structure of the thesis. **Section 1.1** introduces the key debates which this research contributes to: issues of language, knowledge exchange and power. **Section 1.2** highlights the project background, **Section 1.3** identifies a research gap, **Section 1.4** introduces the thesis' research questions, **Section 1.5** provides a quick overview of the research methods and methodology, **Section 1.6** highlights the background of the research before **Section 1.7** provides an outline of the thesis chapters.

1.1 Key Debates

The landscape within which service user involvement operates is incredibly complex. Political and policy rhetoric, enveloped in a raft of legislative documents, abounds with aspirations that service users are in control, with 'patients at the centre' becoming a favoured mantra (Foot et al., 2014). However, for many, the meaningful involvement of service users has historically remained more of an aspiration, where reality has lagged the rhetoric (Ocloo and Matthews, 2016; Madden and Speed, 2017; Beresford, 2019; Rose and Kalathil, 2019). Several studies, exploring service user involvement in healthcare, have documented challenges such as professional dominance, tokenism, competing priorities, role ambiguity and tensions over selection and representation of service users (Cornwall, 2008; Martin, 2008b; El Enany et al., 2013; Beresford, 2013a; Bee et al., 2015; Ocloo and Matthews, 2016). For many observers, the problem lies with the role of organisations, institutional practices and hierarchical power structures, which exhibit centralising tendencies that turn service users into 'passive observers' (Gibson et al., 2012; Farr, 2018; Lambert and Carr, 2018). This passive characterisation results in service users being 'crowded-out' from participatory spaces.

The language of involvement, historically described and interpreted in various ways, has not helped. A range of approaches, informed by different philosophies, histories and perspectives, have subsequently left decision-makers confused over what to make of exhortations to 'engage', 'involve', 'share decisions', 'empower', 'personalise' and so forth (Greenhalgh et al., 2011; Barnes and Cotterell, 2012). Subsequently, there is a gap between the ambitions that form part of policy and organisational directives, and what is taking place in practice (Madden and Speed, 2017; Carter and Martin, 2018; Beresford, 2019). Over the last fifteen years, the involvement of service users in the design and delivery of service users has been endorsed under terminology such as co-design, co-production and co-creation. The resurgence of 'co-' approaches, described by Berwick (2016) as the 'new watchwords' of the current era, are propositioned on transforming service relationships through merging of different values, knowledge and sharing of power (Bradwell and Marr, 2008; Slay and Stephens, 2013; Filipe et al., 2017). There is an important distinction to be made between co-production and more traditional approaches to involvement as to avoid 'cobiquity' (Williams et al., 2020a). Cobiquity, in this sense, transpires as a result of the unhealthy conflation between different involvement approaches and their respective underlying principles. Whilst co-production and co-design are, in particular, underpinned by democratic and egalitarian principles, levelling power dynamics in a system dominated by a well-established biomedical model of delivery is not straightforward (Lewis, 2014; Farr, 2018; Beresford, 2019; Rose and Kalathil, 2019).

An understanding of power is fundamental given the dynamics of the involvement process, where multiple actors with respective interests and knowledge converge (Callaghan and Wistow, 2006; Donetto et al., 2015; Farr, 2018; Pearce, 2021). Competing priorities, professional dominance and role ambiguity may all be considered symptoms of the fundamental issue of power and how power is distributed, exercised and sustained in practice (Callaghan and Wistow, 2006; Carr, 2007; Brosnan, 2013; Noorani, 2013; Ocloo and Matthews, 2016). Professional knowledge and expertise, developed through years of training and celebrated for its objective nature, has traditionally been afforded greater status and value in healthcare (Callaghan and Wistow, 2006; Carel and Kidd, 2014; Rose and Kalathil, 2019).

Theoretical ideas driving QI practice emphasise the importance of collaboration between different stakeholder groups, whereby multiple forms of knowledge ('patient', 'professional' and 'improvement') can be used to identify and implement service improvements (Deming, 1993; Batalden and Davidoff, 2007; Nelson et al., 2007). Fundamental to the meaningful involvement of service users in the practice of QI, then, is the degree to which their experiential knowledge, that has been informed by their lived experience of ill-health, is recognised as credible sources of information (Batalden, 2018; Palmer et al., 2019). This underpins an epistemological argument which concerns how different forms of knowledge are viewed, understood and applied in practice relative to the value assigned by individuals, groups and established sets of criteria (Boote et al., 2012). Respect for diversity of knowledge i.e. acknowledging and accommodating various knowledge sources is a core ethical and epistemological value of service user involvement and co-production (Grim et al., 2019; Groot et al., 2020; Boaz, 2021). Practice underpinned by such values - fairness, truth, aptness and mutual understanding - generates epistemic justice where the power of individual and group experience is reinforced (Carel and Kidd, 2017; Pohlhaus, 2017; Palmer et al., 2019). Epistemic justice pertains to crediting an individual's capacity as a holder and provider of knowledge: *epistemic* refers to the acquisition of knowledge, whilst *justice* is concerned with upholding the rights and values of individuals and groups (Fricker, 2017). The ability to develop one's knowledge and the agency to apply this knowledge in practice represents core human values (Fricker, 2007). In contrast, epistemic injustice manifests where individuals and groups experience exclusion from spaces due to prejudice, stereotyping and dismissal of their knowledge. The absence of epistemic justice, and rather, generation of injustice, can have a profound negative impact on the enterprises of service user involvement and co-production.

Reported tensions of service user involvement are exacerbated when involving groups of individuals considered to have complex care needs (e.g. mental health) (Beresford, 2013a; Lewis, 2014; Mulvale et al., 2019). Persons living with ill-health are susceptible to greater epistemic injustices (Lakeman, 2010; Crichton et al., 2017; Scrutton, 2017; Newbigging and Ridley, 2018). Kidd and Carel (2021) label injustices linked to the lived experience of ill-health as pathocentric epistemic injustices. Mental health services are often seen as being disconnected from the wider health and social care system – institutionally, professionally, clinically and culturally (Ham et al., 2016). The use of mental health services is deeply attached to social stigmas and negative stereotyping whilst services continue to be characterised by features of containment and compulsion. Furthermore, service users' 'credibility and intelligibility' (Fricker, 2007) may be scrutinised due to ill-health and issues of capacity (Bee et al., 2015; Berzins et al., 2018; Lambert and Carr, 2018). In regard to involvement and co-production, then, various social, structural and institutional structures impede service users' access to resources and opportunities to get involved in discussion (Beresford, 2013a; Brandsen, 2021; Mulvale et al., 2021). Service users may feel discouraged, perhaps lacking the confidence and self-esteem to get involved. At the same time, professionals may dictate terms of their involvement, deciding who is involved, how they are involved and what knowledge is used or discredited (Lewis, 2014; Berzins et al., 2018).

1.2 Project Background

This research study originated from an Economic and Social Research Council (ESRC) case studentship in collaboration between The University of Sheffield and a UK-based healthcare QI partner. The collaborative QI partner holds an ambition to drive the development of innovative, evidence-based strategies for healthcare QI, with particular commitment towards the use of CMS methodology: details of the CMS methodological process are introduced in Section 5.3.1. The research studentship was broadly advertised as an opportunity to understand the role of service users in CMS QI practice, which had been arranged in prior agreement between the principal academic supervisor (RF) and the collaborative QI partner.

i) Details of Collaboration

The collaborative QI partner holds an ambition to develop and drive QI practice across local secondary and tertiary healthcare services in the area where this research takes place. The development of QI, and in particular the adoption of CMS methodology, emerged through an academic collaboration between the partner organisation and The Institute for Excellence in Health and Social Systems at The University of New Hampshire (IEHSS) (formerly The Microsystem Academy at The Dartmouth Institute for Health Policy and Clinical Practice, USA). The IEHSS is responsible for developing CMS methodology for healthcare QI. The IEHSS is closely affiliated to the IHI and is home to a group of influential global thinkers in the space of healthcare QI e.g. Marjorie Godfrey, Eugene Nelson, Maren Batalden, Paul Batalden, Frank Davidoff, Kathryn Sabadosa.

The CMS approach to QI has been used globally to develop sustainable healthcare improvements in quality of care and efficiency. Senior Trust Leaders, where this study takes place, hoped to overhaul QI practice and sought to implement a fresh approach to QI. This came on the back of various frontline improvement areas being identified in a review of services (e.g. streamlining care pathways) and general clamour for the prioritisation of healthcare QI. It was believed by senior Trust members that the CMS approach to QI offered a scalable, service-wide opportunity to engage frontline teams in a bottom-up approach to service improvement. The research partner's aims of developing QI practice are briefly summarised:

- Build improvement capability into the workforce
- Maximise quality and value to service users
- Help multi-disciplinary front line teams rethink and redesign services

The timing of the doctoral studentship coincided with the release of a plethora of academic research documenting the importance of QI and healthcare co-production. Several key articles were published by scholars based at the IEHSS, and given the collaborative nature of their relationship, the challenges raised to practice also remained of interest to the research partner. Key papers included:

- The interdependent roles of patients, families and professionals in cystic fibrosis: a system for the coproduction of healthcare and its improvement (Sabadosa and Batalden., 2014)
- Coproduction for Healthcare Service (Batalden et al., 2015)
- Getting more health from healthcare: quality improvement must acknowledge patient coproduction - an essay by Paul Batalden (Batalden, 2018) (See Page 59)

Given this expanding area of development, the research partner was particularly keen to learn how service users may be involved in their CMS QI processes. The involvement of service users in CMS QI was also at the time reflective of a broader expansion of engagement activities taking place in other areas of the Trusts' work. For example, the Trust Continuous Improvement Team had expanded with posts created to oversee QI and service user involvement across the organisation. The possibility of co-producing healthcare QI was a prominent ambition of the organisation as relayed in strategic documents and espoused as key headlines at Trust events. For the research partner, then, outputs of this thesis are seen as vital learning opportunities to better understand improvement capability, the role of service user involvement in CMS QI, and to gain an appreciation of the various barriers and facilitators to involving service users.

1.3 Research Gap

This research study has commenced at a time when increasing attention is being placed on the role of service users within the design and delivery of healthcare services (Renedo et al., 2015; Berwick, 2016; Palmer et al., 2019). The impassioned pleas for healthcare QI to acknowledge co-production (Batalden et al., 2015; Batalden, 2018) as part of a forward-looking ‘third era of medicine’ (Berwick, 2016) call for concepts of involvement, co-production and QI to shift to the centre-stage. These concepts have, to some extent, developed separately with limited knowledge of how QI practice is organised for the involvement of service users (Batalden, 2018; Bergerum et al., 2019; Williams and Caley, 2020; Gremyr et al., 2021).

This thesis examines the space of QI in order to better understand the facilitators and barriers to achieving the collaborative ambition of QI that is espoused within various policies, strategies and frameworks. This research study purposely takes place within a mental health trust as to explore how service user groups, historically excluded from knowledge spaces and facing additional obstacles related to their ill-health, are involved in QI (Lewis, 2014; Brett et al., 2015). Ross and Naylor (2017) describe a pressing need to focus on QI in mental health trusts, whilst further recommending how mental health providers need to harness the potential of co-production in QI. Subsequently, the inquiry and examination that takes place in this thesis is timely as healthcare services increasingly adopt QI methodology to drive service improvement. The findings from this research will be valuable to understand stakeholder engagement with QI and how the involvement of service users is both perceived and organised in QI.

This thesis draws upon QI theory and the concept of epistemic injustice to explore the space of QI for service user involvement. This is both in its capacity, design and purpose, and how different stakeholder groups, particularly service users, are accommodated and involved in QI work. By reflecting the research findings of this study with QI theory, there is greater understanding of the everyday realities of stakeholder engagement with QI. This enables comparison with the theoretical expectations of how QI practice should be organised and implemented. In regard to the involvement of service users in QI, there is a need to critically explore the various actions, roles and relationships between stakeholders, and the differing claims to knowledge and legitimacy that enables certain groups to dominate decision-making practices. These participatory settings (including QI) are rife for understanding how struggles for power are conducted (Callaghan and Wistow, 2006; Donetto et al., 2015; Farr, 2018). Subsequently, taking a critical approach to power, this research draws upon theoretical concepts and informed readings relating to knowledge recognition, vulnerability and power within involvement and co-production spaces of QI. In particular, this thesis draws upon Miranda Fricker's (2007) framework of epistemic injustice and interpretations of this concept that have been developed and applied within a healthcare context (e.g. Hookway, 2010; Carel and Kidd, 2014;2017;2018;2021; Crichton et al., 2017; Grim et al., 2019). Applying an epistemic lens towards QI practice extends upon existing work that documents how service users face challenges to their knowledge during the uptake of services. Within a healthcare context, the conceptual application of epistemic injustice has been largely used to understand individual tensions in care-related encounters (e.g. the credibility of service users' testimonies regarding their symptoms) between healthcare professionals and service users (Carel and Kidd, 2014; Schön et al., 2018; Grim et al., 2019). Taking an epistemic focus to QI practice entails a necessary examination of what forms of knowledge influence service improvement, and how this is enabled in practice. By carrying out this exploration, this study places further attention towards the integration of 'patient knowledge' into QI which is a key ambition (Batalden, 2018; Gustavsson et al., 2022).

This research study applies the concept of epistemic injustice to the more collective activity of QI, arguing the relevance of using an epistemic lens to examine how different forms of knowledge are integrated or excluded from discussions and actions regarding service design and delivery. Moreover, the thesis proceeds to argue how the concept of epistemic injustice finds synergy with the relational elements of QI theory in terms of collaboration and communication, but which otherwise have not prioritised. In particular, QI guidance espouses the need to focus on the emotional, psychological and relational factors driving service improvement work. It can be argued that enterprises of involvement, co-production and QI are, in fact, efforts to enhance epistemic justice through encouraging collaboration between different stakeholder groups and utilising diverse forms of knowledge to improve the design and delivery of services (Glass and Newman, 2015; Groot et al., 2020; de Boer, 2021). Subsequently, recognising situations where potential epistemic injustice can arise is important to enable valuable insight into how valid forms of knowledge may be undervalued and remain unused. Through understanding this space better, possible solutions may be sought.

1.4 Research Questions

In light of the research context, key debates and gaps in research, the following research questions guide the examination conducted in this thesis.

Research Question 1
How are the concepts of service user involvement, co-production and quality improvement constructed and understood by key stakeholders?

The first research question explores how concepts such as involvement, co-production and QI are understood and reflected upon by personnel involved in these process. This line of enquiry is important given that understanding may influence how involvement, co-production and QI is approached in practice. It has also been pursued in light of the conceptual and language challenges reported within the literature, and therefore the research attempts to explore how personnel made sense of these concepts.

Research Question 2
How do the processes of quality improvement initiatives shape the roles and contributions of service users?

The second research question draws together the understanding of concepts with observations of practice to examine the space of QI for service users. Subsequent discussion captures and explores the space where dialogue and learning takes place – 'what is actually happening?', 'how are service users involved?', 'how are they not involved?' what type of actions are they involved or not involved in?'. In doing so, it also compares the 'proposed' ambitions of co-produced QI, as highlighted by QI theory and organisational directives, against what happens in reality.

1.5 Research Methods

The study takes places in a single UK-based Healthcare Trust where CMS QI has been adopted as the trust-wide QI approach. The Trust delivers services covering specialities of mental health, disability and learning difficulties. The research exploration is predominantly grounded at the micro-level. It is at the micro-level where service users and service providers first interact, where new participatory initiatives are often developed and where outputs of QI work are translated into action. There are two overlapping phases to the research. A ‘key informant’ interview phase preceded an observational phase, where three CMS teams (two teams located in a community brain injury service, one team located in a mental health inpatient rehabilitation unit) were followed over a nine-month period. The observational phase included non-participant observation of CMS meetings, analysis of key documents and interviews with CMS team members. Key informant interviews and documents were important to help locate ideas within organisational aims, expectations and motives. Observations were central in grounding research questions in empirical understandings and experiences.

1.6 Researcher Background

In the following discussion, I reflect upon my background which offers insight into my interest in the research and may explain the decisions taken throughout this thesis. I hold a long-standing interest in the area of service user involvement, co-production and QI, which has been influenced by both academic and vocational experiences. Acknowledging this, then, I appreciate that I do not approach the research with a blank slate.

i) Interest in service user involvement, co-production and QI

I first became interested in the space of service user involvement during my role as a local Healthwatch volunteer just under a decade ago[1]. Volunteering within this context is revealing of my enthusiasm for issues regarding the involvement of service users and members of the public in the design and delivery of healthcare. Healthwatch is an independent service user body that holds a remit to elicit and share public feedback to healthcare services with the purpose of improving care standards. In this volunteering capacity, I was involved in raising awareness of young peoples' physical and mental health. This included working with other young people to design local health promotion campaigns, speak to local communities and services, whilst championing the voices of other young people regarding the improvements they would like in respect to accessing health services[2]. I also trained to become an Enter and View Representative, which involved evaluating care standards across local care homes through observing practice, and speaking to professionals and residents. I strongly believe then that members of the public and service users have unique first-hand knowledge that can be positively utilised, and that they also possess the right to be involved in discussions that affects the very services that they use.

At the same time, I was developing an academic interest in issues relating to the organisation of healthcare. This was developed through undertaking a healthcare-based undergraduate degree (Clinical Sciences), which enabled appreciation of both clinical and public health worlds. With a passion to further develop my interest in Public Health, I undertook a Master's degree with areas of health policy, promotion and inequality becoming key interests. This provided an excellent opportunity to continue working with local communities whilst also developing my insight into key academic debates and raft of tensions influencing healthcare service delivery. I began to appreciate more how individuals, groups and communities have multiples realities and experiences that requires diversity of action. Health-related issues are complex and to understand these better requires an element of engagement and collaboration with individuals and communities. This said, whilst reiterating my view that

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[1] This volunteer role came to an end as I moved area to commence with the doctoral study

[2] This, I believe, was my first exposure to health-related co-production, although this was not a term that I was familiar with.

members of the public should have the opportunity to inform the design and delivery of the very services they use, and that healthcare systems have not always been conducive to this, I appreciate healthcare services and professionals have, and continue to face immense challenges and pressures in their work; this is something I have come to appreciate through taking seasonal roles as a healthcare assistant and care home volunteer. Through this merging of both academic and volunteering experience, my interest organically expanded into the organisation of healthcare services, the overarching policy background, and how improvements in care quality were being made. It was this interest that led to pursuing a doctoral studentship, where I could explore some of these issues in more depth.

ii) Influence on Research Design

My research journey has traversed several disciplines that has allowed exposure to different techniques and methods. My 'first foray' into research, in the academic sense, could be best described as being driven by a 'positivist' way of thinking. For example, undertaking an undergraduate Clinical Sciences degree resulted in exposure to the so-called 'hard sciences' (Biology, Chemistry and Mathematics). Investigating evidence-based medical treatment using quantitative methods and statistical techniques embraced a 'positivist way of thinking', where 'truths' are recognised as being objective, unbiased and impartial (Willig, 2013). A Master's degree in Public Health motioned a slight depart from the positivist notions of evidence-based medicine, where, as I mentioned earlier, I had the opportunity to undertake more qualitative work during discussions with local communities.

Entering into the doctoral process also a presented a new challenge. Prior to beginning the doctoral studentship, my worldview had not been necessarily prescribed under distinct labels of epistemology and ontology, and what I had considered at the time as more 'sociological' perspectives. As part of the PhD studentship, I undertook a Master's degree in Social Research. This provided orientation into how we come to 'think and know' (and familiarisation with these labels of ontology and epistemology). It was also instrumental in developing learning about research design, whilst introducing key sociological debates underpinning health and illness. Such learning was imperative in beginning to map out key analytical concepts to focus on in the doctoral study e.g. concept of power in health, epistemic injustice. The PhD studentship itself has been undertaken at the School of Management, where I have been located within research cluster groups of Work Psychology and Organisation Studies. This has also, to some extent, influenced my thought processes e.g. various research discussions with peers, conferences, workshops and training undertaken.

The research that is undertaken in this thesis is to all extent, informed by a qualitative, ethnographic research design. Considering the aims and objectives of this research, a qualitative case study design was selected. The decision to adopt a case study design was guided by the empirical and exploratory nature of the research as well as pragmatic reasons. I have previously taken such an approach when conducting my Public Health Masters' Thesis. My project involved working collaboratively with a partner organisation to evaluate quality care standards across local care homes, through observing care practices, and speaking to professional and residents. I found it extremely valuable to merge the findings from different research methods (interviews, observational methods, document analysis), enabling a fair assessment of services under evaluation. It was also interesting to capture the similarities and differences across views over a shared topic, further emphasising the strength of speaking to different groups and understanding their lived realities.

1.7 Thesis Structure

This introductory chapter has established the research focus of the thesis and outlined the key debates to which this thesis aims to provide a contribution. This thesis proceeds in a systematic fashion, approaching the concepts of service user involvement, co-production and QI separately first. Subsequently, discussion within the earlier chapters of the thesis spends time tracing the emergence and development of concepts before reviewing the key debates.

Chapter 2 makes visible the different arrangements of involving service users in healthcare practice and the challenges of language, before introducing co-production and charting the trajectory of its development. **Chapter 3** reviews the historical and political backdrop of service user involvement, illustrating how the agenda for involvement has been shaped by consumerist and democratic ideologies. **Chapter 4** examines the rationale of service user involvement and co-production, before exploring the key challenges and tensions that have been identified and reported within the literature. **Chapter 5** introduces QI and traces its development and emergence into healthcare practice. CMS improvement methodology is introduced along with key theoretical features of QI. The implications of context and service user involvement in QI are also considered within this chapter. A review of the literature is completed in **Chapter 6** which introduces the concept of epistemic injustice as a means to make visible the role of power in service user involvement and co-production. This is the theoretical lens through which the involvement of service users in QI is analysed.

Chapter 7 details the methodology and methods used in this thesis. It discusses the philosophical position taken in this research and guides the reader through the analytical process navigated. The chapter justifies the choice of a qualitative case study approach to guide research exploration, and details are provided in regards to the selection of cases, methods and analytical techniques. The findings of the study are presented in Chapters 8, 9 and 10. **Chapter 8 and 9** address the first research question regarding how concepts of practice were understood and reflected upon. Chapter 8 focuses on the construction of QI, whilst Chapter 9 focuses on how service user involvement and co-production were constructed. **Chapter 10** addresses the second research question, combining the findings of Chapters 8 and 9 with observation of practice, to deliver an in-depth examination of the role of service users in QI. **Chapter 11** is responsible for discussing and analysing the research findings presented in Chapters, 8, 9 and 10, situating findings within the existing literature. The chapter begins by returning to the research questions to summarise the key findings of the research. It then outlines the empirical findings of the thesis – the role of service users in QI – and the thesis' theoretical findings, related to knowledge recognition, vulnerability and power. **Chapter 12** concludes this thesis. It offers a summary of thesis chapters, clarifies the contributions of this research, reflects upon the research process before ending with possible implications of this research for purposes of practice.

CHAPTER 2

The Language of Involvement

2.1 What is in a Word?

> "There are many words - participation, engagement, consultation, involvement, inclusion, access and representation - for example, which results in no universal understanding of what involving the service user actually means, and therefore results in several approaches and methods." (Robson et al., 2008 p.13)

The rhetoric of involving service users in the design and delivery of public services has been permeated with several metaphors: 'user knows best', 'user at the centre', 'user is king' (Cowden and Singh, 2007; Barnes and Cotterell, 2012). A key theme in the drive towards service user involvement is the opportunity for service users to exercise their rights of 'choice and voice' (Greener, 2008a; Simmons et al., 2011; Dent and Pahor, 2015). Choice can be defined as "giving individuals the opportunity to choose from among alternative suppliers and services" (Public Administration Select Committee (PASC), 2005 p.5). This is closely related to the concept of 'exit' described by Hirschman (1970) as the ability of individuals to select from providers as they wish. Voice can be defined as "giving users a more effective say in the direction of services, by means of representative bodies, complaints mechanisms and surveys of individual preferences and views" (PASC, 2005 p.5).

Possibilities of more choice, louder voices, increased rights, control and so forth, have become synonymous with the 'grand modernising' potential of service user involvement. That is, to reconcile democratic renewal with the reform of public services, delivering a public sector fit for purpose in the 21st century (Gustafsson and Driver, 2005; Martin, 2009; Fotaki, 2011). In healthcare, involving service users is seen as a key part of widespread cultural change and a reshaping of the relationship between the public and healthcare organisations (Tritter and McCallum, 2009). This new relationship is propositioned on service users being actively involved at the individual level in respect to receiving services, and at a collective role in the planning and evaluation of these very services (Fee, 2006). Papoulias and Callard (2021 p.2) describe this ambition of collaboration like “harmonious choreography, where all the actors have a part and move forward together”. Pertaining to involving service users and members of the public in research activities, Rose (2018 p.765) states:

> “One of the founding principles of participatory research […] is that it should level the power relations between researchers and the community in the research itself: in who sets the research agenda, who drives the research process and governs it and who interprets information. In all these aspects of research, the community are no longer ‘subjects’ but equal partners.”

Various concepts, definitions and terminology, originating from disparate social movements, have been used to communicate the importance of involving service users. Reflecting upon Robson et al’s (2008) opening account (p. 1), over a decade old now, ‘new watchwords’ such as co-production and co-design have entered into the lexicon of healthcare service user involvement (Berwick, 2016). These ‘new’ approaches offer further conceptualisations of how service users may be involved in the design and delivery of services. Whilst the proliferation of terms suggests increased attention towards the development of service user involvement, it could be argued that these terms, often used interchangeably, result in the service user role remaining ill-defined. Barnes and Cotterell (2012), amongst others (Telford and Faulkner, 2004; McLaughlin, 2009; Butler and Greenhalgh, 2011; Locock and Boaz, 2019), describe how the language of involvement, at times, can be wide-ranging, contradictory and more diffuse than definitions suggest. Subsequently, the extent to which promises of ‘choice’, ‘voice’ and ‘control’ are achieved can remain somewhat blurred (Mazanderani et al., 2021).

Some scholars have argued that the array of language masks efforts of genuine collaboration and active involvement of service users (Butler and Greenhalgh, 2011; Barnes and Cotterell, 2012; Faulkner et al., 2015; Ocloo et al., 2017). In their study, Carter and Martin (2018) reported the ‘performativity’ of language, noting how a process categorised as ‘public consultation’ rather than ‘engagement’, resulted in different implications for staff and service users, who were bound to a set of principles and legislative requirements. Service users may feel ‘short-changed’ if their roles and influence in activities do not match with what was is initially promised (Bovaird et al., 2019; Ocloo et al., 2021). Beresford (2005 p.475) summarises the issue of language:

> "…some services and service providers have become adept at using 'the right language', but as service users frequently say, while they may 'talk the talk', they remain reluctant to 'walk the walk'."

Similar language issues have been documented concerning the labelling of individuals and groups that use services. A myriad of terms - 'consumers', 'clients', 'public' 'patients', 'survivors' – have been used but they hold different symbolic meanings. This is further conflated by individual preferences for certain terms (Beresford, 2005; McLaughlin, 2009; Butler and Greenhalgh, 2011; Barnes and Cotterell, 2012).[3] Beresford (2005) describes how 'service user' indicates a lack of difference between individuals, whilst Priebe (2021) suggests it ignores the individuals who use services involuntarily. At the same time, Costa et al. (2019) describe how the etymology of 'patient' implies medical activity and suffering. Peck and Barker (1997) distinguish between users as 'consumers' who want to participate more, 'survivors' who want to fundamentally change the foundations of the services and 'patients' who simply wish to receive healthcare. 'Clients' and 'consumers' have been criticised for positioning service users as paying recipients taking the first option offered (Barnes and Cotterell, 2012). Other common terms used in participatory spaces include 'experts-by-experience', 'expert patients' and 'patient representatives'.

Reflecting on the language used to describe a participatory activity and assessing whether the intention or principles of this approach are realised in practice is important: what is being purported, how it is described, how are people involved and what is the end output of collaboration. After all, language is one of the sites of struggle in the power relations between service providers and people who use services (Barnes and Cotterell, 2012; Faulkner et al., 2015; Ocloo et al., 2017).

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[3] Whilst recognising the limitations of this term, this thesis uses 'service user' owing to its broad descriptive utility

2.2 The Ladder of Engagement and Participation

> "The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you." (Arnstein, 1969 p.216)

Amidst various extortions to 'involve', 'engage', 'consult', 'inform' service users, several analytical models have been developed to capture the varying degrees of service user involvement within healthcare (see for example Hart (1992), Wilcox (1994), Oliver et al., (2008), Carman et al., (2013), Johannesen (2018)). A central framework underpinning these models is Sherry Arnstein's (1969) 'Ladder of Citizen Participation' (see Figure 1). Arnstein used a linear model to denominate the different levels of influence and power - the higher up the ladder, the greater control of power for those involved.

Figure 1: The Ladder of Citizen Participation (Arnstein, 1969)

The ladder conceptualisation (Figure 1) highlights varying power agendas that might be implicit within institutionalised narratives of involvement (Tippet and How, 2020). The seminal idea behind the model was frustration at the lack of clarity over what participation was - "between the understated euphemisms and exacerbated rhetoric" (Arnstein, 1969, p.216). For Arnstein, negotiating dynamics of power is fundamental to the success of involvement and the amount of control a service is able to seize in practice (Collins and Ison, 2008; Gibson et al., 2012). The continued application of Arnstein's model may be somewhat surprising given it was developed over fifty years ago in the context of American urban development. However, Arnstein did urge expansion into other areas, "where those without power make demands for power" (Johannesen, 2018 p.4). The simplistic nature of the model may explain why it continues to strike a chord with current debates of service user involvement (Brownhill and Inch, 2019). Details of the various levels are briefly summarised:

No Power (Manipulation, Therapy)

The bottom of the ladder denotes an absence of power with approaches characterised as being *manipulative* e.g. 'illusionary' participation where service users are invited to join boards and committees to engineer support.

Degrees of Tokenism (Informing, Consultation, Placation)

Informing may correspond to persons being told about their rights, and responsibilities but with little opportunity ask questions, provide feedback or influence activities and processes. *Consultation* and *placation* offer greater influence without providing guarantee that concerns will be considered. In respect, then, participation may mirror a 'window-dressing ritual'. At this level, those in power determine the legitimacy of this involvement.

Degrees of Citizen Power (Partnership, Delegated Power, Citizen Control)

Partnership denotes the redistribution of power with an agreement to share planning and decision-making responsibilities across stakeholders that includes service users and members of the public. *Delegated Power* is a further step in this process whilst *Citizen Control* is characterised by citizens having the ultimate responsibilities to influence and negotiate conditions where they are leading the charge.

Whilst Arnstein's ideas have been hugely influential they have not been without critique (Tritter and McCallum, 2006; Madden and Speed, 2017; Johannesen, 2018). Both Haywood et al. (2004) and Collins and Ison (2008) note a failure to recognise service users' personal reasons for involvement, which may not necessarily be driven by wanting control or reaching the 'top rung'. Arnstein (1969) suggests roles and responsibilities change only in relation to changing levels of power (in the dynamic of citizens taking control and authorities ceding it). For some, this overlooks the more complex set of relationships which exist in many participatory situations where roles and responsibilities are less easy to define (Tritter and McCallum, 2006; Bovaird, 2007; Collins and Ison, 2008). Contextual factors such as institutional practices, hierarchies and professional barriers can all determine the extent to which service users are involved (Tritter, 2009). Arnstein (1969 p.217), herself, concedes that this ladder conceptualisation is “obviously… a simplification”.

This section has introduced the Ladder of Participation (Arnstein, 1969) which has played a significant role in the development of the involvement agenda across public services. Crucially, Arnstein’s ideas set the tone for discussion of service user involvement to be firmly based in a vital understanding of power (Gibson et al., 2012; Tippet and How, 2020). Carter and Martin (2018) suggest the ladder of participation may be more relevant to public healthcare systems in the current era than when it was first developed. Furthermore, Tippet and How (2020) note the importance of placement and destination of involvement initiatives: “climbing a ladder is a means to an end, so it is also vital to consider where the ladder is placed [whether it is leaning against the right wall] and where it leads to – the goal” (p.111).

2.3 Situating Co-Production and Co-Design

> “Is co-production old wine in new bottles?” (Paylor and McKevitt, 2019 p.4)

Over the last fifteen years, ‘co-’ language (co-production, co-design, co-creation) has been increasingly used to describe collaborative relationships between service users and professionals (Bate and Robert, 2006; Bovaird, 2007; Verschuere et al., 2012; Brandsen et al., 2018; Elwyn et al., 2019). Instilled with egalitarian principles, ‘co-’ approaches propose an exploratory space where there is a merging of different values, knowledge and power between different actors (Slay and Stephens, 2013; Filipe et al., 2017; Farr, 2018). For some, the turn to co-production and co-design is considered one of the most radical changes in the history of NHS reform (Malby, 2012; Filipe et al., 2017) with Boyle and Harris (2009 p.4), for example, describing this as “the most important revolution in public services since the

Beveridge Report in 1942". Globally, Berwick (2016, p.1330) calls for a greater focus on co-production and co-design within healthcare, proposing them as essential components of the 'third and moral era' of medicine (Era 3): Era 1 was the era of professional dominance; Era 2 was the era of accountability and market theory:

> "… The more patients and families become empowered, shaping their care, the better that care comes, and the lower the costs. Clinicians, and those who train them, should learn how to ask less, 'What is the matter with you?' and more, 'What matters to you?' Co-production, co-design and person-centred care are among the new watchwords, and professionals, and those who train them, should master those ideas and embrace the transfer of control over people's lives to the people" (p.1330)

The surge of interest in co-production and co-design may reflect and indicate how previous forms of service user involvement have fell short of their intentions (Beebeejaun et al., 2015; Hickey, 2018; Pearce, 2021). As Bate and Robert (2006, p.307) denote, "unfortunately what it [patient and public involvement (PPI)] gains in longevity, it seems to lack in vitality and urgency […]. Although these may be providing a particular set of insights and approaches, they may also be suppressing or shielding out others". Within a mental health context, Lambert and Carr (2018) discuss how issues of equality and power remain underexplored within the paradigm of PPI.

2.3.1 Co-Production - The 'Umbrella' Term

The onus on co-production methods to transform service relationships have arisen from calls for a democratic impetus to be strengthened between the state and its publics (Bovaird, 2007; Facer and Enright, 2016; Durose et al., 2017; Bevir et al., 2019). Policy ambitions for co-produced relationships and outcomes represents new architecture, where there is an expectation of a shift in mind-set from "experts know and decide everything to we need to do things together" (Palmer et al., 2019 p.1). Whilst co-production and co-design may represent the 'new watchwords' in healthcare (Berwick, 2016), the origins of co-production can be traced back nearly fifty years. In this respect, concepts of co-production and co-design are experiencing a period of resurgence (Verschuere et al., 2012; Bovaird and Loeffler, 2013; Durose et al., 2017). The concept of co-production is often traced back to the work of Elinor Ostrom, a political economist working in the area of public administration and management. Ostrom (1996 p.1079) described co-production as:

> "The process through which inputs used to produce a good or service are contributed by individuals who are not 'in' the same organisation"

Ostrom (1996) emphasises the synergistic relationship between organisations and members of the public, with both groups equally dependent on one another. Co-production typifies a relationship between "'regular' producers (e.g. police officers, school teachers, health workers) and 'clients', who want to be transformed by the service into safer, better educated, or healthier persons" (Ostrom, 1996 p.1079). Ostrom (1996) acknowledged that this was not a straightforward process:

> "Designing institutional arrangements that help induce successful co-productive strategies is far more daunting than demonstrating their theoretical existence." (p.1080)

Various scholars have developed and further interpreted Ostrom's work in the area of co-production. Bovaird (2007 p.846) defines co-production as a "a negotiated outcome of many interacting systems", whilst Parks et al. (1981) (as paraphrased in Pestoff, 2006 p.506) refer to co-production as "the mix of activities that both public service agents and citizens contribute to the provision of public services". Edgar Cahn (2000) offers what has been described as a more radical view of co-production, aptly captured by the title of his seminal work – *No More Throwaway People: A Co-Production Imperative.* Cahn's ideas originate from areas of social justice, social economy and community development, with co-production positioned to disrupt fixed roles and power relations. Central to Cahn's conception is the notion of 'the core economy', where Cahn acknowledges that everyone has assets, values, resources, strengths and contributions to make.

Needham and Carr (2009 p.1) describe how Cahn's (2000) vision of co-production has now become accepted as "a transformative way of thinking about power, resources, partnerships, risk and outcomes, not an off-the-shelf model of service provision or a single magic solution". Cahn (2010) later suggested his interpretation represents 'Co-production 2.0', which builds upon Ostrom's account of co-production, which he describes as 'Co-production 1.0' (Glynos and Speed, 2012). The Cahnian language of 'sharing power' has gradually become embedded in mainstream discussion and can be seen widely adopted by policy, think tanks (e.g. New Economics Foundation (NEF), National Endowment for Science Technology and the Arts (NESTA)), service user movements and various public sector organisations. Boyle and Harris (2009 p.11) describe how co-production represents a process to share power through "an equal and reciprocal relationship". In doing so, co-production attempts to threaten existing power structures (Sanders and Stappers, 2008). A 'transformation of power and control', visible in many definitions of co-production, has led Carr (2016 p.1), for example, to question "whether co-production is service user participation on anabolic steroids?". Another interpretation of co-production is offered from a service management perspective (Hardyman et al., 2015; Osborne et al., 2016). From this perspective, co-production is recognised as an ever-present component of service delivery. Co-production is not 'added' or 'built in', and occurs whether service users are aware of it or not (Osborne et al., 2016). This type of involuntary involvement may contrast several key principles of co-production identified in other definitions e.g. equality, active engagement. However, at the same time, Osborne et al's (2016) definition highlights that people involved in co-production will have different motives.

Underpinning the range of co-production definitions is an ethic of mutuality, reciprocity, and equality between the different stakeholder groups involved (Tembo et al., 2019; Turnhout et al., 2020). The 'co' is seen to delineate a clearer responsibility of partnership, shared leadership and sharing of power. This said, different fields embrace distinct visions of co-production leading to 'different varieties' (Glynos and Speed, 2012; Thomas-Hughes, 2018). Typologies have included individual, group and public co-production (Brudney and England, 1983), 'slow co-production' (Miles et al., 2018) and 'additive' and 'transformative' forms of co-production (Glynos and Speed, 2012). Williams et al. (2020b p.227) succinctly summarise 'additive' and 'transformative' accents of co-production:

> “Co-production with an ‘additive accent’ involves service users […] but without necessarily changing the way they or the ‘professionals’ involved are seen or see themselves or the fundamental structures through which the service is provided. Co-production with a ‘transformative accent’, in contrast, has more radical potential in terms of altering the statuses and identities of those involved and the possibility for more significant public service reform”

Amidst the rhetoric of co-production, it is not always clear what counts by co-production in practice or what it is that is being co-produced (Vennik et al., 2016; Durose et al., 2017; Nabatchi et al., 2017; Brandsen and Verschuere, 2018; Kaehne et al., 2018; Madden et al., 2020). Several authors have described terminological confusion with the ‘co’ paradigm as ‘conceptual fuzziness’ (Ewert and Evers, 2012; Brandsen and Honingh, 2016; Dudau et al., 2019). Flinders et al. (2016) and Filipe et al. (2017) describe how the scope of co-production changes according to what is being produced, how, by whom, and to which purpose. In this sense, ‘co’ approaches are polysemic, “where concepts mean different things for different people” (Dudau, 2019 p.1578). This, Thomas-Hughes (2018) warns, enables dominant actors and interests to dictate and shape activities even where service users are involved. Definitions of co-production may be conflated with language of ‘collaboration between’, ‘involvement of…’ and ‘involuntary or voluntary exchanges’, which Williams and Caley (2020 p.41) suggest adds more confusion. Bovaird and Loeffler (2013 p.5) differentiate between the different ‘co’ approaches with co-production operating as the umbrella term:

1) Co-commissioning of services (Co-planning of policy, Co-prioritisation of services, Co-financing of services)
2) Co-design of services
3) Co-delivery of services (Co-management and Co-performing of services)
4) Co-assessment (Co-monitoring and Co-evaluation of services)

Bovaird and Loeffler (2013 p.5) position service users within co-production in several ways: ‘*customers as innovators’, ‘customers as critical success factors’, ‘customers as vital resources’, ‘customers as asset-holders’ and ‘customers as community developers’*. Service users possess vital experiential knowledge and skills, and with the appropriate time, commitment and support, their involvement should be meaningfully integrated into service design (Donetto et al., 2015; Brandsen and Honingh, 2016; Farr et al., 2021). Moving away from traditional 'well-ordered practice', co-production suggests new ways of "seeing, thinking and theorising" (Thomas-Hughes, 2018 p.233). Emotional and intellectual challenges (feelings, experiences and processes within projects) are expected as the 'messiness' of co-production is navigated (Thomas-Hughes, 2018; Ní Shé and Harrison, 2021). Subsequently, reflecting upon the challenges presented by collaboration is important to enable the representation of diverse forms of knowledge in practice (Cook, 2009; Flinders et al., 2016; Thomas-Hughes, 2018).

2.3.2 Co-Design

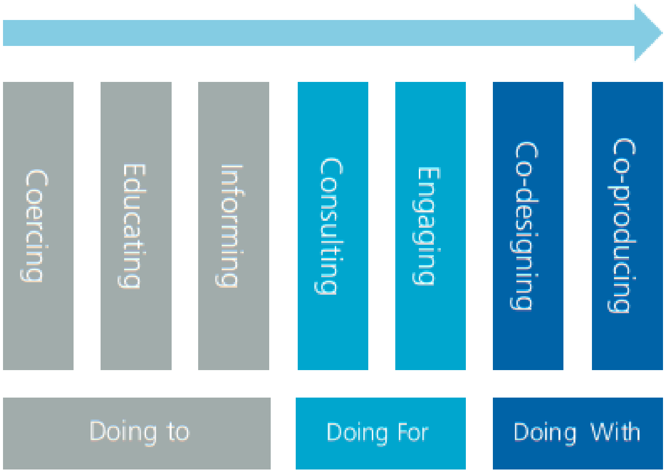
Co-design can be defined broadly "as a collaborative activity that involves different stakeholders in a design process, which 'designs with people, not merely for the people'" (Bradwell and Marr, 2008, p.17). Healthcare co-design applies 'participatory design science' principles that are often observed in fields of engineering, architecture and IT (Bate and Robert, 2006). Healthcare has been described as being similar to 'design-like' fields; both are concerned with 'good design', 'good services' and 'good experiences' (Batalden et al., 2016; Robert and McDonald, 2017). Co-design aims to create new spaces that bring value to lived experiences, emotions, skills and knowledge of people who use services (Barnes and Cottrell, 2012). Service users shift "from being merely informants to being legitimate and acknowledged participants in the design process" (Robertson and Simonsen, 2013 p.5).

Co-design is often associated with collaboration that takes place over a long and sustained period of time. In addition, whilst co-design may be used as a standalone construct, a series of thorough methodologies also come within the remit of co-design e.g. Experience Based Design (EBD), Experienced Based Co-Design (EBCD), and Accelerated Experience Based Co-Design (AEBCD). EBCD is a long-term process (up to 12 months) that involves gathering experiences from service users and staff through in-depth interviewing, observations and group discussions (Bate and Robert, 2006; Tsianakas et al., 2012; Tollyfield, 2014; Donetto et al., 2015). Staff and service users are then brought together to explore the findings and to work in small groups to identify and implement activities that will improve the service or the care pathway. Ultimately, co-design is underpinned by a central principle of service users being involved in “identifying problems […] not just responding to pre-defined problems” (Bradwell and Marr, 2008 p.18).

2.3.3 Placement on the Ladder

Co-production and co-design is underpinned by values of equality, reciprocity and sharing of power, and therefore these approaches extend beyond consultative and advisory modes of communication (Boyle and Harris, 2009; Brandsen and Honingh, 2015; Tembo et al., 2019). Using Arnstein’s Ladder of Participation as a graphic tool, co-production and co-design register at the higher echelons of the ladder. Slay and Stephens (2013) propose the following ladder of participation in response to co-production and co-design within a mental health context (see Figure 2):

Figure 2: An Alternative 'Ladder of Participation' (Slay and Stephens, 2013)



Slay and Stephen’s (2013) ladder has been widely adopted by various voluntary, social and council organisations as a point of orientation towards the involvement of service users. In addition, some local NHS trusts and resources appear to adopt Slay and Stephen’s Ladder of Participation model; for example, NHS Improvement’s (2018) *Valued care in mental health:*

Improving for excellence report uses this model to explain how co-production and co-design should be incorporated in practice.

2.4 Summary

The emergence of co-production and co-design approaches align with calls for the transformation of existing service user-professional relations. The voice of service users has not been prioritised in the design and delivery of healthcare services (Robert et al., 2015). There are multiple and coexisting forms of knowledge - the experiential knowledge of service users and the technical knowledge of professionals - that are vital for the improvement of services (Ocloo and Matthews, 2016; Vindrola-Padros et al., 2017; Beresford, 2020). The underlying assumption, then, is that creation of knowledge, through co-productive endeavours, will reflect local contexts and inform best practice (Verschuere et al., 2012; Chew et al., 2013; Donetto et al., 2015; Vindrola-Padros et al., 2017). Crucially, the service user is recognised as a 'key collaborator and partner' throughout the process of co-production and co-design.

The shift to co-production and co-design, with their rich epistemological values, may be well-intentioned. However, a similar logic is readily applicable to attempts of service user involvement that have preceded, and which also promised change. Whilst 'co-' approaches mirror 'bottom-up', participatory research approaches, it is rational, in part a result of the diversity of language, to ask what possibilities they have to change the status quo of practice? (Rose et al., 2014; Pinfold, 2015). Here, then, concerns persist over whether such 'co-'approaches result in different actions and impact meaningful and transformative change or do they simply remain superficial 'rebrandings' of involvement, continuing to oversee subversive reproductions of hierarchies in healthcare that determines who gets what and when (Fotaki, 2015; Meijer, 2016; Clarke et al., 2017; Thomas-Hughes, 2018).

CHAPTER 3

Historicising the Involvement Agenda

3.1 Consumerism and Democracy

> “I believe that public policy should be designed so as to empower individuals: to turn pawns into queens” (Le Grand, 2003 p. 163)

The discourse of service user involvement positions service users as ‘passive consumers’ of public services or ‘active citizens’ with certain rights and responsibilities (Greener, 2008a; Voorberg et al., 2014; Brandsen et al., 2018). Normative assumptions shaping the involvement agenda have largely fallen under two interweaving dimensions: consumerism and democracy (Beresford and Croft, 1992). From an organisational perspective, consumerism establishes the preferences of those who use services by offering more individual choice (Simmons et al., 2009). A democratic ideology, on the other hand, emphasises equity and empowerment, where citizens have certain rights and responsibilities to actively shape the services they use (Beresford and Croft, 1992). Both approaches have their respective merits and weaknesses, can be utilised in various guides and may also blur into one another (Beresford, 2002). Beresford (2019) highlights the importance of acknowledging the key differences between consumerism and democracy to allow greater understanding of the intricacies of involving service users.

i) Consumerism

The consumerist approach to involvement has been closely identified with a managerialist ideology with a broad interest in maximising market profitability through advancement of the ‘Three E’s’: efficiency, economy and effectiveness (Beresford, 2002; McLaughlin, 2009). There are two main features of consumerist practices: 1) giving priority to the wants and needs of the ‘consumer’, 2) meeting ‘consumer’ needs through the creation of goods and services (Beresford and Croft, 1992). Framed mainly in market research terms of ‘improving the product’, the consumerist stimulus has been led by service providers and tended to focus on consultative modes of involvement e.g. complaint systems, surveys, feedback forms (Green, 2016). Consumerist approaches multiplied during the 1980s and 1990s in an attempt by the state to support the rights of the public to make choices about services (Mold, 2011). However, the role as a consumer has been widely criticised for premising involvement on the satisfaction of individual needs rather than the pursuit of collective good (Prior, 2003). Moreover, the consultative nature of methods employed also question the degree of influence given to citizens.

ii) Democracy

The involvement of service users, driven by democratic principles and values, was a characteristic of various service user movement groups (gender, social classes, and ethnicity) observed in the late 1970s. These groups intended to advance human rights and citizenship with participatory approaches gaining traction as part of the modernisation agenda towards the end of the 20th century (Beresford, 2002; Newman and Vidler, 2006). Involvement shaped on democratic terms offers a greater degree of control to service users with further avenues for strengthening choice and voice (Fee, 2006; McLaughlin, 2009). In this respect, democratic approaches are more individualistic in nature and strike greater chords with discussions of power redistribution in participative processes (Martin, 2010; Komporozos-Athanasiou et al., 2018; Mazanderani et al., 2020).

The institutionalisation of the agenda for involving service users in the design and delivery of services is inherently political. The agenda of citizen and service user involvement has been shaped by consumerist and democratic ideologies. Following the respective principles of these ideologies has led to different designs and formulations of involvement in practice. The following section continues to summarise the trajectory of the involvement agenda, paying attention to the historical and political landscape that has influenced developments in this area.

3.2 The Historical and Political Backdrop of Service User Involvement

> "The nature of participation is political" (Carr, 2007 p.269)

A significant moment in the development of the involvement agenda can be attributed to the WHO (1978 p.1) declaration which stated that "people have the rights and the duty to participate individually and collectively in their health care". In the UK, the recent history of service user involvement can be traced through various community development initiatives and service user movements of the 1960s and 1970s, the consumer orientation of the 1980s and 1990s, and the democratic and citizenship ambitions of the new millennium (2000s).

3.2.1 Consumerism, The New Right and New Public Management

Public resistance to major social institutions heralded the rise of various service user movements during the 1960s and 1970s (Mullen and Spurgeon, 2000). This extended into the health sphere, where 'public interest' had been reduced to the sum of clinical judgements (Klein, 1982; Rowe and Shepherd, 2002). Public dissatisfaction was further fuelled by several healthcare scandals, presenting a challenge to the largely bureaucratic NHS (Harrison and Dowsell, 2002; Mold, 2011). The incorporation of Community Health Councils (CHCs), from local authorities into the NHS in 1974, is recognised as one of the earliest efforts to involve service users in the design and delivery of healthcare services. CHCs aimed to provide formal mechanisms of public representation - 'the voice of the consumer' (Lupton et al., 1998, Mold, 2011). This said, for some, the introduction of CHCs signalled the first real glimpse of consumerism in approaches to involve members of the public (Greener et al., 2006; O'Hara, 2012; Mold, 2015). When health authorities consulted the public through CHCs, often through one-off exercises, these were often carried out when decisions had already been made undermining the legitimacy and status of CHCs (Hogg, 1999).

Consumerist approaches to healthcare dominated practice in the 1980s and 1990s. Mold (2011 p.509) describes this period as where "the patient-consumer moved from the shadows to centre stage". The technocratic approach to health service delivery characteristic of the

1960s and 1970s was replaced with market mechanisms attempting to 'roll back' the state's direct involvement in public services and enable individuals to make choices about the services that they used. Klein (2006) describes this as the NHS' transition from a 'church' model (characterised by paternalism, planning, and need) to a 'garage' model (typified by consumerism, responsiveness, demand and choice). *The Griffiths Report* (1983) introduced the idea of 'satisfied customers', encouraging the use of market research and consumer satisfaction surveys, whilst non-clinical, general managers were introduced into the NHS to solicit opinions about services to 'secure the best possible service for the patient'.

Reforms to public service provision prescribed by the 'New Right' thinking, or New Public Management (NPM) (1990), resulted in proposals to separate purchasers from providers (Department of Health (DoH), 1992). According to the rhetoric, NPM was a means to both increase organisational efficiency and achieve greater responsiveness to local needs (Hood, 1991; Rowe and Shepherd, 2002). The introduction of the NHS internal market and the *1990 NHS Community Care Act* emphasised that users were not merely 'passive' patients but more 'active' consumers of healthcare (Hogg, 1999; Butler and Greenhalgh, 2011). The Care Act (1990) created space to develop the autonomous service user-provider relationship where service users were able to explain what they wanted from their services (Milewa et al., 1998). However, some argued that managerialist reforms continued to favour business metrics over the quality and experience of service users (Lupton et al., 1998). *The Patient's Charter* (1991) was another attempt to make services more responsive by laying out the rights and standards that service users should expect from their health services. However, *The Patient's Charter* (1991) was described as top-down, one-sided and seen to fuse service user rights with aspirations which were impossible to meet (Hogg, 1999; Simonet, 2013).

3.2.2 Democratic Renewal, New Labour and The Third Way

The election of a Labour government in 1997, a period dubbed 'The Third Way', saw a shift towards citizenship and democracy as part of the government's 'modernisation' of public services (Gustafsson and Driver, 2005). This approach intended to draw on the agency of individuals and communities to improve the effectiveness of the state and increase rights and responsibilities (Chandler, 2001). Put simply, it was characterised by an ambition to be more 'in touch with the people' (Barnes et al., 2004): "a public service that is accountable to patients, open to the public and shaped by their views" (DoH, 1997 p.11). As Clarke (2005, p.450) later reflected, "citizens are independent agents rather than dependent subjects waiting on the state's whims".

Legislative developments (e.g. *PPI in the New NHS* (1999)) were accompanied by a series of organisational changes. *The Health and Social Care Act* (2001) placed a statutory duty on all NHS trusts, Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) to involve service users in the provision and planning of local health services. *The NHS Plan: A plan for investment, a plan for reform* (2000) helped to establish the NHS Modernisation Agency (2001), whilst abolishing CHCs and replacing them with Expert Patient Programmes (EPP), Complaints Advocacy Services (CAS) and Patient Advice and Liaison Services (PALS) (in each trust), designed to elevate patients to active partners in the design, delivery and development of local services (DoH, 2001). A 'Patient Tsar' was also appointed (in 2003) to oversee service user experience across the NHS (Noorani, 2013). Roles and responsibilities of CHCs were transferred to newly created PPI Forums, located within each NHS and Primary Care Trust. These were soon replaced by Local Involvement Networks (LINKS), tasked with bringing healthcare services closer to local communities and creating a more user focused service. PCTs and Foundation Trusts were at the forefront of NHS reorganisation, with a legal requirement to include service users in all areas of service development and delivery (Klein 2004).

In theory, New Labour's 'modernisation' agenda proposed greater service user involvement in decision-making and to move past the 'patient as consumer' model. However, a number of writers have commented that involvement continued to have a focus on serving the strategic and operational needs of healthcare providers (Rowe and Shepherd 2002; Tritter et al. 2003; Allen, 2006). Overarching questions remained: who was to participate, at what level and on whose terms (Newman et al., 2004). The ever-changing policy agenda, according to Greener (2008b), left NHS managers perturbed over meeting performance targets, creating a culture of cynicism, where 'game playing' was rife. *The Wanless Report* (2004) criticised certain policies and initiatives (introduced shortly after the millennium) for inadequate preparation and designed for quick results. From a service user perspective, the NHS had been infiltrated by individuals, whose concerns revolved around budgetary control and administrative minutiae, rather than the natural social grounding of care that it had once premised (Allen, 2006).

3.2.3 Liberating the NHS

The new coalition government released the *White Paper, 'Equity and Excellence: Liberating the NHS'* (DoH, 2010), endorsing 'shared decision-making' between professionals and service users as a central priority. This vision was articulated in the phrase, ‘Nothing about me, without me’ (DoH, 2012) and came on the back of the Darzi Report, *High Quality Care for All – NHS Next Stage Review* (2008), which emphasized a broad spectrum of involvement, from individual patient decision making through to community involvement: “the NHS forges a new partnership between professionals, patients and their carers”.

The *2012 Health and Social Care Bill* proposed changes to replace LINKS with Healthwatch, a network of 152 local organisations across with statutory responsibilities of seeking and using local voices in service improvement (Carter and Martin, 2018). The tripartite relationship between local authority, host and LINks had made it difficult to delineate responsibility and accountability, whilst a lack of national guidance led to concerns over credibility and responsiveness (Community Services Review, 2011). NHS Citizen (2012) was formed with a manifesto of ensuring people and communities had an increasing say in health policy development and service commissioning, design and delivery. These were to coordinate actions with partners such as Healthwatch, NHS Improvement and Care Quality Commission (CQC), and set the foundations for cultural change across NHS England. The CQC (2015 p.67), the public regulator of health and social care services in England, stipulated that ‘‘providers [as part of governance] must seek and act on feedback from people using the service, those acting on their behalf, staff and other stakeholders, so that they can continually evaluate the service and drive improvement’’.

More recent policy commitment towards the involvement of service users has been relayed in the *NHS Five-Year Forward View* (2014) (updated in 2017), *National Institute for Health Research (NIHR) Going the Extra Mile* (2015) and *The Public and Patient Participation Policy* (2017). The Public and Patient Participation Policy (2017 p.6), for example, seeks to fully enforce the legal duty, under section 13Q of the *National Health Service Act* (2006) (as amended in the *Health and Social Care Act* (2012)) to "properly involve patients and the public in its commissioning processes and decision-making". Within the directorate set out in the *Five-Year Forward View* (2014 p.9), a forward vision of a new relationship with "empowered service users and engaged communities" was expressed:

> "Rather than being seen as the 'nice to haves' and the 'discretionary extras', the conviction is that these sort of partnerships and initiatives are the sort of 'slow burn, high impact' actions that are now essential." (*NHS Five-Year Forward View* (2014 p.14)

The publication of the *NHS Five-Year Forward View (2014)* coincided with a period in which 'co-' approaches were gaining real traction This said, 'co-' approaches are not explicitly referred to in the document. Rather, the language of co-production was first visible in the *NHS Five-Year Forward View for Mental Health* (2016), a report from an independent taskforce to NHS England: "Co-production with experts-by-experience should also be a standard approach to commissioning and service design" (p.20). Policy guidance and strategy (2015 onwards) is more explicit with the vision of co-production and co-creation as a conduit for greater collaboration. Many strategies have been created in collaboration with service user leaders, grassroots organisations and charities such as INVOLVE, NICE, National Voices and The Kings Fund. Marshall et al. (2019 p.155) note how the UK Government healthcare mandate, since 2017-18, has included an overall goal to, "ensure that patients, their families and carers are involved, through co-production, in defining what matters most in the quality of experience of services and assessing and improving the quality of NHS services". Co-production and co-design, then, must also be seen within the wider political backdrop. Oliver et al. (2019 p.3) emphasise this point describing how the discourse of co-production is presented as "changing the attitudes of different groups to attain a particular end, even to the extent of being explicitly framed as a political and strategic response to diminishing belief in public services".

3.3 Summary

As has been demonstrated, the institutionalisation of the agenda for involving service users in the design and delivery of services has been informed by various historical and political shifts. The current range of policies, plans and strategies show heightened interest in service user involvement, which is now *de rigueur* within healthcare. Current healthcare policy emphasises democratic ambitions of involvement in an attempt to harness the 'renewable energy' of service users. This is reflected in several mantras, for example, 'with' or 'by' rather than 'to', 'about' or 'for'. Encouraging services to become more responsive and accountable indicates a desire to move beyond consumerist-driven involvement. This, however, requires much more fundamental shifts in power between professionals and service users (Callaghan and Wistow, 2006; Mold, 2015). Furthermore, 'new' plans and practices do not necessarily provide guarantees of change especially if they fail to challenge deeply embedded discourses and structural obstacles (Komporozos-Athanasiou et al., 2019). To this effect, Beresford (2019 p.8) writes that whilst policy atmosphere appears supportive of service user involvement, "policy's direction of travel is in many ways antagonistic […] with fewer resources made available to support it".

CHAPTER 4

The Rhetoric and Practice of Involvement

4.1 Rationale for Involving Service Users

> “Involvement can be seen as an ‘end in itself’ as a democratising and rights-based process, or as a ‘means to an end’ to improve outcomes” (Lord and Gale, 2014 p.717)

The rhetoric of involving service users in the design and delivery of services is universally endorsed; Staniszewska et al. (2018 p.10) quote of PPI, “if [it] were a drug, it would be malpractice not to prescribe it”. The discourse of involving service users is heavily engaged with language of openness and transparency, breaking down barriers and improving outcomes for all. Central to this ambition is facilitating a space where service users’ experiential knowledge, developed through continuous and layered experiences of ill-health, is recognised as key sources of information (Borkman, 1976; Noorani et al., 2019). Carr (2007 p.274), for example, describes lived experience knowledge as “critical intelligence”. Noorani (2013 p.50) has previously described how service users have “a privileged understanding of their distress, what they need for their recovery, and how current service provision is, and is not, providing it”. Experiential knowledge may be further developed through collective action, for example, where service users interact and share experiences with others in similar positions. Grim et al. (2022 p.2) describe service users’ knowledge, then, as “situated knowledge perspectives that are continually co-constructed through merging lived experiences with collectively shared knowledge and scientific (e.g. medical) knowledge”.

Many of the purported benefits for service user involvement are identical across the range of involvement activities and initiatives: healthcare research, service evaluation and QI (Crawford et al., 2004; Mockford et al., 2012; Armstrong et al., 2013; Brett et al., 2014; Omeni et al., 2014). Boote et al. (2012) suggest epistemological, moral and consequentialist arguments underpin the policy commitment towards service user involvement. This can also be classified into democratic (consequentialist and moral) and technocratic (epistemological) rationales of involvement as suggested by Martin (2008a). The epistemological and technocratic argument concerns the origin and value of a certain form of knowledge and how this knowledge can potentially contribute to key discussions: “Knowing how, ways of wanting and ways of feeling.” (Liabo et al., 2022 p.9). Within the space of involvement, the epistemological argument highlights the strength of service users’ ‘lay’ perspectives and knowledge that is informed by their everyday lived experience (Boote et al., 2012). This type of knowledge is intrinsic to the activities being carried out (Hutchison et al., 2017). Professionals, although studious in treating illness and providing care, may be unable to always understand or capture the reality of living with ill-health (Fox, 2008; Faulkner, 2017; Noorani et al., 2019; Gustavsson et al., 2022). This is not to negate that many professionals will also have lived experience of ill-health. Beresford (2013b, p.147) develops this epistemological argument, proposing “the shorter the distance between direct experience and interpretation, offered by public involvement, then the less distorted, inaccurate and damaging the resulting knowledge can be”.

Service user involvement resonates with consequentialist ambitions, that is, actions with the best outcomes for everyone: these include improved safety, clinical outcomes and service user experience (Lord and Gale, 2014; Omeni et al., 2014; Gustavsson, 2016). Further benefits include safeguarding public interests, cost-effectiveness, better information for service users, greater service ownership and improving staff and service user morale (Hogg and Williamson, 2001; Crawford et al., 2002; Greenhalgh et al., 2011; Dent and Pahlor, 2015; Engström and Elg, 2015). The multiplicity of views and knowledge embraces polyphony whereby different perspectives strengthen decision-making processes (Pinfold, 2015). Thirdly, and finally, the moralistic argument for involvement is concerned with service users’ rights and responsibilities, insofar, that they have the right to be involved in projects that may impact on their health status or health services they receive (Caron-Flinterman et al., 2007; Omeni et al., 2014; Dent and Pahlor, 2015; Hutchison et al., 2017; Friesen et al., 2019). In their study, Armstrong et al. (2013) describe how service users can act as ‘persuaders’ and ‘knowledge brokers’. The former concerns how service users act as powerful advocates for issues they feel strongly about. Service users as knowledge breakers relates to how service users facilitate key knowledge exchange with professionals and services.

The various arguments and motivations presented above are readily applicable towards the practice of co-production and co-design. This said, there is one caveat in that co-production seemingly indicates greater control and power for service users. Oliver et al. (2019 p.2) list four arguments, summarised from the literature, for co-production with service users. They suggest: 1) *substantive* improvements in the quality of work owing to a better understanding of issues and context, 2) *instrumental* benefits as a result of collaborative practice that may lead to more impactful changes, 3) *normative* strengths as practice will be ethical, fair and accountable, and 4) *political* gains whereby co-production can change attitudes, improve trust and produce outcomes that are more credible and legitimate.

4.1.1 Failings in Care

Involving service users in service improvement has intensified as a result of several high-profile failings in care (Ocloo and Fulop, 2012; Martin and Dixon-Woods, 2014; Berzins et al., 2018; Fulop and Ramsay, 2019). These include, for example, Alder Hey Hospital (2001), Bristol Royal Infirmary (2001), Mid-Staffordshire NHS Hospital Trust (2005-2009), Winterbourne View (2011) and Morecambe Bay (2013). Various investigations have been conducted in response: see, for example, The Francis Report (2013), The Keogh Report (2013) and The Kirkup Report (2015).

- ***Mid Staffordshire NHS Foundation Trust***

A public inquiry into the failings at Mid-Staffordshire NHS Hospital Trust (2005-2009) reported years of appalling care standards leading to a number of avoidable deaths: 290 recommendations were made with the Trust being described as the ‘perfect storm’ of systemic failings in care at multiple levels (Francis Report, 2013). The inquiry identified ‘an unhealthy and dangerous culture’ characterised by the following features: 1) lack of candour and defensiveness, 2) looking inwards 3) misplaced assumptions of trust, 4) acceptance of poor standards, 5) failure to put the service user first, and 6) pursuit of target-driven priorities. A failure to properly utilise complaints procedures, service users reluctant to air concerns, and a defensiveness culture, were described as a ‘toxic cocktail’ (Dyer, 2014; Berzins et al., 2018). Gibson et al. (2012 p.533) paraphrase the words of the National Director of Primary Care, who “felt very strongly that a lack of good patient engagement was the key to why Mid-Staffordshire NHS Hospital Trust continued to provide poor care for a protracted period of time”. The resultant public outcry, from this inquiry and others, has placed expectation on healthcare systems to seek new ways of delivering healthcare. The role of service users in this is considered hugely important.

A key finding of the Mid-Staffordshire Trust enquiry was a poor organisational culture, and in particular, a culture of defensiveness; this is not restricted to Mid-Staffordshire with poor culture implicated in various examples of negative healthcare practice. In the context of interaction between services and service users, a culture of defensiveness can be characterised by weakening of communication and trust between healthcare professionals and service users. Cornwell (2015) describes how even well-intentioned healthcare professionals may be daunted at the prospect of engaging with service users. Such hesitation may arise at the fear of being criticised for their work and the care they deliver or engaging with service user demands that may be deemed unrealistic. Without the necessary support (e.g. time, training, guidance) healthcare professionals can retreat into defensive behaviours as a means of protecting themselves and their organisation. This inwards focus leaves key challenges unaddressed, with lost opportunities for diverse knowledge and evidence to inform decision-making. Changing this culture is as much addressing structural deficits as it is improving the experience of healthcare staff (e.g. support, satisfaction, local work group climate). This is particularly important given that existing research demonstrates how experience of healthcare staff is the antecedent for positive service user experience (Maben et al., 2012; Dixon-Woods et al., 2013).

4.1.2 Motivation behind Involvement

Various personal benefits have been highlighted as motivations for service users to get involved (Staley, 2009; Barnes et al., 2012; Thompson et al., 2012; Pestoff, 2013; Van Eijk and Steen, 2014; Engström and Elg, 2015). Involvement may align with service users’ normative interests in civic society and democracy (Barnes et al., 2012). An often-quoted reason for getting involved is a sense of altruism, where service users want to 'give something back' (Cotterell, 2008; Engström and Elg, 2015; Tanner et al., 2017). Closely related to altruistic motivations are expressive incentives of service users feeling they have important things to contribute (Brett et al., 2010; Omeni et al., 2014; Van Eijk and Steen, 2014; Locock et al., 2016). Other benefits, intrinsic in nature, include improved confidence, self-esteem, better knowledge about their conditions, helping with recovery, improving the relationship with professionals, and professional development (Staley, 2009; Omeni et al., 2014; Tanner et al., 2017). Staley (2009 p.53) describes five positive impacts of involvement on service users:

- Acquiring new skills and knowledge
- Personal development and accessing new opportunities
- Support and friendship
- Enjoyment and satisfaction
- Financial rewards

More general skills such as IT skills, teamwork, and communication may also be developed, which could improve employment prospects of service users or allow for reintegration back into work (Telford and Faulkner, 2004). Furthermore, service users may use opportunities of involvement to fill the void that has opened as a result of ill-health or retirement. Given that many service users have had to contend with the emotional challenges of ill-health, involvement offers an opportunity for service users to redefine their identities (Thompson et al., 2012).

4.2 Challenges in Practice

> "Being in favour of better public involvement is rather like being against sin; at a rhetoric level, it is hard to find disagreement, yet studies show there is." (Harrison and Mort, 1998 p.66)

The previous section highlighted the various motivations of service users to get involved and how involvement can lead to a range of personal benefits. However, Thompson and colleagues (2012 p.52) offer a note of caution “against the adoption of a perspective in which [involvement] is seen as offering unproblematic access to spaces whereby certain aspects of identity can be simply and easily reconfigured in positive terms”. This resonates with a growing acceptance that the reality of involving service users in the design and delivery of services has lagged the rhetoric (Ocloo and Matthews, 2016; Madden and Speed, 2017; Beresford, 2019; Rose and Kalathil, 2019; Papoulias and Callard, 2021). Cornwall (2008) describes how spaces prepped for involvement have traditionally been carefully managed, from whom is selected to participate to what can be said or done within the exchanges that take place. Snape et al. (2014) identify a host of barriers: professional attitudes, perceived importance of involvement, difficulties in communication and relationship-building, and resource shortcomings (funding of activities, provision of training and support for stakeholders). Some barriers and challenges to involvement and co-production may be clearly visible, whilst others subtler and complex (Beresford, 2013b).

4.2.1 Outcomes of Collaboration

The effectiveness and impact of service user involvement remains a key topic of debate (Donetto et al., 2015; Durose et al., 2017). Some scholars have argued that the diversity of methods used within participatory exercises and the design of studies (inadequate descriptions, poor reporting) has made it difficult to assess impact (Greenhalgh, 2011; Mockford et al., 2012; Ocloo et al., 2017; Lloyd et al., 2021). Oliver et al. (2019) (in raising the ‘dark side’ of co-production) and Ní Shé and Harrison (2021) (whom describe the unintended consequences of co-production) ask similar questions over the effectiveness of co-productive practice. Simply put, these arguments question whether the added investment into co-production (time, resources, emotional labour) is worthwhile without the guarantee of impact.

4.2.2 The Credibility of ‘Lay’ Knowledge

The experiential knowledge of service users is assumed to retain the ‘ordinary’ norms and values of society (Hogg and Williamson, 2001; Shaw, 2002; Henderson, 2010). However, in practice, the credibility of service users' knowledge can be scrutinised with concerns over this knowledge being anecdotal and subjective (Caron-Flinterman et al., 2007; Renedo et al., 2018; Beresford, 2020; Knowles et al., 2021a). Rose and Kalathil (2019, p.4) write, "where the knowledge of professionals is seen inviolable, consistent and legitimate, service user knowledge is seen as legitimacy unstable". Questioning the legitimacy of experiential knowledge because it fails to meet standards associated with academic and professional knowledge has been described as professionals engaging in a process of 'boundary defence' (Ward, et al., 2010; Knowles et al., 2021a).

The authenticity of experiential knowledge may also be subject to challenge based on when service users last received care or used services (Cotterell and Morris, 2012). Some services stipulate rules that service users may only be involved where there has been an extended period away in order to create some distance. However, this creates a paradox. Authenticity may be challenged where knowledge may be too recent, and challenged again, if too much in the past (Cotterell and Morris, 2012). Seemingly, at the crux of the above arguments is what represents 'valuable knowledge' in practice. The value of knowledge has often been left for professionals to decide thereby highlighting the power asymmetries inherent in the system (Fudge et al., 2008; Johnsen and Martínez Guzmán, 2013; Renedo et al., 2015; Mazanderani et al., 2020).

4.2.3 Tokenism

Tokenistic practice manifests where involvement of service users serves to legitimise the goals of professionals and services (Beresford, 2002; Martin, 2009; Morrison and Dearden, 2013; Ocloo and Matthews, 2016; Madden and Speed, 2017; Friesen et al., 2019). Harrison and Mort (1998) use the phrase 'technologies of legitimation' to describe practices where citizens (even if involved) lack power to influence meaningful change. Papoulias and Callard (2021 p.6) describe service users' roles in tokenistic practice "as a kind of limpet on a ship", where service users may be asked their opinions, but this is far from the "missing jigsaw piece" rhetoric used to describe their involvement. Wicks et al. (2018) liken such instances to a type of 'virtue signalling'. Several research studies report involvement practices being 'patchy', ‘tick-box’ exercises and often concentrated at the lowest levels of involvement where involvement is more characteristic of a consultation (Telford and Faulkner, 2004; Johannesen, 2018). Tokenism, then, is an “empty ritual of participation” (Arnstein, 1969 p.216) compounded by a failure to create fair dialogical knowledge exchanges that may have initially been promised at the beginning of collaboration (Knowles et al., 2021a). Snape et al. (2014 p.9) describe a self-fulfilling prophecy of tokenism within participatory settings: “Public involvement when undervalued leads to tokenism in involvement practice; tokenistic practice fails to demonstrate the value of public involvement; and hence, public involvement is therefore perceived as not adding value to health and social care research”.

Tokenistic involvement illuminates the power asymmetries that operate within spaces (Beresford and Branfield, 2006; Flinders et al., 2016; Madden and Speed, 2017; O’Shea et al., 2019; Mazanderani et al., 2020). Research studies have reported professionals feeling threatened by the notion of involvement. This is either through trepidation of receiving criticism from service users around conduct and practices, or feeling hesitant to share ‘inside’ information with ‘outsiders’ (Bennetts et al., 2011; Brett et al., 2014; Bee et al., 2015). This echoes earlier discussion concerning defensive attitudes and behaviours in healthcare (p.35). Another argument is a simple resistance to engaging in new principles and methods of working that require moving out of one’s comfort zone - ‘this is how we have always done it’ (Donaldson, 2008). Nonetheless, the route for service users to get involved may be obstructed through minimising access, providing inadequate information about initiatives or a lack of appropriate knowledge and training (Bee et al., 2015; Ocloo and Matthews, 2016). Professionals may feel pressure to ‘tick boxes’ led by narratives of ‘we have to do it’, and this can further result in superficial adoption of involvement where the authentic beliefs and principles of collaboration are lost (NIHR, 2015, p.116). Tokenistic practice concealed in a lack of commitment and enthusiasm has negative consequences with service users feeling undervalued and distrusting of services (Stickley, 2006; Brett et al., 2014; Bee et al., 2015; O’Shea et al., 2016).

4.2.4 Selection and Representation

Given the ever-changing diversity of communities, there is an important challenge to accommodate a range of views within the design and delivery of services. In practice, issues of selection and representation – who should be selected and why – pose key challenges. Existing research describes how service users have been poorly represented in arrangements of involvement (Shaw, 2002; Martin, 2008b; Happell, 2010; Thompson et al., 2012; O'Shea et al., 2019; Mazanderani et al., 2020). This said, Contandriopoulos et al. (2004, p.1590) note how "any individual claim to belong to or represent the public will face some opposition from other categories of actors", illustrating the key paradox of representation.

There is a view that service user involvement initiatives have been far too reliant on the selection of certain groups of service users. Akin to a type of "convenience sampling" (Williams et al., 2020b p.222), oft-recruited individuals may be known to staff and teams – representing a 'safe pair of hands' (Hogg, 1999 p.100) – or they may be perceived to be more intelligent and educated (Church et al., 2002; Martin, 2008b; El Enany et al., 2013). There is a concern that 'safe' service users tend to 'ally' with professionals rather than challenge them (Crawford et al., 2004; Lakeman et al., 2007). This can lead to professionals selecting views that align with their interests, whilst excluding more critical views (Rose, 2010; Happell, 2010). Therefore, the selection of service users may reflect social asymmetries; service users involved may possess certain levels of health, expertise, wealth and skills (El-Enany, 2013; Vennik et al., 2016). Nonetheless, such selection concerns contrast the democratic ambition of all service users having the opportunity to participate (Verschuere et al., 2018).

Selecting 'known' service users has advantages in that identification and training, often time and resource-intensive processes, have been completed (Hogg, 1999; Stickley, 2006). Yet, at the same time, these service users (willing to give up their time and knowledge), are increasingly being labelled, somewhat derogatory, as the 'usual suspects' (Beresford, 2013a; Durose et al., 2013). There is evidence to suggest how certain groups of service users may be dismissed on grounds of 'bringing the same voice' (Happell, 2008; Beresford, 2013a). Challenges to representation (or lack of) are indicative of unequal power relations (Martin, 2008b; Williams et al., 2020b). Several authors describe how professional challenges to representation may be concealed in ploys to maintain power and control over the process (Beresford and Campbell, 1994; Barnes, 1999; Martin, 2008b). The selection of ‘right’ service users, in itself, resembles acts of power given professionals decide what is ‘right’ (Happell, 2008).

Service users may face judgement about how typical they are of the local community or equally whether they are simply expressing their own views (and therefore pursuing their own agendas) (Scholz et al., 2019). In contrast, professionals’ ‘representativeness’ is rarely questioned, leading to an ‘us and them’ situation where there is one rule for service users and another for professionals (Telford and Faulkner, 2004; Happell and Roper, 2006). Reflecting on Beresford and Campbell’s (1994) study of service user involvement and representation, Martin (2008b p.1758) describes how the authors described “a sort of acute hypocrisy”, whereby professionally generated structures left service users in unfair positions contributing to their struggle for involvement. For example, ‘a seat at the table’ is offered to only one service user, but then this single view is ‘too subjective’ and lacks credibility (Hogg, 1999; O’Shea et al., 2016).

Further tension is visible in how some service user communities are described counter-productively as ‘hard to reach’ or ‘seldom heard’ (Cook, 2002). These labels purport the view that these group of service users are ‘not doing enough’ to get involved (Jones and Newburn, 2001; Cook, 2002; Rose and Kalathil, 2019). Williams et al’s (2020b p.222) account is particularly pertinent here as they describe how “if some people are ‘hard to reach’, it is in part because ‘reaching’ is a dual dynamic that reveals as much about those reaching (or not)—and the institutional contexts they work within—as about those seemingly beyond reach”. These arguments point to how recruiting a broad range of service users is only possible when organisations realise and act upon the disincentives to involvement (Rutter et al., 2004; Friesen et al., 2019).

4.2.5 'Professionalization'

Labels of 'professionalization' and 'expert service user' straddle a delicate line between unique 'lay' knowledge and this knowledge losing its 'laity' to mirror professional and expert forms of knowledge (Barnes and Cotterell, 2012; O'Shea et al., 2016; Maguire and Britten, 2017). In their study, Thompson et al. (2012) documented a form of 'proto-professionalization' (Shaw, 2002) whereby involved service users internalised the stances of professionals to become 'credible'. A danger remains in that whilst service users may be involved, the power of their authentic service user voice is lost (Faulkner and Thompson, 2021). In contrast, Ward et al. (2010) report how researchers can question the authenticity of 'professionalized' service users. Pertaining to issues of professionalization, Learmonth et al. (2009 p.108) describe a 'Catch-22 situation', where various expectations placed upon service users are, in fact, contradictory. There is expectation that service users present themselves as 'ordinary', however when involved, their conduct must share many characteristics of professionals to be recognised as 'credible' knowledge partners.

The subject of professionalization is revisited during discussions of whether service users should receive training (Ives et al., 2013; Staley, 2013) and remuneration for their involvement efforts (Happell, 2010; Filipe et al., 2017). Ives et al. (2013 p.183) acknowledge that service users may access training in order to substantiate their involvement, but this comes at a potential cost of compromising their 'lay' status. This leads to 'a professionalization paradox'. Whilst experiences of ill-health and service access will always remain, education and training is likely to result in a process of professional socialisation where the legitimacy of service users' knowledge is tamed (Van de Bovenkamp and Zuiderent-Jerak, 2013). Staley (2013, p.186) vehemently opposes the view that training results in the loss of laity, but rather, training provides a basic introduction and starting point to work from. Moreover, education and training helps to overcome key challenges of confidence and teamwork, which enables the service user to be effective in their role whilst maximising their lay knowledge (Turk et al., 2016; Friesen et al., 2019; Scholz et al., 2019). This latter assessment reflects the current view within health services research, with training and education counteracting the challenge of service users lacking 'appropriate' knowledge on which they have traditionally been discredited (Turk et al., 2016; Hutchison et al., 2017; Staley, 2021).

Similar arguments have been raised over whether payment and remuneration obscure the gap between lay knowledge as a non-expert and professionalization (Happell, 2010; El Enany, 2013; Filipe et al., 2017). This is followed by concerns over whether payment places too much pressure on the service user (Beresford, 2013a) or whether it encourages involvement for the wrong reasons (Rutter et al., 2004). The immediate retort to this view is that lack of payment undermines service users' contributions, time and commitment. Moreover, the professional will be receiving payment for the same type of work (Happell, 2010). Service users may be compensated through various channels that include money (based on hours worked), gift cards and reimbursement of travel, whilst many may wish to simply volunteer and not receive any financial contribution; ultimately service users should decide. All these arguments naturally correspond to organisations which have the capacity to remunerate service users, with many struggling financially. There is further complexity over how payment may clash with welfare benefits that a service user may be in receipt of (Rutter et al., 2004; Beresford, 2013a). Consequently, service users may be wary or discouraged to get involved as they lack clarity over how it may affect their benefits policy.

4.2.6 Utilising Service User Experience Data

Several different methods and platforms have been developed to enable service users to share their knowledge and experiences e.g. surveys, questionnaires, Friends and Family Test (FFT), service user interviews and open forum meetings. Complaints and compliments are also considered as vital sources of experience data, and these can be given in a range of ways e.g. online websites (Care Opinion), feedback forms and social media. There are some arguments to suggest the type of method chosen dictates the extent of service user involvement. For example, quantitative survey methods align with consumerist principles in which service users predominantly adopt consultative roles (Ocloo and Matthews, 2016). Although important, the nature of this method restricts feedback to simple answers and therefore where relied upon as the main source of data, could potentially limit the opportunity for more ‘in-depth’ information (McLaughlin, 2010; Ocloo and Matthews, 2016; Miles et al., 2018).

Nonetheless, the diversity of data collection made has led to what Sheard et al. (2019 p.51) describe as an ‘explosion’ in the collection of feedback from service users. However, there is limited evidence as to show how such data can influence improvement (Reeves et al., 2013; Coulter et al., 2014; Sheard et al., 2017; Montgomery et al., 2020). Robert and Cornwell (2013 p.67) note how use of surveys has “contributed to a tick box or compliance mentality” with organising boards falsely assuming that attention is being paid. Experience data has been described as difficult to manage because it is driven by subjective preferences, personal attitudes and behaviours. Flott et al. (2017) and Sheard et al. (2019) identify issues pertaining to staff scepticism and mistrust of data, analytical complexity and lack of expertise and skill with Gleeson et al. (2016) also adding challenges of time and resources. Complaints, for example, may highlight poor staff attitudes and behaviours, in which the service retreats into a defensive mode (Cornwell, 2015). Sheard et al. (2019 p.51) conclude that “too much data is being collected from patients in relation to the little amount of action that is taken as a result of it”, in part owing to the neglect of the complexity of this process (Reeves et al., 2013). Ultimately, the lack or misuse of experience data is to the detriment of service user given the time and effort they may have put in to providing this knowledge.

4.2.7 Summary

This section has summarised the rationale behind service user involvement and co-production, whilst further highlighting the competing tensions reported in practice. The strength of service user involvement is underpinned by service users’ unique experiential knowledge, and there are several reasons for the involvement of service users that may be underpinned by democratic and technocratic rationales (Martin, 2008a). Yet, competing tensions continue to play out in practice with an underpinning current of power (Beresford and Campbell, 1994; Callaghan and Wistow, Ocloo and Matthews, 2016; Farr, 2018). The selection or non-selection of service users to how experiential knowledge is disputed may all be viewed within a lens of power. Where the power differentials are particularly pronounced, the practice of involvement may become tokenistic leading to frustration and driving service users further away (Bovaird et al., 2019). With these challenges and tensions in mind, it becomes important to explore and examine the various actions and behaviours of those involved that may either facilitate the development of knowledge spaces, or equally, constrain these spaces (Callaghan and Wistow, 2006; Farr, 2018).

4.3 Co-Production with Vulnerable Groups

> "Living under harsh conditions […] is perhaps more an indication of strength than vulnerability" (Røhnebaek and Bjerck, 2021 p.742)

This section considers the practice of service user involvement and co-production within settings where individuals and groups may be considered particularly vulnerable[4]. This thesis acknowledges that vulnerability is often misaligned with damaging and patronizing narratives, which imply personal weakness or shift blame onto service users for making 'poor' life choices and behaviours (Brown, 2013; Liabo et al., 2018; French and Raman, 2021; Røhnebaek and Bjerck, 2021). As such, the description of vulnerability as "the inability to fully participate in the economic, social, political and cultural life of society" (French and Raman, 2021 p.778) and where "access to resources and opportunities may be limited in comparison to what one is expected to possess" (Brandsen, 2021 p.529) is taken in this study. Various social, structural and institutional structures impede access to resources and opportunities for vulnerable service user groups to get involved (Eriksson, 2019; Trischler et al., 2019; Park, 2020; French and Raman, 2021).

4.3.1. Individuals living with Brain Injury

Traumatic brain injury is defined as an "alteration in brain function or other brain pathology caused by an external force" (Menon et al., 2010 p.1637). Individuals experience reduced quality of life with long term cognitive, psychological, emotional and social effects (Slomic et

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[4] This research takes place across two different services: 1) people living with traumatic brain injury, 2) people living with mental ill-health requiring inpatient rehabilitation care.

al., 2017; Mäkelä et al., 2019). This can impact self-awareness, social and vocational participation, may require dependency on others for care, and can also lead to further mental ill-health such as schizophrenia, bipolar disorder and clinical depression (Headway, 2019). Despite prognosis, service users with traumatic brain injuries continue to encounter stigma leading to mistaken and misattributed beliefs. Krahn (2015 p.1515) describes how "there are risks of a 'spoiled' and 'negative' identity" as per societal barriers attached to the experience of stigma, social distancing, withdrawal and isolation of brain injury survivors". On occasions, brain injuries are not readily visible (compared to physical injury) and the 'invisibility' of injury can lead to stigma that "there is nothing wrong with the injured persons" (McClure et al., 2006 p.1029). Attached stigma and characterisation of individuals living with brain injury as members of the 'walking wounded', diminishes efforts to facilitate their involvement in every day social living (Krahn, 2015).

4.3.2 Individuals living with Mental Ill-Health

Cultural and societal attitudes towards users of mental health services have been largely negative with individuals described as 'deviant', 'mad' and 'unreasonable' (Thornicroft, 2003; Carr et al., 2016; Le Blanc and Kinsella, 2016). Stigma, discrimination and shame attributed to having a mental health diagnosis can create barriers to involvement. Service users may feel embarrassed and therefore feel discouraged to get involved, or, services hold low expectations and discredit the value of knowledge these groups may share (Lewis, 2014; Berzins et al., 2018; Lambert and Carr, 2018). Beresford (2009, p. 43) adds "their [service users] processing in the psychiatric system is related not only to them being seen as defective, but also frequently dissident, non-conformist and different in their values". Mental health services are often seen as being disconnected from the wider health and social care system – institutionally, professionally, clinically and culturally (Naylor et al., 2017 p.5). Issues of power, hierarchy and fixed role dynamics are particularly visible within the organisation of mental health care (Happell, 2008; Farr, 2012; Boxall and Beresford, 2013; Lambert and Carr, 2018; Sangiorgi et al., 2019). Services continue to be characterised by features of containment and compulsion, where people can be still detained and treated against their will (Bee et al., 2015; Millar et al., 2015; Berzins et al., 2018).

4.3.3 Summary

This section has highlighted the possible implications of co-production and co-design in the context of working with vulnerable service user groups. Pathologically, brain injury and mental health result in characteristic cognitive, psychological, emotional and behavioural effects which can influence every-day functioning e.g. difficulties with speech, memory, language and communication (Slomic et al., 2016; Headway, 2019). Tensions in mental health settings such as disempowerment, stigma and coercion are likely to amplify barriers to service user involvement (Lambert and Carr, 2018; Tindall et al., 2021; Grim et al., 2022). Incorporation of service user knowledge into the design and delivery of services will rely upon the degree of credibility assigned to this form of knowledge amid the surrounding tensions. Before this, involvement is first dependent upon whether service users have access to suitable formats and spaces to describe and share their experiences, views and opinions (McIver, 2011).

Exploring the possibility of co-production in mental health, Rose and Kalathil (2019 p.2) describe how co-production opens a hybrid ‘Third Space’ (Rutherford, 1990) with a “new era of meaning and representation”. However, the authors also raise caution, interrogating whether the creation of this ‘Third Space’ is possible given “current configurations [of mental health] which demarcate elite sites of privilege in knowledge generation” (p.8). The delivery of mental health services is predicated on a dominant biomedical paradigm that prioritises objective, third-person, clinical knowledge (Brosnan, 2013; Newbigging and Ridley, 2018; Rose and Kalathil, 2019). From a service user perspective, negative practices of power and control remain defining features of mental health service provision, yet co-design is explicitly about progressing ‘a transformation of power and control’ (Farr, 2018). This contrast, then, has left many curious over the potential of co-design and co-production in settings where power inequalities are particularly entrenched (Tembo et al., 2019; Rose and Kalathil, 2019; Brandsen, 2021).

CHAPTER 5

Quality and Quality Improvement

> “No needless deaths; no needless pain or suffering; no helplessness in those served or serving; no unwanted waiting; no waste; and no one left out” (Institute for Healthcare Improvement (IHI), 2010 p.2)

Improving the quality of care remains a core ambition for healthcare systems across the world. In the last decade, efforts have intensified as demand for services rise against the backdrop of demographical shifts and societal changes. A host of systemic and structural issues concerning the organisation of healthcare are well documented in practice that include resource shortages, lack of funding, performance gaps (e.g. waiting lists) and challenging working conditions (Dunn et al., 2016; Gleeson et al., 2016; Ham et al., 2016). Whilst advancements in technology and treatments offer promise, operational processes have not adapted with the shifting landscape (Hellström et al., 2015; Dixon-Woods and Martin, 2016). Service users’ expectations of care have also changed escalating the demand on new ways of delivering high-quality, safe care (Burgess and Radnor, 2012; Bergman et al., 2015). There is, also, recognition that high-quality care has no end point and that there will always be room for improvement.

Within the UK healthcare context, the response to increasing the quality of care has been initiated by a strong policy rhetoric e.g. ‘High quality care for all’ (DoH, 2008), ‘Quality at the heart of everything we do’ (NHS, 2015;2021). The quality agenda has been a central part of healthcare reform and is reflected in various policies pursued by successive governments. Policies and reforms introduced by the 1997 Labour government, for many, are recognised as laying the key foundations for how approaches to quality are considered today: key documents include *A First Class Service* (DoH, 1998) and *An Organisation with a Memory* (DoH, 2000). Traditionally, quality assurance and control was largely undertaken through auditing exercises. However, this practice was criticised for emphasis on sanctions and discipline, and which led to alienating many members of the workforce (Scally and Donaldson, 1998). Whilst a proliferation of policy interventions released in subsequent years advanced focus on QI, Ham et al. (2016 p.5) describe how policies put forward were “sometimes old policies in new clothes”. In the last decade, well-publicised policies driving QI include *Hard Truths: The Journey to Putting Patients First* (DoH, 2014) and *Five-Year Forward View* (2014). Changes proposed in these policies included the establishment of NICE and the CQC, introduction of the Commissioning for Quality and Innovation (CQUIN) framework and duty of candour, formation of NHS Improvement and calls for greater transparency of performance data. *The Five-Year Forward View* (2014), the national plan for improving services in the NHS in England, called for improvements in three main areas:

- Improving quality of care
- Improving the broader health and wellbeing of the population
- Improving financial efficiency

5.1 What does ‘quality’ mean?

There is unanimous agreement that all healthcare services should strive to deliver high quality care. However, defining what high quality care looks like has not always been straightforward (Boaden, 2011; Dixon-Woods et al., 2012; Swinglehurst et al., 2014; Gustavsson et al., 2015). There is no universal definition of quality with Swinglehurst et al. (2013 p.3) describing quality as a “curiously amorphous word […] yet which receives considerable rhetorical leverage”. Underpinned by the hippocrateon concept of ‘do no harm’ (Donabedian, 2003), definitions of quality can range dependent on the extent to which subjective and objective measures are incorporated (McIver, 2011; Lillrank, 2015). In their interaction with services, people may have different expectations and also experiences of the same care (Donabedian, 2005; Lillrank, 2015). The Institute of Medicine (IOM) (2001) suggests quality can be achieved by making improvements in six key areas:

- Safe - free from harm or injury and minimising risk
- Effective - providing evidence-based care to improve health outcomes
- Patient-centred - provision of care that considers the views of the patient
- Timely - avoiding delays and delivering treatments and care at the right time

- Efficient - maximising resources while reducing waste and poorly organised care
- Equitable - providing equal care irrespective of patient background

The NHS regulatory framework developed by the CQC (2013) defines quality based on three criteria which draws upon the IOM's six aims of improvement listed above:

- Patient safety - doing no harm to patients
- Patient experience of care - showing compassion, dignity and respect
- Clinical effectiveness of care - preventing people from dying prematurely, enhancing quality of life and helping people to recover following episodes of ill-health

Lillrank (2015 p.363) argues each dimension of quality is ontologically, epistemologically and technically different. Each dimension has a distinct goal and responsibility, attaching to different stakeholders within the health setting. For example, clinical decision-making responsibility has traditionally been entrusted to medical professionals. On the other hand, patient experience emerges from communication with service users, families and carers. Neither dimension is easy to measure but it is widely accepted that patient experience has failed to receive the same focus (Locock, 2003; Swinglehurst et al., 2014; Montgomery et al., 2020; Ocloo et al., 2020). This could be in part due to the domains of clinical effectiveness and patient safety fitting more neatly into the biometric and standardised formats used within healthcare practice.

Differing and often conflicting desired outcomes lead to a lack of clarity about how to pursuit ideals of quality (Porter, 2010; Flott et al., 2017). Øvretveit (1997 p.221) notes how "quality becomes a battleground on which professions compete for ownership and definition of quality". Alderwick et al. (2017) report improving quality and reducing costs are sometimes seen as conflicting aims. Notably, the challenge to operate under financial constraints and meeting clinical targets does not necessarily align with areas that service users would consider high priority (Elwyn et al., 2019). Swinglehurst et al. (2014 p.65) argue the following questions need to be considered when discussing quality: 1) What are the different values underpinning quality and who is involved in the discussions? 2) What are the trade-offs when decisions are made in regards to pursuing a form of quality? It may be unrealistic to suggest that the pursuit of quality will never be contested. However, pursuing quality initiatives where certain 'effective' markers of quality (clinical effectiveness and safety) are prioritised not only contradicts ambitions of meeting quality criterion, but may also be detrimental to the quality of care provided (Swinglehurst et al., 2014; Flott et al., 2017; de Longh and Erdmann, 2018).

5.2 'Quality Improvement'

> "Transforming the NHS depends much less on bold strokes and big gestures by politicians than on engaging doctors, nurses and other staff in improvement programmes." (Ham, 2014 p.3)

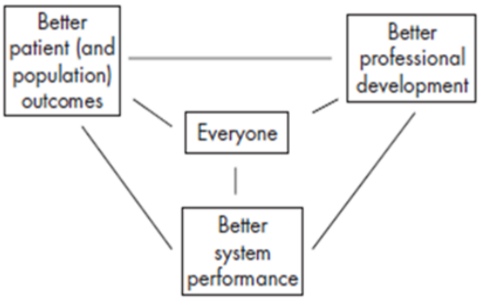
Over the last two decades, industrial principles and practices have gradually been integrated into healthcare practice in the form of various QI methodologies and tools (Nelson et al., 2007; Burgess and Radnor, 2013; The Health Foundation, 2013; Williams and Caley, 2020). This area of QI in healthcare has also been described as improvement science or a science of improvement (Batalden and Stoltz, 1993; Langley et al., 1996; Bergman et al., 2015). Notwithstanding the need for greater resourcing of healthcare systems, Dixon-Woods (2019a p.47) argues key questions remain over how to get the best from what is available. QI aims to address this by utilising the best possible research evidence to narrow the gap between current practice and the best possible practice (Lifvergen, 2013; Hellström et al., 2015; Williams and Caley, 2020). QI approaches represent new ways of designing and delivering care, challenging the traditional 'organisational treadmill', where improvements have often been implemented without formal evaluation (Locock, 2003 p.54).

The roots of QI approaches can be traced back to the rationale of production quality control that emerged in the early 1920s (Boaden, 2011; Bergman et al., 2015). These approaches were developed further during the 1940s and 1950s by QI gurus such as Juran, Crosby, Feigenbaum and Ishikawa with shared characteristics that include: 1) commitment of stakeholders, 2) planned actions and prioritisation of process, 3) teamwork, 4) use of processual tools, 5) management and leadership, 6) 'customer' focus (Nelson et al., 2007; Boaden, 2011). W. Edward Deming's (1993) ideas are particularly useful within the concept of improvement science (Batalden and Stoltz, 1993). Deming (1993 p.96) developed the Theory of Profound Knowledge and emphasised four key domains for QI:

1. **Appreciation of a System -** knowledge of the interrelationships between processes and within systems to avoid any 'unintended consequences'.
2. **Knowledge of Variation -** awareness, understanding and mitigation of common cause (variation from the system) and special cause variation (variation from outside the system).
3. **Theory of Knowledge -** process of organisational, team and individual learning and development of expertise to utilise specialist tools for service improvement.
4. **Understanding of Psychology -** understanding, managing and encouraging communication, interaction and innovation amongst different stakeholder groups.

QI methodology aims to help teams better understand the system, address variation, develop professional and specialist expertise, and attempt to bring stakeholders and their different forms of knowledge together (Batalden and Stoltz, 1993; Batalden et al., 2015). QI can be interpreted in several ways but primarily involves the use of specific methods and tools to produce meaningful change (Øvretveit, 2013; The Health Foundation, 2013; Shah, 2020; Williams and Caley, 2020). Whilst QI shares common elements with activities of research, clinical audit and service evaluation, it is recognised as a distinct approach (Backhouse and Ogunlayi, 2020). Shah (2020 p.1) offers the following definition: "QI is a systematic and applied approach to solving a complex issue, through testing and learning, measuring as you go, and deeply involving those closest to the issue in the improvement process". The ambition of QI can be succinctly summarised to helping achieve collaboration, change and effectiveness (Williams et al., 2009). The following heuristic, devised by Batalden and Davidoff (2007), conveys the linked aims of QI (Figure 3):

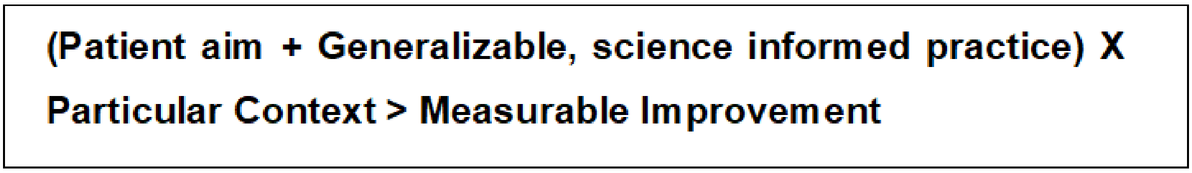
Figure 3: Linked Aims of Quality Improvement (Batalden and Davidoff, 2007 p.2)



*"The combined and unceasing efforts of everyone - health care professionals, patients and their families, researchers, commissioners, educators - to make changes that will lead to **better patient outcomes (health), better system performance (care), and better professional development (learning)**"*

Further to this heuristic, Batalden (2018) has developed the following formula to depict how services may improve and achieve change (Figure 4):

Figure 4: 'Modified' Quality Improvement Formula (Batalden, 2018)


(Patient aim + Generalizable, science informed practice) X Particular Context > Measurable Improvement

The above taxonomy represents an updated version of the earlier QI formula devised by Batalden and Davidoff (2007). Significantly, it has been modified to reflect the growing role of service users in QI, indicated by the inclusion of the domain - 'patient aim'. In making this domain more visible, Batalden (2018) highlights how QI practice should move beyond an operational focus and being the responsibility of a few, to, adopting a more collaborative and 'co-produced' approach where multiple stakeholders, including service users, have important roles to play in dictating service improvement.

5.3 Clinical Microsystems Quality Improvement

Many QI methods such as Lean and Six Sigma have been regurgitated from manufacturing and production industries, whilst others have been developed specifically for healthcare e.g. The IHI Model, which uses Process Mapping and Plan-Do-Study-Act (PDSA) cycles (Nelson et al., 2007; Øvreteit, 2013; Smith, 2020). There is no clear evidence that one approach is superior. Rather, many QI methods share underlying features with consistency to one approach recognised as the critical success factor (Walshe, 2009; Jabbal, 2017; Shah, 2020).

In this section, a particular QI methodology called Clinical Microsystems (CMS) is introduced[5]. A microsystem represents the local milieu in which members of the public, service providers, professionals, and various other processes first come together (Mohr et al., 2004). Based on systems thinking and organisational development principles, the seminal idea of CMS originates from the work of James Quinn (1992). Quinn (1992) noted success in global organisations often revolved around continually engineering frontline relationships that adequately reflected the needs of the consumer (Mohr et al., 2004). These companies were producing successful results by focusing on the smallest areas of their business which involved providing service user-facing teams with the knowledge and understanding of their system and how their actions interlinked with the broader aims of respective organisations. Put simply, the quality and output of a service can be no better than that delivered by the functional units of which the system is made up off (Mohr and Batalden. 2004; Godfrey et al., 2007; Nelson et al., 2007). Such a view, then, was believed to be replicable to the healthcare system:

> “CMS are small, functional, front-line units that provide most health care to most people. They are the essential building blocks of larger organisations and of the health system. They are the place where patients and providers meet. The quality and value of care produced by a large health system can be no better than the services generated by the small systems of which it is composed” (Nelson et al., 2007, p. 3).

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[5] The Trust where this empirical study takes place adopts a service-wide CMS approach to QI.

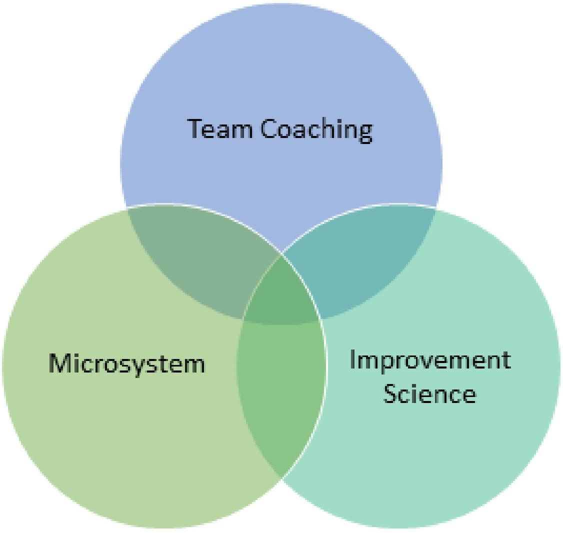
The CMS approach reflects a structured, bottom-up approach to QI. Advocates of the CMS approach highlight a purposeful flattening of hierarchies to allow greater autonomy for frontline teams that are 'closest to the issue' (Mohr and Batalden, 2002; Nelson et al., 2007; Côte et al., 2020). This is not to completely remove the role of senior leadership as they are responsible for setting the organisational stage for QI (e.g. strategic intent, cultivating learning environments). In addition, CMS teams are not isolated from one another, and rather, success is predicated on inter-connectivity between the micro and meso-level as this enables shared learning across the organisation. However, primarily, senior leaders are responsible for allowing individual CMS teams to create their own innovative strategies for improvement that first and foremost prioritises their service user population (Mohr et al., 2004).

An ambition remains for QI to become routine practice where frontline healthcare teams are continually reflecting on the services they are providing and making iterative changes that have been informed by a suitable level of assessment and collaboration. This suggests that CMS has the capacity to both be used as a general tool for ongoing service improvement (process-focused) whilst also responding to particular issues concerning health outcomes (Abrahamsson et al., 2020). The following represent some of the key aims of CMS QI: (1) greater standardisation of common activities and customisation of care to individual patients, (2) greater use and analysis of information to support daily work, (3) consistent measured improvement in performance, (4) extensive cooperation and teamwork across disciplines and specialities within the microsystem, and (5) an opportunity for spread of best practices across microsystems within their larger organisations (Mohr and Batalden, 2002 p.45).

5.3.1 The Process of Clinical Microsystems Quality Improvement

The CMS approach to QI encourages frontline teams to critically evaluate their service, review their individual roles, responsibilities and relationships, and implement realistic actions that will help bring positive change. The CMS approach is arranged around three key domains (Figure 5):

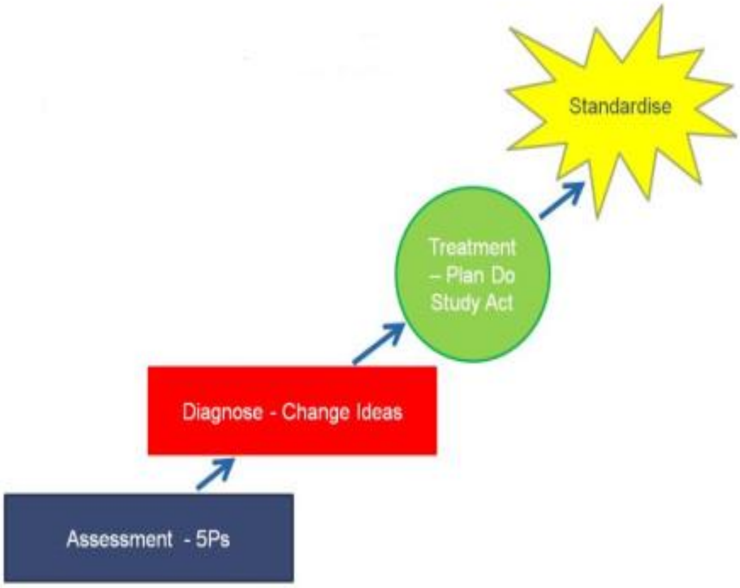
Figure 5: Elements of Clinical Microsystem Improvement (Nelson et al., 2007)



- **Team Coaching** - A specialist QI coach works with local teams to build their capability and embrace improvement science principles
- **Improvement Science** - Specialist tools and methods e.g. process mapping, PDSA cycles, time series management are employed to test changes
- **Microsystem** - Active involvement of the CMS team and regular meetings to work on improvement. The CMS team should include a range of healthcare staff and service users

The CMS approach is divided into four key phases which the CMS team is expected to navigate over the duration of a project (Figure 6):

Figure 6: The Structure of Clinical Microsystems Improvement (Nelson et al., 2007)



- **Assessment** - Understanding the system before trying to improve it
- **Diagnose** - What ideas of improvement have developed?
- **Treatment** - Testing improvement ideas and measuring changes
- **Standardise** - How to embed and sustain improvements in practice?

The starting position for designing or redesigning CMS is to evaluate the system which is undertaken using a ‘5Ps’ approach (Godfrey et al., 2003):

- The **purpose** of the microsystem
- The **patient** subpopulations that are served by the microsystem
- The **professionals** who work together in the microsystem
- The **processes** the microsystem uses to provide services
- The **patterns** that characterise the microsystem’s functioning

The 5Ps process helps the team acquire the initial knowledge to begin the improvement process – the *Assessment* phase – which is followed by stages of *Diagnosis, Treatment* and *Standardisation*. These phases may require use of improvement techniques such as Change Ideas, PDSA cycles and Fishbone diagrams to devise potential improvements, whilst the team may create Global and Specific Aims (similar to mission statements) to fine-tune their focus (Godfrey et al., 2003; Nelson et al., 2007).

5.4 The Role of Context in Quality Improvement

QI is most successful when articulated as part of a long-term and coherent system-wide approach, underpinned by a degree of stability, constancy of purpose, and organisational maturity (Nelson et al., 2007; Godfrey, 2013; Drew and Pandit, 2020): creating a ‘culture of continuous improvement’ is a widely-versed QI statement (Fulop and Robert, 2014; Jabbal, 2017; Mannion and Davies, 2018; Coles et al., 2020). Bamber (2014 p.2) describes “how QI success is more likely to occur where there is constant interaction between the importance of what is being done (intervention), how this is put into practice (implementation) and the environment within which this implemented”.

A key contextual element of the QI process is the way in which frontline teams are organised and managed to ensure effective collaboration. Human relationships are central in QI and this identifies the importance of relational factors driving QI. QI is often described using the following quote (attributed to Marjorie Godfrey): “QI is 20% technical and 80% human”.

Relational characteristics of QI interlink with psychological behaviour, change and safety (Deming, 1993). Psychological safety is premised on a view that members of a particular group or within organisations will not feel unsafe for speaking up with ideas, questions, concerns or mistakes (Kahn, 1990; Edmondson, 1999). In team settings, psychologically safety is considered key to allow for interpersonal risk taking and to help foster a team climate of interpersonal trust and mutual respect (Kaplan et al., 2014; Batalden et al., 2016; Jones et al., 2021). Drawing on Kahn's (1990) team engagement theory, four factors are identified that influence psychological safety in teams:

1. **Interpersonal relationships** – relationships are supportive and trusting
2. **Group and inter-group dynamics** – conscious and unconscious alliances that are formed within teams that leads to delineation of roles, responsibilities, authority and control
3. **Management style** – managers have to be supportive, resilient and able to clarify expectations
4. **Organisational norms** – clarity of organisational boundaries so teams know the consequences of their actions and behaviours

The concept of psychological safety is captured in Deming's (1993) Theory of Profound Knowledge, which drives the development of QI work. In the following domains, *'Appreciation of the System'* and *'Understanding of Psychology'* (see Pge X), an emphasis is placed on understanding interaction between work systems and people, and how people work best individually and collectively e.g. How people relate to change? What are the factors influencing people's motivation? Subsequently, creating psychologically safe spaces allows teams to experiment with new methods, offers space and time for QI, increases individual and team confidence, and encourages collaboration (Baker, 2018; Spranger, 2018; O'Donnell, 2019; Jones et al., 2021).

The degree of fidelity is also fundamental to QI practice (Dixon-Woods et al., 2011; Jabbal, 2017; McNicholas et al., 2019). Fidelity is defined as "the degree to which a method is carried out in accordance to the guiding principle of its use" (McNicholas et al., 2019 p.356). Whilst there is an expectation for QI work to employ a long-term focus, projects may be pursued with quick, short term results in mind. Quick results may mask genuine problems and potentially introduce further issues. Dixon-Woods et al. (2011 p.169) used the term ‘cargo-cult QI’ (informed by Feynman’s (1974) ‘cargo cult science’) to describe poor reporting of QI methods; failure to describe what activities were undertaken, what was achieved and how, and the challenges encountered. Feynman (1974) coined the phrase ‘cargo cult science’ to describe “practices that achieve the outward appearance of science but fail to yield meaningful results because they lack essential elements of the scientific method”. Braithwaite (2018) suggests there is often a preference towards optimism, or even a grandeur of delusion, when adopting QI initiatives. Implementation of QI practices, without full attention to key processual drivers, and, at times, fuelled by organisational pressures to make progress - ‘magic bullets and quick fixes’ (Alderwick et al., 2017) - creates a setting rife for cargo-cult QI (Dixon-Woods, 2014; Smaggus and Goldszmidt, 2017).

5.4.1 Quality Improvement in Mental Health Services

In their evaluation of QI in mental health services, Ross and Naylor (2017) concluded that whilst there were no fundamental differences in approach to QI methodologies (between mental health and other healthcare services), there is a pressing need to focus on QI in mental health trusts. Robertson et al. (2017) detail how funding cuts continue to pose challenges to the organisation of mental health care. Crisp et al. (2016), in an independently commissioned review, cite a host of issues that include access to evidence-based therapies, inadequate availability of inpatient care and a lack of clarity over expectations and outcomes. They suggest the adoption of QI methodologies to address some of the problems.

There is limited evidence of how QI practice has been undertaken in mental health services, with current evidence relying upon self-reported data. Poots et al. (2014) reported QI methods improved access to mental health services (though no evidence for improved clinical outcomes was found). Abdallah et al. (2016) reported improvement in service users’ engagement with physical health monitoring as a result of QI work. Brown et al. (2015) reported a reduction in the number of violent incidents on an older people’s mental health ward. Whilst service user involvement was noted in these examples, to what extent they were involved and in what aspects, was not necessarily clear. Ross and Naylor (2017, p.37) highlight three notable characteristics of mental health services which require consideration before QI work: 1) the community-based model of care, 2) diversity of provision of mental health and other related services, 3) history of service user and carer involvement in mental health. Visibly relevant to this latter point was one of the report's recommendations to harness the potential of co-production in QI; "this is one aspect of QI where there is considerable potential for mental health providers to innovate and to share learning with others across the health system" (Ross and Naylor, 2017 p.3).

5.4.2 The Role of Service Users in Quality Improvement

The involvement of service users in QI mirrors the collective democratic and technocratic rationale as described in Section 4.1. Service users have a legitimate stake in defining and creating value for services that they use. The involvement of service users can also help broaden the focus of QI to avoid the process being limited to professionals and their self-interests (Pomey et al., 2015; Fulop and Ramsay, 2019; Gremyr et al., 2021). The NHS mandate (2020) for service user experience and QI echoes an ambition of co-produced QI, whilst the CQC report, *Quality Improvement in Hospital Trusts* (2018), is also similarly vocal:

> "Putting the patient at the centre of the QI journey sharpens the focus on delivering high-quality patient care and aligning improvement activity to outcomes and experience for patients. To deliver this, patients must be involved and enabled as true and equal partners for QI." (p.4)

Whilst it is consistent for QI approaches to emphasise a 'service user focus', this is not guaranteed in practice (McIver, 2011; Robert et al., 2015; Böstrom et al., 2017). An uncertainty in how to orchestrate the involvement of service users in QI remains a concern (Wiig et al., 2013; Gustavsson et al., 2015; Böstrom et al., 2017; Bergerum et al., 2020; Williams and Caley, 2020; Locock et al., 2020; Robert and Donetto, 2020). Robert et al. (2015 p.2) note how approaches to involvement "continue to be hindered by a deeply engrained perception of patients and families as passive sources of data rather than active partners in implementing change”. Korttiesto et al. (2018) report how service users involved in the planning and management of services was less positively received by professionals compared to their involvement in individual care and treatment. The EBCD intervention, as described in Section 2.3.2, is specifically designed as a localised QI approach that involves service users and teams, and existing research has shown some success in involving service users across a range of clinical areas (Tsianakas et al., 2012; Donetto et al., 2014; Blackwell et al., 2017; Gustavsson and Anderson, 2017; Borgstrom and Barclay, 2019). However, not all healthcare services employ or have the capacity to adopt this specific long-term approach (Borgstrom and Barclay, 2019).

The findings from several QI studies (including EBCD) report how the involvement of service users has often been restricted to early stages of the QI process (Piper et al., 2012; Armstrong et al., 2013; Boaz et al., 2016; Bergerum et al., 2020; Locock et al., 2020). This conscious staging of service user involvement contrasts guidance which suggests for greater effectiveness that “involvement of service users should run through the full cycle of every QI project, as an integral part of the fabric” (Healthcare Quality Improvement Partnership (HQIP), 2016 p.26). In a QI evaluation of five hospitals, Vennik et al. (2016) reported involvement varied according to improvement theme. Exclusion of service users was documented where service users were believed to lack the necessary knowledge, when ill-health affected ability to participate, and when professionals felt enough input from users had been yielded. Armstrong et al. (2013) reported exclusion of service users in QI on the grounds of inability to understand the technicalities of the process. Clarke et al. (2017, p.9) noted how improvements (where service users were involved) were often limited to simple practical changes, “sweating the small things”. Though changes were positively received by participating service users, their involvement did not necessarily illustrate the high-impact vision that was targeted.

There is an argument to suggest the lack of service user involvement (in certain areas) may be due to legitimate concerns over the severity of ill-health. Moreover, not all service users will wish to participate. However, this may equally point to the ‘unpreparedness’ of services or highlight a professional skill gap in regard to facilitating involvement of service users in different ways (Amann and Sleigh, 2021). Smith (2020) notes how the involvement of service users should be facilitated early on in the process, in line to have a practical impact. Renedo et al. (2015) describe how service user involvement in QI requires new forms of practice and relationships between service users and professionals. QI has a broader but refined focus on service design, whereas service users' past experiences of involvement (where involved) may have revolved around research activities or care-based encounters (Pomey et al., 2015; Williams and Caley, 2020).

5.5 Clinical Microsystems Quality Improvement: The Evidence Base

The CMS approach to QI has been implemented in several areas that include general practice, community and inpatient mental health, specialised care unit, emergency and ambulatory care (Batalden, 2003; Nelson et al., 2007; Williams et al., 2009; Likosky et al., 2014; Gerrish et al., 2018; Abrahamsson et al., 2020; Côte et al., 2020). The development of CMS (along with other QI models) been supplemented by a proliferation of QI frameworks, guides and manuals. Despite this widespread implementation, the evidence base relating to the effectiveness of CMS approach remains unclear (Côte et al., 2020). This is not isolated to CMS, with a failure to develop a robust evidence base observed across the field of QI (Braithwaite, 2018; Bircher, 2019; Dixon-Woods, 2019a). Individual improvement projects often tend to report positive results but replicability of these to larger evaluation studies is poorly demarcated (Nicolay et al., 2012; Dixon-Woods, 2019a). Dixon-Woods (2019a) documents a host of reasons for failure to develop an evidence base, that include, the frequency of self-evaluated projects often using poor indicators, a reluctance to fund evaluations and conflict over what constitutes evidence for purposes of improvement.

Pertaining to the effectiveness of CMS, an independent evaluation of a series of pilot CMS projects (Williams et al., 2009) and a solitary systematic review (evaluating 35 studies) (Côte et al., 2020) represent the main sources of evidence (where multiple projects have been reviewed). The systematic review conducted by Côte and colleagues (2020) was undertaken with an intention to view how CMS approach met several dimensions of quality performance: 'quality of care and patient safety', 'patient expectations', 'interactional dynamics between stakeholders', 'appropriate learning strategies'. The review reported how the systematic nature of the CMS approach (with in-built theory) enabled a focus on frontline performance and allowed consideration of issues deemed ‘urgent’ by frontline teams. Studies included in the review namely reported higher quality and safe care, which was attributed to the involvement of different stakeholder groups (predominantly clinician involvement), flattening of hierarchies and alignment of systems; similar findings were reported in the much earlier study conducted by Williams et al. (2009).

At the same time, Côte and colleagues (2020) acknowledged various study limitations that include a number of studies being undertaken by the designers of the CMS approach (limited to a North American context and prone to the reporting of successful experiences), distinct heterogeneity across the studies in terms of design, outcome of interest and study population, and limits to data aggregation (owing to the different qualitative and quantitative outcomes used in respective studies). Both Williams et al. (2009) and Côte et al. (2020) documented barriers that include time for CMS, need for technical/technological support, data collection gaps and poor fidelity, competing priorities, pace of implementation and lack of leadership impacting upon stakeholder engagement. These are barriers that have also been reported across wider QI practice (Wiig et al., 2013; Hayes et al., 2014; Iedema, 2015; Dixon-Woods and Martin, 2016; Gremyr et al., 2021). Referring to the effectiveness of CMS, Williams et al. (2009, p.129) concluded that “given the multiplicity of ways in which CMS may be interpreted, the question is not whether CMS “works” as an improvement methodology, but instead is more nuanced relating to whom it works for, when and how”.

5.6 Summary

The process of QI calls for the combined efforts of various stakeholders to come together to make changes that will lead to high-quality care. The role of the service user in QI has received significant attention over the past decade and this is demonstrated by the modified QI formula (See Figure 4 p.53), which highlights the growing importance of service users to QI. However, there are important questions that need to be addressed within participatory spaces of QI e.g. how is quality being defined? what is the role of the service user in QI? what impact does involvement have in QI? Quality is a nebulous term whilst the service user experience component has often been side-lined in favour of more ‘objective’ markers of quality.

There are also broader questions concerning the uptake of QI despite the ever-growing interest. Current challenges in the practice of QI include lack of awareness, poor fidelity of QI mechanisms and mixed results in terms of the evidence-base. Within the implementation of QI approaches and methods, organisational context plays as big a role as does the involvement of service users. Organisations are crucial in forming the backdrop against which QI initiatives are played out. Social and cultural elements of the organisation, for example, the commitment and attitudes of key stakeholders are crucial for the success or failure of meaningful involvement (Contandriopoulos, 2004; Abelson et al., 2007; Renedo and Marston, 2011). However, mechanisms through which these or other elements of organisational culture can become resources for service users in their participatory role remain under explored (Renedo et al., 2015; Böstrom et al., 2017). Understanding these cultural characteristics, along with the various attitudes and behaviours of stakeholders involved, is vital, to move beyond ‘cargo-cult’ QI and create meaningful improvement that embodies a collaborative effort from multiple stakeholders (Dixon-Woods et al., 2011; Böstrom et al., 2017; Batalden, 2018).

CHAPTER 6

Service User Involvement, Co-Production and Epistemic (In)justice

> "Without attention to power and difference, engagement can lead to a lack of presence, presence without a voice, and voice without influence" (Pratt, 2019 p.46)

Policy and academic literature on service user involvement is heavily engaged with language of improving public services, empowering service users, advancing humans rights and so on. However, post-structuralist critiques argue this language can be used as a smokescreen to draw users into new fields of control and further illuminate the power dynamics at the heart of these processes (Lindow, 1999; Rose, 1999; Callaghan and Wistow, 2006). Power is a multifaceted concept with various theories contesting how power is created and mobilised (Farr, 2018). A neutral meaning of power cannot be found, since the meaning of power is always embedded in a theoretical context (Guzzini, 2005; O'Shea et al., 2019). Yet, an understanding of power is fundamental given the dynamics of the involvement process, where multiple actors with respective interests and knowledge converge (Donetto et al., 2015; Ocloo and Matthews, 2016; Farr, 2018; Mulvale et al., 2019; Pearce, 2021).

There is a need to explore the various actions, roles and relationships between stakeholders, and the differing claims to knowledge and legitimacy within which exchanges of power are conducted (Callaghan and Wistow, 2006; Pearce, 2021). Fundamental to the involvement of service users in the design and delivery of services is the degree to which their experiential knowledge is recognised as credible sources of information. The uniqueness of service user experiential knowledge was described earlier in Section 4.3. Co-production is underpinned by meaningfully sourcing and using multiple sources of knowledge (Hickey et al., 2018; Palmer et al., 2019; Groot et al., 2020). Creating meaningful spaces where service users can be involved is congruent with their "new epistemic identity as a knowledgeable and relational consumer" (O'Donovan and Madden, 2018 p.4).

Given the importance of knowledge recognition and mobilisation, the concept of epistemic (in)justice (Fricker, 2007) is particularly pertinent. A concise way to define epistemic justice is as “the proper inclusion and balancing of all epistemic sources” (Geuskens, 2014, p. 3). On the other hand, epistemic injustice refers to “a wrong done to someone specifically in their capacity as a knower” (Fricker, 2007, p.1). Focusing upon the epistemic aspects of knowledge recognition can yield improvements that are both inclusive and effective (Beresford, 2003; Caron-Flinterman et al., 2007; de Boer, 2021). Palmer et al. (2019) discuss how mechanisms of recognition and dialogue result in epistemic justice whereby the power of individual and group experience is reinforced. Respect for knowledge diversity i.e. acknowledging and accommodating various knowledge sources (academic, practical and experiential) is a core ethical and epistemological value of involvement efforts (Grim et al., 2019; Groot et al., 2020). However, in the absence of such supportive conditions, characterised by a lack of appropriate value and respect assigned to the voice of service users, the potential for epistemic injustice amplifies. Limited recognition or opportunities for service users to develop their knowledge are characteristics of broader power inequalities (Russo and Beresford, 2015; Rose and Kalathil, 2019; Massé et al., 2021; Pearce, 2021). Subsequently, the absence of epistemic justice can affect how service users are involved within the co-production and co-design of healthcare QI.

Prior studies have illustrated that epistemic injustice is a valuable concept to understand how service users face exclusion during the uptake of services (Carel and Kidd, 2014; Newbigging and Ridley, 2018; Schön et al., 2018; Grim et al., 2019). These studies have been mainly focused at the individual level of care with the concept of epistemic injustice helping to clarify problematic instances that arise during consultation e.g. a service user’s testimony about their symptoms not taken seriously by their healthcare provider because of their status. This thesis broadens the concentration of epistemic injustice to explore the integration of service user knowledge in co-production and QI. QI is a collective effort that involves multiple stakeholders with intention to deliver a broader impact beyond that of individual care. Moreover, the values and principles of co-production and service user involvement underpin a democratic right of service users to be involved in decisions that influence the services that they use. This thesis draws upon Miranda Fricker’s (2007; 2013; 2017) framework of epistemic injustice and interpretations of this concept that have been developed (e.g. Hookway, 2010;

Carel and Kidd, 2014; 2017;2018;2021; Grim et al., 2019) to guide research exploration. The following sections introduce the concept of epistemic injustice in more detail before focusing upon how this concept has been applied within the setting of healthcare.

6.1 Epistemic Injustice

Organisations, institutions and services are structured in ways that simultaneously strive towards epistemic values of truth, equality and understanding (Pohlhaus, 2017). Fricker (2013) suggests that epistemic justice may be better understood by recognising, rather, where injustices occur, "whose negative imprint reveals the form of the positive value" (p.1318). Epistemic injustice is "a specific form of injustice 'done to someone specifically in their capacity as a knower'" (Fricker, 2007 p.1). Epistemic injustice manifests where individuals and groups are excluded from epistemic practices with their capacity to develop, share or question knowledge being unfairly wronged. The epistemic character of injustice is grounded in the fact that when individuals and groups share their knowledge, they do so on the basis of this being informed by their lived experiences. In most circumstances then, this knowledge presents an accurate representation of one's feelings, opinions and thoughts (Hookway, 2010). Fricker (2017) clarifies that the epistemic injustices explored in her work are discriminatory rather than distributive:

> "My chief purpose in invoking the label [of epistemic injustice] was to delineate a distinctive class of wrongs, namely those in which someone is ingenuously downgraded and/or disadvantaged in respect of their status as an epistemic subject. This kind of epistemic injustice is fundamentally a form of discrimination, either direct or indirect." (Fricker, 2017 p.53)

Critical to Fricker's (2007) account of epistemic justice is an exchange of social power which can manifest in two forms: *agential and structural.* Agential power can operate actively or passively and refers to the capacity of agents (individuals, groups, institutions) to influence actions and behaviours in the social world. Structural forms of power operate in the absence of social agents, characterised by "the shared institutions, meanings and expectations" within the social world (p.12). Fricker (2007 p.14) broadens the analysis of epistemic injustice to accommodate ‘identity power’ which is exercised and dependant, in part, upon “shared imaginative conceptions of social identity”. Identity power can be agential or purely structural and can operate positively to produce action or negatively to constrain it. The importance of identity power, as Fricker (2007 p.17) emphasises, is:

> “…because of the need for hearers to use social stereotypes as heuristics in their spontaneous assessments of their interlocutor’s credibility. […] Notably, if the stereotype embodies a prejudice that works against the speaker, then two things follow: there is an epistemic dysfunction in the exchange – the hearer makes an unduly deflated judgement of the speaker’s credibility, perhaps missing out on knowledge as a result; and the hearer does something ethically bad – the speaker is wrongfully undermined in her capacity as a knower”

Attention to identity power enables exploration of who is able to develop knowledge, how this knowledge is shared and to whom, and whom stands to gain from sharing or listening to this knowledge (Fricker, 2007 p.90). Subsequently, epistemic injustice also closely resembles forms of social injustice, whereby marginalised social groups encounter unjust situations owing to the ‘credibility and intelligence’ of their knowledge coming under question. Fricker’s conception of epistemic injustice was borne from feminist standpoint theory (McKinnon, 2016) and also drew upon Foucauldian concepts of power (although rejecting the reductionist view of being unable to separate truth from power). For Fricker (2017 p.56), any starting point for philosophical analysis should commence at the interpersonal level:

> “What was needed, I believed, was something much more easily recognisable as making sense of the lived experience of injustice in how a person’s beliefs, reasons and social interpretations were received by others, even conscientious well-meaning others.”

6.1.1 Testimonial and Hermeneutical Injustice

There are two foundational kinds of epistemic injustice: testimonial and hermeneutical. An identity prejudice against one's social identity drives both forms (Anderson, 2012). Testimonial injustice refers to where "a speaker receives a deficit of credibility owing to the operation of prejudice in the hearer's judgement" (Fricker, 2013 p.1319). This type of injustice is largely perpetrated by individuals and pertains to when a prejudiced view informs decisions about '*whom is credible*' (Blease et al., 2017). A hearer's prejudicial stereotyping causes the listener to attribute a reduced level of credibility to a speaker's testimony than they otherwise would have given if the prejudice were not present (Carel and Kidd, 2014; 2017). This does not mean that the speaker is always disbelieved but may be taken less seriously. A vast collection of studies has identified the existence of negative stereotyping across various groups that include sex, gender and race. Testimonial injustice may lead to hermeneutical injustice (Fricker, 2007 p.162).

Hermeneutical injustice is characterised by structural tensions and the inaccessibility of speakers to make sense of their experiences due to the absence of conceptual resources. This leads to disadvantages for speakers in spaces of exchange and collaboration (Carel and Kidd, 2014; Byrne, 2020; Byskov, 2021). Such practice may also be described as hermeneutical marginalisation where disadvantaged groups are blocked, intentionally or unintentionally, from access to knowledge in comparison to groups possessing greater privileges (McKinnon, 2016). Epistemic privilege corresponds to status and embodies a certain degree of control and power: this is explored shortly. To summarise, hermeneutical injustices result in "a collective inadequacy of understanding" (Byrne, 2020 p.372) where the marginalised group encounters cognitive disadvantage, preventing them from making sense of their experiences.

i) Other forms of Injustice

Fricker (2013 p.1318) acknowledges epistemic injustice as an umbrella concept, which should be "open to new ideas about quite which phenomena should, and should not, come under its protection". Subsequently, the development of the concept continues (See, for example, Hookway (2010), Anderson (2012), Dotson (2012); Pohlhaus (2017)). Hookway (2010) proposes the exploration of epistemic injustices through informational and participant-based perspectives. The informational perspective mirrors the mainstream concept of testimonial injustice, whereby certain groups and individuals are not recognised as credible sources in the possession and sharing of knowledge.

A ‘participatory perspective’ is slightly different. Individuals not only fail to be seen as credible participants in knowledge sharing, but also in their ability to “ask questions, float ideas, consider alternative possibilities and so on” (Hookway, 2010 p.156). Grim et al. (2019 p.159) describe participant-based justice as where “not only that a person’s accounts are assessed with due credibility, but also that the person is acknowledged as ‘a contributor in knowledge-gathering practice’ and ‘a capable collaborator in shared inquiry’, as someone who can ask pertinent questions and recognise relevant information in problem-solving inquiries’’. An example of participant-based injustice, then, may be where individuals and groups are actively discouraged from taking part in certain types of activities or where their access is limited to particular areas.

6.2 Epistemic Injustice in Healthcare

The organisation of healthcare contributes to knowledge asymmetries through the selection and privileging of certain types of knowledge and styles of expression, making it “liable to generating epistemic injustice” (Carel and Kidd, 2014 p.534). Professional knowledge and expertise developed through years of medical training is assigned greater value and epistemic authority. This type of knowledge is heralded for being impartial, objective and better tailored towards evidence-based guidelines and measures. In contrast, the knowledge of service users, based on the social, physical and emotional effects of ill-health, has often been questioned on grounds of subjectivity, leading to and perpetuating “types of power imbalances that have traditionally excluded and alienated patients” (Bleakley et al., 2011 p.xiii). Crichton et al. (2017 p.67) posit how healthcare professionals have tended to “regard patients as objects of their epistemic enquiry rather than participants”.

Kidd and Carel (2018) group together testimonial and hermeneutical injustices, that occur in medical settings, as forms of pathocentric-based epistemic injustice (injustices linked to ill-health). Well-publicised examples of failings in care (e.g. Mid-Staffordshire NHS Hospital Trust) have occurred, in part, due to pathocentric epistemic injustices, where there has been serious failure to listen and respond to the concerns of service users (Kidd and Carel, 2021). The challenges of ill-health can affect epistemic agencies, confidence and capacities of service users (Beresford, 2013a; Carel and Kidd, 2017; French and Raman, 2021). Notwithstanding the debilitating effects of ill-health, certain groups of service users may require permission for everyday tasks whilst some groups dependent upon others (e.g. carers, family members) for care. Situations where autonomy and control are blurred can increase the susceptibility of service users to potential epistemic injustice.

Kidd and Carel (2017 p.184) describe two strategies through which service users are denied hermeneutical agency: 1) *strategies of exclusion*, excluding groups from practices "where social meanings are made and legitimated", 2) *strategies of expression*, whereby the groups' expressive style is "not recognised as rational or contextually appropriate". Service users wanting to share their lived experience lack the necessary concepts and resources to articulate their views. Moes et al. (2020 p.7) report how service users have had "meagre resources to produce the 'hard evidence' which they could make themselves intelligible leading to hermeneutical marginalisation and misrepresentations in collective preferences".

The lack of training, the use of non-expert language, and the behaviours of service users are incongruent with dominant medical expertise and 'professionalised forms of communication' (Carel and Kidd, 2017; Naldermici et al., 2020). In 'language games' that take place during professional-service user encounters, well-articulated speech is assigned greater credibility and value. This, then, can manifest into a certain preference for the involvement of particular individuals and groups, where "a type of social imaginary" takes place (Medina, 2011 p.32). Selected individuals are granted 'credibility excesses' which confers privilege and therefore greater likelihood of their testimonies being listened to ahead of others (Hutchison et al., 2017; Naldermici et al., 2020). Several tensions of service user involvement may be indicative of epistemically-toned unjust practices. Strategies through which injustices manifest may be implicit or explicit, but nonetheless result in the exclusion of groups from the very spaces that concern them (Knowles et al., 2021b).

6.2.1 Epistemic Injustice and Mental Health Services

People living with mental ill-health are susceptible to greater epistemic injustices (Lakeman, 2010; Crichton et al., 2017; Scrutton, 2017; Newbigging and Ridley, 2018; Kurs and Grinshpoon, 2018). There are deeply attached social stigmas and negative stereotypes attached to the use of mental health services. As described in *Section 4.3: Co-Production with Vulnerable Groups*, mental health services continue to be characterised by features of paternalism, containment, compulsion and irrationality (Bee et al., 2015; Millar et al., 2015; Le Blanc and Kinsella, 2016; Rose and Kalathil, 2019). Judgements of irrationality, in particular, can lead to service users being considered as lacking coherence, logic or credibility (Happell, 2008; Lakeman, 2010). It has been well documented how mental health service users report feeling left out or being excluded from decision-making spaces (Lewis, 2014; Le Blanc and Kinsella, 2016; Kurs and Grinshpoon, 2018). The consequence of deeply-rooted assumptions leads to a credibility deficit where service users are undermined in their capacity as credible epistemic knowers and contributors (Le Blanc and Kinsella, 2016; Crichton et al., 2017; Newbigging and Ridley, 2018).

6.3 Epistemic Authority and Privilege

Epistemic privilege has three interacting components. Professional privileges are gained as a result of medical training and development of specialist expertise which give authority to define concepts. This authority is sometimes warranted: when a service user arrives at a consultation with illness, they want to be looked after, and for highly-trained professionals to make decisions based on their specialist knowledge of disease. (Greenhalgh et al., 2015; Wardrope, 2015). A second component of epistemic privilege is where certain individuals are responsible for controlling who is included within epistemic exchanges. The third component of epistemic privilege is concerned with the ‘power of decision’, in that someone is ultimately responsible for having the final decision on a particular issue. Carel and Kidd (2014) give the example of a healthcare review committee and how decisions are made in regard to who is selected to participate and what roles are adopted (who acts as the chair and so forth). This example can be similarly extended to the practice of QI: whom is granted a ‘seat at the table’, whom is denied, and where involved, what roles and responsibilities do individuals have. In these organised settings, service users traditionally lack epistemic authority despite experiencing a level of privilege. Service users gain privilege through having unique, first-hand knowledge of their situation which others do not possess (including healthcare professionals). However, professional knowledge is assigned higher epistemic status and therefore authority.

There has been discussion over the degree of consciousness and deliberateness in the actions of epistemic injustice (Carel and Kidd, 2014; Fricker, 2017). Fricker (2017 p.54) describes how testimonial injustice occurs as a consequence of “discriminatory but ingenuous misjudgement” rather than deliberate manipulation or individual intent. Within healthcare, Carel and Kidd (2014 p.536) point out that issues of agency operate within complex background arrangements that are constraining for both service users and healthcare professionals:

> “We do not suppose that culpability for epistemic injustice should be placed at the feet of healthcare practitioners; for instance, the attitudes and actions of those practitioners will be shaped by particular models of the patient-clinician relationship which they were trained in or are required to operate with.”

Yet, Fricker (2017 p.58) warns that “non-deliberateness does not entail non-culpability”. In this sense, Carel and Kidd (2014) point to an ignorance and failure to engage with frameworks which aim to include service users as equal epistemic agents; Pohlhaus (2012) describes this as ‘willful hermeneutical ignorance’. For example, professionals may attribute challenges of service user involvement to workforce issues and a lack of resources. However, ignorance may be observed if professionals actively fail to pursue avenues to develop their knowledge around service user involvement and related concepts. In this manner, professionals may be unwillingly epistemically unjust in their actions.

6.4 Summary

Fundamental to the involvement of service users in the design and delivery of services is the degree to which their experiential knowledge is recognised as credible sources of information. Co-production is underpinned by meaningfully sourcing and using multiple sources of knowledge (Hickey et al., 2018; Palmer et al., 2019; Groot et al., 2020). Subsequently, viewing practices of service user involvement and QI through an epistemic lens may provide a greater understanding of the power asymmetries underpinning these processes. As has been discussed, the generation of epistemic injustice in healthcare is likely greater given the organisation of healthcare, the stereotyping attached to ill-health and the status and authority assigned to professional knowledge. Furthermore, ill-health can affect epistemic agencies, confidence and capacities of service users. Within mental health services, stigma and negative stereotypes attached to individuals and groups leads to even greater epistemic injustice, where service users are excluded from knowledge-producing spaces. Addressing these deficits, then, are important if collaborative and democratic ambitions of service user involvement and co-production are to be realised in QI.

CHAPTER 7

Research Methodology and Methods

This chapter describes the research methodology and the methods used to collect and analyse data. In doing so, it attempts to justify research decisions whilst providing an overview of how the research process was navigated. The principle focus of this research was to explore the understanding and interpretation of the following concepts, service user involvement, co-production and QI, before examining practice to see how these were reflected in action.

This chapter begins with a background to the study. Second, the philosophical assumptions underpinning this research are presented and how this informed the methodological approach taken; notably, the research adopted qualitative methods within exploratory case study research. Third, details are provided regarding the selection of cases owing to a particular interest in the area of mental health and disability. In the final sections of the chapter, data collection and analysis methods are presented, ethical considerations are reviewed and a reflexive summary of the research process is offered. It may become clear through reading this section how pragmatic decisions were made during the period of the research; research in practice may not necessarily run as smooth as one plans and hopes. As such, I reflect upon the research journey with the aim of offering a fair and honest description.

7.1 Background

7.1.1 Setting the Scene

The design of this study was predominantly an academic endeavour led by discussions between myself and the supervisory team. Conversations with the QI partner were helpful in familiarising myself with the CMS QI process, providing access and helping to connect with local CMS teams. At the beginning of the studentship, for example, I shadowed a QI coach across acute healthcare settings as they worked with individual teams to drive service improvement. During this period, I also attended the trust-wide QI introduction course delivered by the collaborative partner to healthcare staff. This series of actions provided orientation around CMS methodology. As a result, I did not approach the research completely blind, with some prior understanding of how teams are expected to engage with the CMS process e.g. design and frequency of meetings, nature of improvement projects, understanding of QI language. Conversations with the research partner lead at the beginning of the research were also important to understand what organisational learning had already taken place and the Trusts' ambitions towards CMS QI. For example, it was an ambition for each team in the Trust to prioritise service improvement, and where feasible, utilise CMS methodology to help drive service improvement efforts; importance was placed on individual teams being able to drive their own improvement. The pre-research groundwork undertaken provided important context before the research commenced.

Whilst there was a practical element to the research, I also recognised that there was a space to contribute to academic debates around service user involvement and co-production that were developing (across various disciplines including psychology, sociology and management). Beginning with a wide remit of understanding how CMS teams involved service users in QI work, the research focus was narrowed through engagement with the literature, interaction with the field and discussions with the supervisory team. Through a review of the literature, I was drawn to the various debates regarding the involvement of service users, and the space in which more 'recent' forms of co-production and co-design were beginning to emerge. It also became apparent how the concept of power was central to current narratives of involvement. After all, ambitions to involve members of the public are couched in language of power: equality, reciprocity, ‘with’ rather than ‘for’.

7.1.2 Study Aims

I was interested, with this research, to understand how practice of service user involvement, co-production and healthcare QI was understood and constructed by stakeholders responsible for organising, managing or participating in such activities. This was then followed by an intention to see how ‘co-production of QI’ was operating in practice: ‘what is actually happening?’, ‘how are service users involved?’, ‘what type of actions are they involved or not involved in?’, ‘what are the different discussions take place in regards to the involvement of service users?’ In light of existing research and the developments of these concepts, I argue these are important questions to ask in order to understand how service users can play meaningful roles in QI as appears to be the ambition. This knowledge may help maximise improvement efforts by highlighting the facilitators of good practice. Equally, it may highlight the barriers and challenges which need to be understood if ambitions for the involvement of service users in the design and delivery of services are to be realised. The research was led by the following questions:

- ***Research Questions***

Research Question 1
How are the concepts of service user involvement, co-production and quality improvement constructed and understood by key stakeholders?

Research Question 2
How do the processes of quality improvement initiatives shape the roles and contributions of service users?

- ***Aims and Objectives***

The following aims and objectives underpinned the approach to answer research questions:

- Compare ambitions of service user involvement and co-production in QI against what is happening in reality
- Explore how understanding of concepts translates into approaches adopted in practice
- Describe the various processes and structures influencing practice
- Assess the influence of organisational context (vision, infrastructure, culture, commitment) within QI
- Examine the relationships and spaces in which dialogue and learning takes place

This section has provided an overview of the research background and highlighted the intentions of the research. The next section moves onto the philosophical underpinnings of this research. A short introduction into concepts of epistemology and ontology is offered before describing the theoretical stance taken in this research and how this influenced the design of this research study.

7.2 Philosophical Position

All research has a philosophical foundation relating to how knowledge is generated, developed and mobilised (Bryman, 2012). As such, researchers are called to conduct a period of 'theoretical groundwork' before commencing research where they reflect upon their assumptions, belief systems and theoretical perspectives (Symon and Cassell, 2012; Willig, 2013). By specifying the positions taken in this research study, I hope the reader will be able to make their own judgements about the validity of the research undertaken.

A paradigm or worldview is defined as a basic set of beliefs that guide action (Guba and Lincoln, 1994). Epistemology is "the study of the nature of knowledge and the methods of obtaining it" (Burr, 2003, p. 202). Epistemology is concerned with research-oriented questions like 'how can I go about gathering knowledge about the world?' and 'how do I know what I know?'. Ontology, on the hand, concerns the nature of the world – 'what is there to know?' (Guba and Lincoln, 1994 p.108). There are a number of different philosophical perspectives making straightforward classification difficult (Guba and Lincoln, 1994; Burr, 2003; Creswell, 2009; Willig, 2013). Guba and Lincoln (1994) describe four research paradigms: positivism, post-positivism, critical theory and constructivism. These philosophical paradigms may be further mapped within a positivism (realism) - relativism continuum. Positivism follows that knowledge production progresses though direct observation of concrete phenomena. On the other hand, relativism considers that 'facts' only gain 'truthfulness' after significant discussion, and knowledge cannot be objective or detached from the phenomenon under investigation (Symon and Cassell, 2012). However, Burr (2003) notes this continuum is more fluid in reality with many subtle variations and overlaps rather than the rigid formation of two sharply divided camps.

In this research, I draw upon a social constructionist approach. The epistemological and ontological stance within this approach drives research that is subjectivist and relativist in nature: this follows that there are multiple truths and their representations can be captured through interaction (Guba and Lincoln, 1994; Bryman, 2012). In respect to the study population, I appreciate that the knowledge and actions of different stakeholders are influenced by their everyday lived experiences, and that this will lead to different conceptualisations of the same phenomena (Denzin and Lincoln, 2005). Moreover, stakeholders' views and perspectives are generated before, during and after the research. The research, in itself, is a way of capturing some of the lived realities of stakeholders through interaction, before trying to make sense of why things are the way they are. Furnival (2017) describes how healthcare quality, safety and performance are often highly subjective and value-laden concepts that can be conceptualised in different ways depending upon the position of the stakeholder.

Given the intention to interact with a diverse group of stakeholders, professionals and service users, and to understand the different perspectives and locate findings within their natural settings, a social constructionist approach was appropriate for the aims of this research (Guba and Lincoln, 1994). In addition to this, I was also interested in the inherent power relations that underpin how people make sense of their actions, and how they are able, or unable, to contribute in constructing reality. In summary, the social constructionist position taken was seen as an appropriate paradigm, aligning my assumptions and worldviews with the intentions of the research. At the same time, I also respect that other researchers may present equally valid and non-contradictory explanations of the same phenomenon (Hammersley, 2013). Section 7.2 has described the philosophical underpinnings of the research. It has provided a summary of my background to highlight research motivations, before moving onto detailing the philosophical position adopted in this research study. The following section(s) now advance discussion to explain the research methodology and the methods used in the research.

7.3 Qualitative Case Study Research

Considering the aims and objectives of this research along with my philosophical assumptions, a qualitative case study approach was selected. The decision to adopt a case study design was guided by the empirical and exploratory nature of the research as well as pragmatic reasons. My research was interested in understanding the role of service users in the CMS QI process and how relevant stakeholders - 'those closest to the process' - made sense of this course of direction. Subsequently, the research focus was concentrated on the "perspectives of those being studied rather than prior concerns of the researcher" (Bryman, 2012 p.47). By using qualitative inquiry, I was interested in exploring how persons interpret, construct, and attribute meaning to their experiences (Merriam and Tisdell, 2016). Therefore, guiding research exploration was an intention to offer a view of what was going on before advancing this focus to make theoretical claims and generate new insights (Bryman, 2012).

The collaborative nature of the project naturally bore some influence on the research design. A focus on CMS methodology had been determined prior and the collaborative partner was also expecting deliverable outputs from the research: learning more about CMS practice, how CMS teams were engaging with QI work, and how the process could accommodate the role of service users. Given my interests, as discussed in Section 7.1, I wanted to locate the research exploration in settings delivering services for particularly vulnerable groups. In addition, I intended to observe the CMS QI process over time in all of its particularities, employ a range of methods to guide research exploration and assess who did what and why (Creswell, 2009). Yin (2014, p.1) adds how "case studies are the preferred strategy when 'how' and 'why' questions are being asked, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real life context". Subsequently, in light of these arguments and research aims, a qualitative case study approach was favoured.

i) Embedded Case Study Design

An embedded single-case study design was used to explore the process of CMS QI in action. Within an embedded design, subunits reside within the main unit (Yin, 2009). The main unit in this case study was the participating UK-based Trust – 'Cranton' - whereas the subunits of analysis were two healthcare departments: 'Oston' and 'Dexton'. Much of the direction, support and training around service user involvement, co-production and CMS methodology for individual teams, often came through centrally organised Trust channels. Yet, nested cases allowed greater reflection and more intensive focus on what was happening in practice.

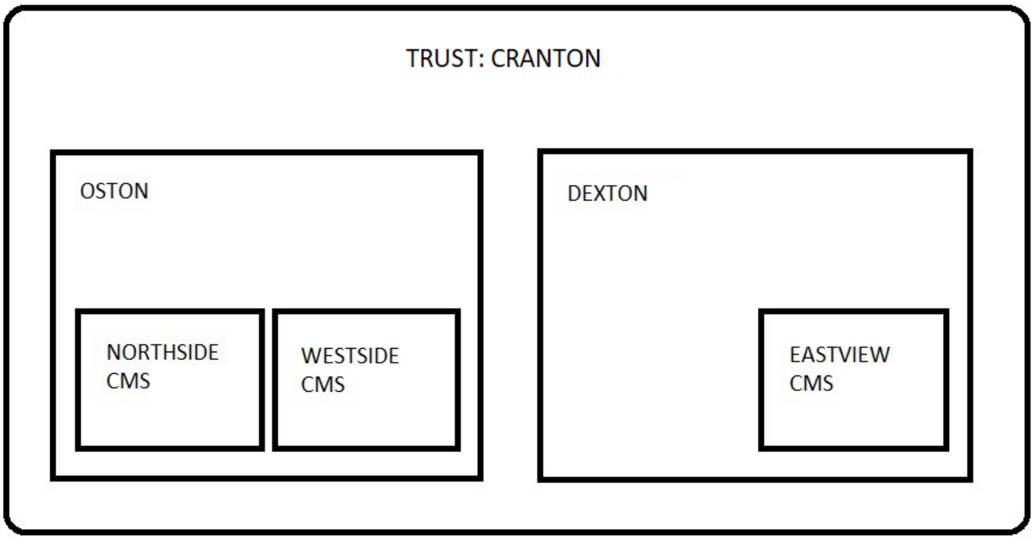
ii) Selection of Sites

Provisional access to the main case site had been granted pertaining to the collaborative nature of the project. Cranton Trust delivers services covering specialities of mental health, disability and learning difficulties. Additional decisions over the selection of CMS teams included whether CMS methodology was being used. Where this was visible, it was expected that teams had been using the methodology for a period of greater than six months. This meant the research was not solely concentrating on how teams were getting to grips with the process. Another key selection criterion was the extent to which service users were involved in CMS teams. This narrowed the selection of possible cases (indicative of wider study findings). Eisenhardt (1991, p.622) notes how debate over number of cases can be obscuring:

> "The concern is not whether two cases are better than one or four better than three. Rather, the appropriate number of cases depends upon how much is known and how much new information is likely to be learned from incremental cases"

In this manner, information-orientated strategies (purpose, time frame, study population, accessibility) guided site selection rather than randomisation (Emmel, 2014). Several discussions took place with the Trust Continuous Improvement Lead who was involved in coordinating many of the service's CMS teams. Two cases were identified: 1) A community-based neurological conditions service - Oston, 2) An inpatient mental health rehabilitation unit - Dexton. Oston constitutes three integrated services with each team using CMS methodology: 1) Northside CMS 2) Westside CMS – an administrative team, 3) Southside CMS. Oston has one CMS team – Eastview CMS. Preliminary meetings gathered insight into the 'suitability' of teams e.g. range of service user involvement, frequency of meetings, and team engagement with the process. Following positive discussions with CMS teams, it was decided that all three Oston-based teams (Northside, Westside, Southside) along with the single Eastview team would be followed. However, just before the research commenced, the Southside CMS team paused their CMS process for an indefinite period of time and it was decided to remove this team from the research; further details are provided in Section 7.7. The final embedded case study research design is summarised below in Figure 7. Details of participating CMS teams are further presented in Table 1 (p.92):

Figure 7: Embedded Case Study Research Design



Eisenhardt (1989) and Yin (2014) note two considerations when selecting sites as cases: cases have to be selected because they exhibit or are likely to exhibit variations in the mechanism under scrutiny or its context, whilst comparative work is more effective if something is already known about the generative mechanism(s) involved. Contextual differences between the two services and across teams initially appealed to the research:

- Nature of clinical area - traumatic brain injury and mental health rehabilitation
- Community-based vs. inpatient service
- Size of teams and range of staff groups involved
- Period of participating in the CMS process

The research approach slightly deviated from a strict comparative-case approach. It became clear from initial discussions and field observations that the involvement of service users still presented somewhat new territory across teams. Therefore, it made sense to approach the research in a manner where a wider understanding and practices of service user involvement and co-production across descriptive case sites became the focus. Nonetheless, the embedded research design had strengths in allowing the examination of CMS process across multiple teams, and comparing similar and contrasting results (Yin, 2014).

iii) Generalisability

Generalisation is broadly understood as the ability to draw conclusions about some general phenomena and extend this consideration to other cases (Mills et al., 2013). Qualitative case study research may be criticised for failing to produce results that are 'formally' generalizable and replicable. However, this stance comes from a positive standpoint, which this thesis, as noted in Section 7.2.2, rejects. Furthermore, it could be argued that 'formal' and 'logical' labels of generalisation can be deterministic and too inductive, failing to accommodate the intricacies and nuances (the 'depth') of research (Lincoln and Guba, 2009; Hammersley, 2013). 'Formal' generalisation, for example, fails to take into account the role of the researcher, who influences the study through adopting different positions and carrying out a range of actions.

This research progressed with the intention of providing rich and detailed accounts of phenomena in order to allow readers to make sense of the particularities and conclude whether findings are 'transferable' (Lincoln and Guba, 2011): Case study inquiry is "carried out so that certain audiences will benefit – not just to swell the archives, but to help persons towards further understandings" (Stake, 2011 p.19). Subsequently, although understanding that this study may not meet conventional features of generalisation, the study hopes to generate possible theoretical inferences through identification of relationships in the findings (Gomm et al., 2009). On this note, I argue certain findings raised in the research contribute empirical and theoretical understanding (e.g. understanding and language, experiences of practice, dynamics of power), which should be viewed through a broader lens with possibilities of being applied more widely (Gillham, 2000). The research study was also undertaken with a purpose of meeting particular objectives as defined with the collaborative partner.

In light of the above discussion, several features of the study design need to be made clear. The study takes place in a single UK-based Healthcare Trust where CMS represents the trust-wide methodological approach to QI. The particularities of this single case possess specific characteristics which may differ in other settings. For example, several QI methodologies exist and it is possible that these propose alternative methods of practice e.g. different ways of involving service users or engaging teams in the process. Moreover, wary of the potential overlap of healthcare activities, the focus of this research has been on the methodological and systematic processes of QI that utilises various tools and techniques to develop and test solutions (Backhouse and Ogunlayi, 2020; Shah, 2020). Latterly, the research also takes place within services delivering long-term chronic care meaning they may be organised differently from more acute care settings.

Table 1: Details of Participating CMS Teams

Oston		
Northside CMS	**Context:** *Reintegration of service users back into the community after a diagnosis of traumatic brain injury* **Professional Groups:** *Physiotherapists, Occupational Therapists, Speech and Language Therapists, Therapy Assistants, Clinical Psychologists, Administration Staff* **Team:** *6-10 Staff Members, Two Service User Volunteers (joined Month 7 and 8): in-person attendance*	**CMS Meeting Format:** *2hr-monthly meetings* **CMS Projects pursued over research period:** *- Improve use of clinical IT system (SystmOne) to streamline methods of communication between staff and service users* *- High and Low Complexity Work Streams (co-ordinating service user care across range of professionals seen)*
Westside CMS	**Context:** *Supporting service users with neurological conditions/brain injury by linking the relevant services and their care needs together* **Professional Groups:** *Case Managers, Psychologists, Administration Staff* **Team:** *4-5 Staff Members, One Service User Volunteer (contact through email)*	**CMS Meeting Format** *1hr-fortnightly meetings* **CMS Projects pursued over research period:** *- Improvement of care plan documentation: produce version of service users' complexity profile document*
Dexton		
Eastview CMS	**Context:** *Inpatient support service for service users with long term mental ill-health. Assist residents with preparing to leave the service or maintain level of recovery* **Professional Groups** *Nurses, Psychiatrists, Psychologists, Occupational Therapists, Music Therapists* **Team** *6-8 Staff Members*	**CMS Meeting Format:** *1hr-fortnightly meetings* **CMS Projects pursued over research period:** *- Introductory site brochure for potential new service user residents: what new residents can expect at the service*

7.4 Research Methods

Qualitative research methods were used in this study: semi-structured interviews, non-participant observations and analysis of key documents.

i) Semi-structured Interviews

Semi-structured interviews were conducted in two phases: 1) Key informant interviews, 2) One-to-one interviews with members of CMS teams. These phases were conducted side-by-side. A key informant phase (N=16) was conducted with key stakeholders involved in, or having extensive knowledge of service user involvement, co-production and QI activities. Interviews were conducted with persons from the Trusts' Senior Executive Team, Continuous Improvement and Service User Experience Teams, Service User Engagement Group, QI leads and collaborating third sector partner leads. Key informant interviews were important to 'set the scene' and locate ideas within organisational aims, expectations and motives (Lindlof and Taylor, 2002). Interviews lasted between 60 to 90 minutes.

A second set of interviews (N=10) were conducted whilst observing CMS meetings: Northside CMS team (N=5), Westside CMS team (N=3), Eastview CMS team (N=2). In this set of interviews, participants were asked to reflect upon their experiences of service user involvement, co-production and the CMS process. These interviews further served as valuable opportunities to clarify issues that had been observed in meetings. Interviews lasted between 45 to 75 minutes. Given the size of CMS teams, the intention was carry out four to five interviews per team. This said, not everyone wanted to be interviewed for various reasons whilst service users were largely absent within the CMS process. Cancellation of meetings and irregular attendance of team members also meant it was difficult to establish rapport with teams; this was particularly the case within the Eastview CMS team.

Eight of ten interviews (in the second localised phase) were conducted with CMS staff team members. The remaining two interviews were conducted with two long-term Northside service user volunteers. Although they were not involved within the CMS process (the original remit of interviews), both volunteers were heavily involved within the service's PPI group in which the progress of the CMS teams and volunteer recruitment were often discussed. These interviews also offered a view into the culture of involvement within the service e.g. provision, opportunities, training. Given that interviews were combined with other sources of data collection, the number of interviews (N=10) in this second phase represented a sufficient number with additional interviews only adding marginal knowledge (Eisenhardt, 1989). Many of the introductory questions asked (i.e. understanding of concepts) were similar across both types of interviews. There was some divergence with team-based interviews where questions reflected some of the researcher observations of CMS meetings.

Semi-structured interviewing was used to allow responses to key questions that I had formulated, but also questions to emerge from the conversation itself. In two interviews, for example, participants shared materials in respect to service user involvement and co-production, which the flexibility of a semi-structured approach allowed. Interview topic guides were developed from areas identified within the literature, beginning with general questions before "funnelling" into more specific areas of interest (Smith, 1995). Broadly, the interview was separated into 1*) understanding of concepts, 2) expectations and experiences of practice, 3) further development and possible changes.* The interview schedules are presented in Appendix 1. Key informant interviews took place at locations based on participants' preferences, often in personal offices or meeting rooms at the Trust headquarters. Interviews conducted with CMS team members took place at the case site in a separate meeting room and usually after a CMS meeting. Before the interview, research aims and the topic guide were discussed with participants given an opportunity to ask questions about the research. A short period was set aside to reflect on the interview experience once it had finished. Details of interview participants can be viewed below in Table 2 and 3 (p.97 and p.98). Research participants have been assigned a pseudonym to protect identity.

ii) Non-Participant Observation

Non-participant observation was used to follow CMS teams as they carried out service development activities in meetings. I observed 22 CMS meetings over the research period: Westside CMS (N=8), Northside CMS (N=7), Eastview CMS (N=7). Service PPI meetings were also observed within Westside CMS (N=2) and Northside CMS (N=2) teams; these two-hour meetings took place every three months. Overall, 40 hours of meeting observations were carried out. Observations of meetings was important to ground research questions in empirical understandings and experiences. This enabled focus on the various discussions taking place, insight into the topics and issues pursued, and how decision-making processes were made - 'what is being said, what is being seen, what is being done' (Silverman, 2016). In addition, observation of service PPI meetings provided key insight into the respective teams' approaches towards service user involvement and co-production.

The conduct of observations was influenced by a three-stage funnel process (Liu and Maitlis, 2012): 1) *descriptive observation* to map out the setting, 2) *focused observation* to pay attention to 'interesting' discussions, 3) *selected observation* to explore relations between these chosen themes of interest. Field notes were taken during meetings to record what had been observed. I decided not to use audio or video recording material for meetings, considering this too intrusive. Field notes allowed capture of key incidents and exchanges during meetings with the ability to revisit this data after fieldwork had finished. Where key exchanges occurred, field notes attempted to capture near verbatim quotes of what people said. Field notes were also further informed by my reflections which were recorded immediately after meetings had ended.

iii) Document Analysis

A third qualitative method, document analysis, was used alongside interviews and observational data. Document analysis was an on-going process throughout the duration of the study as it was important to account for new releases of information. Analysis of key documents helped to provide background information and contextualise research within the setting (Bowen, 2009). As Merriam (1988, p.118) points out, "documents of all types can help the research uncover meaning, develop understanding, and discover insights relevant to the research problem". I analysed relevant Trust reports (published between 2016-2020): this included publically available documents such as the Annual Plan, Quality Improvement and Assurance Strategy, Quality Report, Service User Engagement and Experience Strategy, Volunteer Policy. I also analysed key documents pertaining to CMS methodology and respective teams’ progress. Minutes of CMS and PPI meetings were also an essential source of information allowing me to clarify observational notes, track progress of teams and record points of action (between meetings).

Table 2: Details of Interviewees in the Key Informant Phase

Key Informant Interviews		
Name	**Role(s)**	**Based**
David	Chief Executive	Cranton
Jane	Deputy Medical Director	Cranton
Daniel	Non-Executive Director (additional roles: Co-Chair of a National NHS Strategic Mental Health Oversight Group). *Lived experience of MH services.*	Cranton
Ian	CMS Programme Lead	Cranton
Rachel	Continuous Improvement Manager and QI Coach	Cranton
Michelle	Co-Chair of Trust's Service User Engagement Group	Cranton
Levi	Engagement Manager	Cranton
Emma	QI Fellow and QI Coach	Cranton
*Nathan	QI Fellow, QI Coach and Patient Safety Investigator	Cranton
*Thomas	Trust QI Facilitator and QI Coach	Cranton
Nancy	Service User trained CMS coach	Cranton
Eve	Service User CMS volunteer	Cranton
Edward	Lived Experience Educator (additional roles: Service User Representative of a National Mental Health Professional Body). *Lived experience of MH services*.	Cranton
Maureen	QI Lead	*Sirville
Rebecca	Head of Co-Design & Improvement	*Sirville
Joanna	Participation Co-ordinator	*Tanview
** In addition to holding key QI roles within the Trust, Nathan and Thomas were also QI coaches of the Eastview CMS team. Both were interviewed in two respects: 1) Key informant, 2) QI coaches of the Eastview CMS team being observed* ** Sirville is a local housing charity that works closely with Cranton Trust* ** Tanview is a local mental health charity that works closely with Cranton Trust*		

Table 3: Details of Interviewees in the Team-based Phase

CMS Team-based Interviews	
Service - Oston	
Northside CMS Team	
* Simon	QI Coach
Adam	Staff Team Member
Lauren	Staff Team Member
Jason	Staff Team Member
Northside PPI Group	
Aisling	Service User (Carer)
Eric	Service User
Westside CMS Team	
* Simon	QI Coach
Victoria	Staff Team Member
Ruth	Staff Team Member
Service - Dexton	
Eastview CMS Team	
Nathan	QI Coach
Thomas	QI Coach
** Simon was the QI coach for both Northside CMS and Westside CMS teams. The interview conducted was separated into segments to allow for reflection on each team separately*	

7.5 Analytical Approach

The choice of analytical approach in this research was guided by the project's purpose and the alignment of my philosophical assumptions, research questions and methods. My intention was to make sense of the ambition of co-production and QI, capture participant's perceptions and experiences, and observe what was happening in practice. Doing so, I hoped to provide a coherent interpretation of the data that would generate significant insight.

My analytical approach in this study, then, to all extent, was informed by a thematic approach. In particular, I drew upon the analytical approach described by Hammersley and Atkinson (2007), which aims to identify and develop patterns and themes in the data to produce higher level analytical outputs that provide a reflection of the data collected. Describing this approach as 'grounded theorizing', the authors discuss how data analysis is an iterative approach that requires constant interplay between data and ideas throughout the research process. My analytical approach also utilised a constant comparative element (Glaser and Strauss, 1967; Hammersley and Atkinson, 2007) in order to compare and examine data items with one another.

In conducting data analysis, Hammersley and Atkinson (2007, p.162) note how the researcher should rely upon their "theoretical muse" above anything else. This more flexible process combines a host of analytical choices and therefore may not be seen as a distinct stage of the research. In this respect, my analysis began in the pre-fieldwork phase when formulating research questions which were embodied in my ideas and 'hunches', and which naturally developed during the conduct of fieldwork e.g. field notes captured what was being seen and discussed, but were also developed through my own reflexive thoughts of what I thought had gone on e.g. discussion of service user involvement by teams in my presence as someone specifically there to research these phenomena or the short informal interactions that took place after the cancellation of CMS meetings. I felt such data was imperative and wanted the analytical process to be able to capture this: "not only what is being told, how it is being told and the conditions of its being told, but also all the data surrounding what is being told" (Glaser, 2001 p.145). In this respect, Van Maanen's (2011) three task delineation - fieldwork, headwork and textwork - was also helpful as a means to make sense of the different research intricacies in light of the study's research objectives.

The 'first' phase of data analysis involved organisation of the data followed by data immersion. Data collected in the research was inputted into the coding software programme NVIVO 12 which provided a location to store and easily move between the data set. Observational notes of meetings had been electronically typed, whilst I had self-transcribed interviews verbatim feeling this was necessary to get a sense of 'what was going on in the data'. I initially organised interview transcripts and other data sources by participant group and site (CMS teams, senior executive teams, service users) in order to facilitate an understanding of the similarities and differences in perspective between groups. During data immersion, I listened to audio recordings of interviews, read each transcript several times and checked back against recordings for 'accuracy'.

A period of data immersion was followed by the generation of codes, which was guided by an inductive approach (Saldana, 2016). This inductive approach was data driven as I was not attempting to fit the data into any pre-existing coding frame at this point but rather be led by 'interesting', 'new' and 'unusual' interpretations. The analysis was guided by a hybrid format that explored codes at a latent and manifest level, with same coding used across all stakeholder groups. This, for example, meant using participants own words to provide a descriptive outlook (manifest), but also looking to identify hidden meanings within the text (latent) (this, I appreciate, derived from my reading of the literature) (See Table 4 below).

Table 4: Example of Latent and Manifest Coding

Type of Coding	Excerpt	Code
Manifest	*"I think it all means involvement really, there are these **buzzwords that you hear all the time like co-production**"*	Co-production is a buzzword
Latent	***"we'll frequently compromise** on what data we are collecting [during the QI process]"*	Poor fidelity to QI method

I coded using the ‘free node’ tool (on NVIVO), and after some extensive refinement, I had identified 36 categories (with various sub-categories), containing between 18 to 320 coded excerpts (‘references’). I went back into each interview transcript again, and compared ‘significant’ categories (with greatest references) identified across the different professional groups and service users to get a sense of similarities and differences, noting particular points of contention (using a comparative approach). I then looked at these categories one by one (on NVIVO), exposing me to the data as organised on a thematic level, moving back and forth from an individual and team view. I wrote a summary of each category to assist my own thought processes, which detailed key points, shared views across groups or key points of contention e.g. lack of time for QI work was construed differently between frontline staff and senior level of staff.

At this point, I returned to my topic guide to assess the fit between identified categories and the research questions, and which followed a process of grouping categories under different domains (See Appendix 2a) In this respect, then, the topic guide acted loosely as a priori framework. This I felt was necessary in preparation for writing the analysis with an appropriate structure that captured the various intricacies but also showed the linkage between categories. For example, my first research question concerned the understanding and experience of concepts such as service user involvement, co-production and QI. This was split into two parts: *1. Understanding, Expectations and Purpose,* and *2. Experiences: 2i) Positives of QI/Service User Involvement/Co-production work, 2ii) Tensions related to QI/Service user involvement/Co-production work.*

My second research question was more focused on service user inclusion and exclusion in the CMS process, drawing more on the observational work that had been conducted and reflection on field notes. It has become visible early on that service users were unlikely to be involved in meetings. My field meeting notes were analysed with a ‘lighter touch’, and rather used to compare my interpretations with what was being said and the categories that I was identifying. Subsequently, categories were grouped under *1. Barriers to engagement (Absence of Service Users), and 2) Conditions for Involving Service Users in QI (Presence of Service Users).* Some overlap in matching categories was observed although this was expected e.g. barriers to service user engagement and exclusion of service users in the CMS process raised similar tensions. I also took various steps beyond coding data and refining nodes that helped me to visualise and better conceptualise the relationship between analytical constructs. For example, I used loosely informal situational maps to guide my thought processes (also using readings derived from the literature) and further help map out an appropriate structure for presenting the analysis (Hammersley and Atkinson, 2007) (See Appendix 2b) e.g. mapping out the sub-categories and their respective linkages, along with my interpretations.

The analysis of the data is presented distinctively in an outwardly-facing direction (in the following chapters) to reflect the ordering of the research questions and hopefully present a logical flow which makes sense and can be easy to follow. In this respect, the presentation within each chapter moves gradually from a descriptive to a more analytical focus. This is also more noticeable across the chapters:

Chapter 8 - The Construction of Quality Improvement

Chapter 9 - The Construction of Service User Involvement and Co-Production

Chapter 10 - The Absence and Presence of Service Users in Quality Improvement

Within these findings chapters, data synthesis and contextualisation takes places with data cross-referenced to key discussions identified and presented in the literature e.g. QI theory, psychological safety, dynamics of power, framework of epistemic injustice, literature on selection and representation. In addition, I was also conscious that in the process of placing data into various codes and categories, some element of participant’s meanings may be lost. Subsequently, in presenting the findings, interview extracts and field notes are offered, at times, with considerable description to strengthen the accounts provided. It is hoped that greater justice is done to the data, a balance between highlighting important descriptive details and interpretation of key concepts is achieved, and the various arguments presented are easier to follow and provided with further insight.

7.6 Ethical Considerations

The research study received approval from the University of Sheffield's ethical review committee (see Appendix 3), whilst NHS HRA approval was also sought to allow entry into the research site and to engage with CMS teams and participants. An IRAS form was completed with a Research Ethics Committee (REC) Board (Reference: 19/NW/0258) confirming approval of the study in June 2019 (see Appendix 4a). REC approval is required when NHS service users are participating within the research in order "to protect the rights, safety, dignity and well-being of research participants and to facilitate and promote ethical research that is of potential benefit to participants, science and society". A REC review meeting in late April 2019 was arranged to discuss the research aims, evaluate research documentation and consider possible ethical issues. After receiving REC approval, access and authorisation was granted by the participating Trust's Research and Development team in mid-June 2019. The service research manager was allocated as the formal research study gatekeeper with respective QI leads acting as gatekeepers within CMS teams. An amendment for a four-month study extension was also granted approval by the same REC Board in January 2020 (see Appendix 4b). There were a number of ethical considerations that required attention before and during the research: informed consent, risks of the study, confidentiality and anonymity, and data management. These are detailed below.

i) Interviews

Participants were provided participant informant sheets with completed consent forms indicating approval to participate (see Appendix 5). Participants were notified of the intention to audio-record conversations but this could be replaced with written notes if preferred; no concerns were expressed over audio-recording interviews. Interview topic guides did not require substantial personal details to be revealed e.g. care history, treatment plans, staff role numbers. However, there could be a chance that some topics may lead to the recalling of uncomfortable experiences e.g. poor service relationship. Where service user interviews were conducted, support mechanisms were in place in the event of this occurring (e.g. discussing concerns with the department service lead in a designated separate room). Such issues did not arise during the study. In addition, participants were notified of their rights to terminate the interview session at any point and given 21 days from the date of interview to withdraw data. Beyond this point, data collected in the interview began to be processed and analysed.

ii) Cases

A series of preliminary meetings were organised with the QI leads of respective CMS teams, representing the first step in gaining access to sites. After initial discussions, research was introduced to CMS teams with members having the opportunity to ask any questions about the research. Participant informant sheets were given to team members with teams given additional time to decide amongst themselves whether they would like to take part (see Appendix 6a). This also provided sufficient time for the QI lead to discuss the research with other team members not present at these initial meetings. A consent form signed by the QI team lead (in agreement with team) signalled group consent for the research (see Appendix 6b). It was reiterated to teams that if for any reason during the observation phase my involvement as a researcher came into question this would be addressed through discussion with the service lead and collaborative partner. Where my research position was untenable, this would lead to the potential reassessment of research plans. Group consent was confirmed in every meeting through an attendee sign-in sheet (See Appendix 6c).

iii) Anonymity, Confidentiality and Data Management

The identities of interviewees have been removed and replaced by pseudonyms as a means of protection (see Table 2 (p.97) and Table 3 (p.98)). Furthermore, interviewees were informed that where information was offered with a request for strict confidentiality, this would be respected and not included. In the event of information being disclosed that required further action, for example, evidence of any wrongdoing or a risk to safety, then, my duty as principal investigator would be to break confidentiality. This was relayed to interviewees and teams with any subsequent course of action being discussed with the participant. There were no instances of having to break confidentiality during the research and no participants withdrew over the research period. Audio-recordings and interview transcripts were retained in encrypted format on a password-protected University of

Sheffield system. Consent forms and any additional notes taken during the interviews were securely stored within a locked filing cabinet until their digital upload before being subsequently destroyed. Within transcripts, details of identity (name, work) replaced by a pseudonym. The intention to store study data in a secure UK-based data repository was also explained within information sheets given to participants.

Using a case-study design, best possible attempts have been made to anonymise specific details of the case (using pseudonyms) and irrelevant details of the case have been ignored. However, this takes place with the acknowledgement that complete anonymity is difficult to guarantee owing to the size of the study. For example, key persons such as the academic supervisory team and Trust Continuous Improvement Lead are aware of the teams selected for the research. Nonetheless, best attempts have been made to mask identities and maintain assurances of anonymity and confidentiality.

7.7 Fieldwork Challenges

The previous section has described the various research methods used and offered justifications for their selection. Despite careful planning, however, a number of fieldwork challenges influenced research design and data collection. Some of these challenges have been drawn out as wider research findings, whilst equally illustrating the intense and emotional process of conducting doctoral research (Hubbard et al., 2001; Pellatt, 2003). The following section outlines some of the challenges experienced and briefly summarises key reflections to “trace steps in either direction” (Yin, 2014 p.105) and advance “my research story in a meaningful and verifiable way” (Glesne, 1999 p.5).

i) Delays in starting fieldwork

After a lengthy ethical process (study approval was received mid-June 2019) and with an intention to commence research immediately upon approval, the Southside CMS team placed their CMS process on pause for three months; this break was further extended beyond the three months. By this time, research had commenced across other Oston-based CMS teams, and with issues often overlapping and shared across these teams, it was agreed to remove this case from the research altogether given the study timeline. A delayed start was also encountered with the Eastview CMS team with the research start date put on hold owing to the absence of QI leads. As this was a singular case in a different setting (central to research plans), communication was maintained with the hope of involving the team in the research; fortunately, research commenced here three months after intended. A study extension was submitted to compensate for fieldwork challenges and create more opportunities to engage with CMS teams. Unfortunately, teams paused their CMS work with the onset of the COVID-19 pandemic. Given the already-stretched study timeline and in lieu of studentship implications (funding, submission dates, university requirements) the research was brought to a close.

ii) Cancellation of Meetings

An issue experienced throughout the research was the cancellation of CMS meetings (See Table 5 below). This is a pertinent finding which reflects wider engagement with QI. Cancellation of meetings was less evident in the Northside CMS team but the team had decided to shift to monthly two-hour meetings rather than fortnightly one-hour meetings. Team members decided this was better arrangement in terms of their availability and completing work. Naturally, then, this influenced the number of meeting observations that were originally planned.

Table 5: Details of CMS meetings observed

CMS Teams	Meetings			
	Frequency	Scheduled	Observed	Cancelled
Northside	Monthly - 2hr	9	7	2
Westside	Fortnightly - 1 hr	16	8	8
Eastview	Fortnightly - 1 hr	13	7	6

The cancellation of meetings had a further impact on the ability to establish rapport with team members. A particular research ambition was to hold individual interviews with team members. This was particularly difficult within the Eastview CMS team given meetings often varied in numbers and personnel, and where rapport was difficult to establish. At times, this meant one month would expand between research visits. I also recall on two occasions where the CMS meeting was cancelled after no team members attended. On both occasions, the QI coach and myself were left sat waiting in the meeting room before the coach went to 'check what was happening'; this is a research finding that is drawn out. When meetings were cancelled, this was often followed by feelings of frustration and disappointment. Cancellations did not only affect time and preparation undertaken ahead of meetings but also caused wider apprehension on how this would reflect on the data and my capacity as a researcher: whether the case decisions were made correctly? Do I have enough data? Were there better methods? Is there something else that I could have done? (Punch, 2012 p.89).

iii) The Absence of Service Users

A key element of the research was to examine how service users participated in the QI process. Meeting observations and interviews were intended to provide vital insight into service users' experiences of being involved. It was also on the basis that service users were engaged in the QI process that CMS teams had been selected. It had already been expected that a small number of individuals would be participating within each team (up to two service users), however service user presence in meetings, on the whole, was largely absent.

A participating service user within the Northside team left soon after the research had commenced (they had not attended meetings up until the point of leaving). Whilst the service user indicated an interest to have a conversation (through an email with the Team lead) this did not transpire. Towards the end of the research, the Northside team recruited two service user volunteers. However, given that they were new and had not received significant exposure to the QI process yet, I felt it would be unfair for them to be interviewed on their experiences. Given the inability to hold these interviews, much emphasis was placed on how service users were discussed in the process by staff, both in meetings and where interviews were conducted. Therefore, the research became more interested in seeking to understand reasons behind non-absence and the other modes in which a service user view was or could be inputted within the process, if at all. Nonetheless, I experienced considerable frustration at the inability to hold service user interviews, leading to further inquisition of the research particularly as core research concepts regarded involvement and co-production. Considerable time and care was taken to fine tune details of involving service users and gathering informed consent in these contexts.

7.8 Summary

In this chapter, I have offered a background into how the research study came into fruition, reflected on my philosophical position and detailed the research methodology and methods that have guided research exploration. Considering the aims and objectives of this research along with my philosophical assumptions, a qualitative case study approach was selected. The decision to adopt a case study design was guided by the empirical and exploratory nature of the research in addition to pragmatic choices. Through this research, I was interested in understanding the role of service users in the CMS QI process and how relevant stakeholders made sense of this course of direction. In this respect, the research was led by wanting to understand how different stakeholders understood the various concepts and orders of practice, before observing how service users were involved in the CMS QI processes of teams. Subsequently, a number of complimentary research methods, interviews, observations and analysis of documents, were used to answer research questions. To achieve the aim of observing practice, three CMS teams were selected. Within these teams, CMS were observed for an extended period of time, providing valuable opportunities to explore the research issues in depth.

This chapter has also detailed the process of data analysis, noting how a thematic approach was used to formulate codes and themes to provide a coherent account of the data collected and present a clear story line. Towards the end of this chapter, I have reflected on my ethical responsibilities as a researcher, describing how relevant ethical approvals were sought before the research could commence. I have also reflected on some of the challenges of conducting the research and how this has impacted the study. Hopefully, this chapter, then, has provided a fair and honest description of the research journey enabling a more informed view for the reader when analysing the study results that are presented in the upcoming chapters.

CHAPTER 8

The Construction of Quality Improvement

Chapter 8 introduces the first set of research findings pertaining to how QI was constructed by personnel involved. The findings are organised under two headings: **8.1) Purpose of Quality Improvement** and **8.2) The Ability to do Quality Improvement**

The first heading, **Purpose of Quality Improvement**, explores how personnel constructed the concept of QI, from the intentions of CMS QI work through to what they believed was being achieved in practice. The purpose of CMS and QI, or certainly the ideal, was positively characterised by participants, and reflected the linked aims of QI proposed by Batalden and Davidoff (2007, p.2): *"better patient outcomes, better system performance and better professional development"*. The second heading, **The Ability to do Quality Improvement**, is somewhat antithetic to this first theme, in that it captures some of the challenges of interacting with the CMS process as experienced by personnel and observed in practice. This section examines these tensions, namely the instability of supporting contexts, issues of time and the need for permission, all which could be seen to influence team engagement with QI. The division between these two themes has been made purposefully with the aim of highlighting the rhetoric of QI against the reality. Both appear to be captured in this account offered by Simon, the QI Coach of the Northside and Westside CMS teams:

> *"I am quite confident that QI is essential to make sure that the services we provide continue to be right for our service users and for the staff.* ***The difficulty is… getting help supporting people to appreciate how important it is, and actually it is as important as the day-to-day direct delivery of care, and helping people to give themselves permission to step away from that delivery of care, and take some time to think about what they are doing, and thinking about occasions where they can do things differently****. To get off that, you know, that hamster wheel, because everyone is just so busy keeping that spinning around, that it just doesn't seem they have the luxury" (Simon, QI Coach, Oston – Northside & Westside CMS)*

It is evident in Simon’s account (above) how tension exists between belief in QI work and the practical realities of getting involved and engaging with this type of work. The following chapter navigates through these issues, moving from the understanding of QI through to the implementation of QI principles and participating in the process. It is broken down into the following themes and sub-themes with the aim of delivering a concise and critical examination of QI practice:

8.1 Purpose of Quality Improvement

- 8.1.1 What is Quality Improvement?
- 8.1.2 ‘Superior Outcomes’

8.2 Ability to do Quality Improvement

- 8.2.1 Quality Improvement: A Luxury
- 8.2.2 Permission for Quality Improvement

8.1 Purpose of Quality Improvement

> *"A group of people that work together with common goals who want to improve things within the team and the service" (Ruth, Staff Member, Oston – Westside CMS)*

The following section charts how personnel constructed the concept of QI in regards to what QI is, why they thought they were involved in QI and what they believed could be achieved with QI work. These findings were drawn from across the full set of interview data, researcher observations and reflections of CMS meetings.

8.1.1 What is Quality Improvement?

There were several ways in which participants constructed QI. A number of informants narrowed QI solely down to the CMS process and the use of a methodological framework. Others operationalised QI in broader terms of service development with QI seen as the sum of various activities e.g. staff recruitment, healthcare research, day-to-day care activities. This latter broader construction tended to be present in discussions that took place with frontline team members. Within these same conversations, CMS work could be considered an extension of previous service development work albeit with a specific methodological framework. Adam, a staff member of the Northside CMS team, describes this:

> ***Interviewer: Before the introduction of CMS was there anything in place here?***
> *A: So yeah, we did, it wasn't labelled this way (CMS) but it was essentially about service development, to better meet the need of the clinicians we work with, so yeah, QI, I guess was done.* ***If I had thought about it as QI, I probably would have called it service development, but it was, it doesn't feel that QI is significantly different to how it was… it is just labelled in a different way"*** *(Adam, Staff Member, Oston – Northside CMS)*

Repackaging previous service development work as CMS improvement (as Adam (above) indicates) could suggest key features conferred by methodological QI approaches (e.g. measurement and analysis) may potentially be overlooked and underappreciated. The absence of key methodological features was a particular worry for Ian, the Trust CMS Programme Lead, noting how 'service developments' could often take place under the guise of QI:

> *"I think I see variation more with forms of QI that don't have, and they're not really QI, but they get called improvement, QI, around action plans, around responding to incidents and complaints and all that other stuff.* ***Basically we just respond to something, so we come up with a plan, that hasn't been PDSA-d, hasn't been tested with one patient, it's not built into a regular QI approach to know whether it's worked or not, so it can, I see that sometimes as something that is just introducing things, that, don't necessarily work*** *[…] and to be honest it is probably far too common." (Ian, CMS Programme Lead, Cranton)*

An evident concern expressed by Ian was the lack of attention placed on data analysis and measurement which are distinguishing features of CMS QI. The description, 'cargo-cult QI', has been used to describe QI initiatives implemented without proper understanding and lacking in fundamental processual elements (Dixon-Woods et al., 2011). This is indicative of poor fidelity and can result in actions that instead yield worse outcomes (Dixon-Woods et al., 2011, Davidoff et al., 2015). As has been described earlier in this thesis, fidelity is "the degree to which a method is carried out in accordance to the guiding principle of its use" (McNicholas et al., 2019 p.356). Importantly, whilst QI complements activities such as audit, research and service evaluation, it differs in both intent and application (Backhouse and Ogunlayi, 2020). Therefore, clear differentiation enables clarity over the expectations of CMS work and what type of projects it is best used for, helping to disentangle and dissociate outcomes of CMS from other activities. The project pursued by the Eastview CMS team over the research period may further highlight an example where QI was not sufficiently differentiated from other service activities. The team's CMS project revolved around the design of a brochure for new service user residents. On the surface, this project did not require in-depth analysis or the use of specialist QI tools such as PDSA cycles. Such action, then, is potentially indicative of a lack of understanding and also highlights a misuse of time allocated for QI work given other non-CMS approaches would have been suitable for this project.

In respect to participating in CMS QI work, frontline staff spoke positively about the ability to 'step back and take stock', whilst the democratic nature of the process - *'everyone has a voice'* - was also roundly credited. Senior members of the Trust seconded the notion of CMS QI levelling authority and using a bottom-up approach to allow services to dictate their own improvements. Improving team communication was highlighted as a particular strength of CMS QI, and it was visible in the two larger CMS teams (Northside and Eastview) that meetings were attended by various professional groups including non-clinical and administrative staff. There is agreed consensus that QI teams should include a range of stakeholders to reflect the diversity of skills, knowledge and experience (Rowland et al., 2018; Locock et al., 2020). This is also reflective of existing research that describes how QI work has traditionally been limited to small and localised activities carried out by 'QI experts' (Alderwick et al., 2017; Dixon-Woods, 2019b).

A noticeable omission across CMS teams was the presence of service users. One CMS team (Westside CMS) recruited two service users as the research drew to a close, but for the majority of the research period, there was a noticeable lack of service users involved: discussions and observations in regards to the involvement of service users are explored in more detail in Chapter 10. The absence of service users in CMS teams was surprising given assurances of involvement before the research commenced and also that involvement was *taking place* in other areas of services e.g. interview panels, reading groups. The CMS framework is explicit about involving service users in meetings and being part of the 'core' CMS team before a project starts. Incidentally, the first phase of the process (the assessment stage) begins with a '5Ps' process (Purpose, Patients, Professionals, Process, Patterns) which encourages reflecting on the service user population e.g. demographics, experience living with their condition, experience of the service (see Page 62). This assessment phase corresponds to what Deming (1993) calls an appreciation of the system before any QI work can take place.

Two long-term service user volunteers (Oston - Northside), who were part of the service PPI group, were interviewed to gather their thoughts on involvement, QI, and CMS. Both were not involved in CMS work given their commitment to other service volunteering opportunities. It was striking, however, that both associated CMS with a technological intervention:

> ***Interviewer: What do you know about the CMS process here?***
> *A: "I didn't touch CMS because it screamed computers and whatever… although I probably didn't ask enough what CMS was, so I didn't…you know pursue it […]. We get told about it [CMS] in the PPI meetings sometimes, but it doesn't appeal because it seems technical, heavy going… I guess compared to the other stuff" (Aisling, Service User Volunteer, Oston - Northside)*

> ***Interviewer: What do you know about the CMS process here?***
> *E: Like to do with computers and stuff? Tech stuff? It's all a bit strange… (Eric, Service User Volunteer, Oston - Northside)*

QI has been described as technically-orientated affairs with much of this attributed to the theory-laden, improvement science components of the process (e.g. PDSA Cycles, Process Mapping, Change Idea Concepts) (Boaden, 2011; Armstrong et al., 2013). It is possible that Aisling and Eric allude to this technical perception of QI, whilst at the same time, querying whether they saw themselves as a 'right fit' for CMS QI. A similar comment, noted with sarcasm, was made in a service PPI meeting (Oston - Northside) as discussion revolved around the current CMS project – High and Low Work Complexity work systems:

> *"Sounds riveting! If I show interest in joining that [CMS], slap me down" (Service User Volunteer, Oston - Northside)*

The above range of quotes collectively illustrate how QI may be seen as complicated and technical processes by individuals not necessarily equipped with extensive QI knowledge or exposure. It may also characterise QI as a mundane activity that largely remains a space for particular individuals, professionals or groups. Such characterisation could have subsequent implications on what areas or stages of QI, service users can be involved in or feel that they could be involved in. For example, the role of service users could be limited to canvassing opinions and collating feedback. This is a role service users have traditionally adopted within such partnerships but this limits access to the ‘more impactful’ decision-making responsibilities of QI processes. In respect to the CMS process, this could mean involvement at the early 5P’s assessment phase (deciding what improvement area to focus on), but less involvement in the diagnostic, treatment and standardised phases of the CMS process (deciding how to implement improvements in practice).

There were distinct theoretically-informed practices in the CMS process which were generally well-received by teams e.g. effective meeting skills approaches and post-meeting evaluation activities where each team member reflects on the meeting before grading their experience of it; this reflection provides learning points for future meetings. Each team had a QI Coach. The benefit of having a QI coach was markedly visible to keep CMS teams on track and, where necessary, to clarify QI concepts and terms. Applying complex principles such as PDSA cycles can be difficult (Davidoff et al., 2015; McNicholas et al., 2019) especially where these are new concepts and there is an absence of prior training; most team members had not undertaken the service-wide QI training. Despite the benefit of being guided by a QI coach, there sometimes appeared to be an over-reliance on the coach from other team members to lead the process as the ‘expert’ in the room. This was particularly noticeable when the coach was absent, as meetings were not as efficient and progress could be disrupted. In such situations, it highlighted the need for team members to take on greater responsibility to ensure the CMS process remained a collaborative project. Further processual features of CMS methodology include brainstorming, affinity grouping and multi-voting, which are used to generate, categorise and choose amongst several ideas to pursue. The reflection, below, describes an example of how the Northside team, used some of these features, to decide on a QI project to pursue.

Field Notes: Northside CMS - Meeting 3 - Deciding a new QI project to pursue

> *A list of seven project options accumulated over the past several meetings were written down on a large whiteboard in the main room. Each staff member present was given an opportunity to cast an anonymous vote for what project to pursue in*

> *time for the next meeting (the following month). This was open to all staff regardless of whether they participated in CMS meetings. The votes of those not present at the time was sought during the break in between meetings, with the whiteboard left in the main meeting room for respective staff to cast a vote. Unanimous voting was seen vital to ensure there was no 'danger of influence'. Subsequently, the project that received the most votes was pursued.*

By all accounts, using affinity grouping and multi-voting represented attempts to uphold a democratic process and it was noticeable that time was afforded for non-participating staff members (over a month) to select from the project options available. However, no time was extended to canvass opinions of any service users or put current plans to the service user PPI group. Pertinently, one of the seven project options (that teams had to select from), which concern practical site issues, was recognised as being more service user facing. Concerns over site accessibility had been raised in service user feedback but this information had been collected two years earlier (at the time of the meeting). Given the focus on practical site issues, team members questioned the timing and relevance of this for a CMS project and therefore stood less chance of being selected as a project to pursue. The democratic nature of the CMS process is widely credited, and this was no different amongst the teams. Simple dynamics of group membership e.g. one or two service users present in a team of ten, would suggest the voice of staff members is always likely to dominate. Nonetheless, there are questions whether this ideal of 'team democratisation' is viewed as a success through the achievement of engaging staff rather than wider stakeholder input from service users.

This section has provided an overview of how QI and the CMS process was understood, whilst particularities of the process have also been drawn out. These particularities have been considered within the view of stakeholder engagement. The following section advances focus on the purpose of QI work and explores what participants believed was being achieved through their involvement in this type of work.

8.1.2 'Superior Outcomes'

> *"QI is basically about kind of changing something, using some sort of method for a superior outcome, so it involves a change, involves a method,* ***involves some sort of superior outcome for everyone****" (Emma, QI Fellow and Coach, Cranton)*

Most participants described QI as a process to attain better outcomes that included the ability to provide the best possible service, improve quality of care for service users and increase the effectiveness of operations. The reasons cited mirrored those echoed in Batalden and Davidoff's (2007, p.2) vision of QI, *"to make changes that will lead to better patient outcomes, better system performance and better professional development"*. QI coaches expressed hope of QI becoming a 'day-to-day' reality for staff and a core part of 'everyone's' job - *"people should approach everything within their job, with their QI hat on" (Thomas, Trust QI Facilitator and Coach)*. Below, Rachel describes the importance of QI work to pursue 'never-ending' quality outcomes:

> *"You are continually looking to provide a service that meets the needs of the people…* ***It's a never-ending, it is a process that never has an end-point, because quality doesn't have an end point****… you're always striving for better" (Rachel, Continuous Improvement Manager and QI Coach, Cranton)*

Quality was described using phrases such as 'good as it can be', 'fit for purpose' and 'the perfect service'. These descriptions drew upon IHI and NHS definitions - safe, timely, effective, efficient, person-centred and equitable. Including the voice of the service user, through various modes, was characterised as a feature of good quality.

> *"There has to be client, patient voice in there, and feedback, regular feedback from the clients and carers, and* ***that has to be at the heart of everything we do, otherwise it is not, I don't think that is quality care.****" (Lauren, Staff Member, Oston – Northside CMS)*

> *“**It’s not really valid if you haven’t got service user opinion**, because, the service is for them [laughs], it’s not our service, so we need to know what they want, and so we can try and provide that” (Ruth, Staff Member, Oston – Westside CMS)*

At the same time, whether potential service user input translated into collaborative work with staff was not clear. The CMS process was often described as delivering outcomes and services *for* rather than *with* service users. Where sought, service user input was helpful but only in the process of assisting staff in their decision-making processes. This can be seen in Ruth’s account (above), and similarly in this sentence captured during a conversation between Northside CMS staff team members: *“they tell us what needs changing and we try our best to do it”*. Although a semantic observation, the use of ‘we’ in these quotes appeared to emphasise that professionals, consciously or unconsciously, saw themselves in control of the QI process. Daniel, a lived experience professional and Non-Executive Director of the Trust, did note caution of adopting a ‘default’ description of quality that places the service user at the ‘heart’ of services:

> *“So, for me, like I say, quality is, for me, **it has become a word like co-production which is like, kind of, we use it as if we know what it means… for the service user**. I guess for me it probably means the character of the service as experienced by the person receiving it, **but I think it is easier to say that if you know what I mean and I think people do**…” (Daniel, Non-Executive Director, Cranton)*

Daniel described quality as a buzzword suggesting definitions often given reflect what people want to hear. The difficulties of defining quality were reflected upon by personnel in conversations. A particular tension concerned how to merge quality dimensions of ‘patient-centeredness’ and ‘clinical effectiveness’. This is consistently debated within the literature (Swinglehurst et al., 2014; Lillrank, 2015; Robert et al., 2015). Maureen, a QI Programme Lead, poetically captured these warring tensions between the different dimensions of quality:

> *“I think there is data, I think quality is about quality assurance, it’s kind of, are we hitting the absolutely minimum here and what is the data telling us, there’s quite a lot you can do in a darkened room, kind of gathering stuff in, and that’s I guess*

> *related to mainly what the organisation says is quality,* ***so what do we think is quality? what do we think is good enough or what?... but then there's patient experience, I think it's possible, that never the twain meets, how do you do it?****"*
> *(Maureen, QI Programme Lead, Sirville)*

In conversations, frontline staff distinguished between an 'ideal' view of quality, which placed importance on service user experience, and an 'organisational' view of quality, which revolved around meeting certain expectations, performance indicators and targets. The latter denomination appeared to be made with some hesitation with acknowledgement that this is what services are measured on. The significance of this, then, relates to how although staff may feel they were using the CMS process to make improvements in a bottom-up manner, it was also, to some extent, informed by overarching top-down criteria. Evidence of this was visible within the QI project being pursued by the Westside CMS team - improving care planning documentation - with the following quotes expressing some of the team's frustration at their progress:

Field notes: Westside CMS - Meeting 4 - Staff comments around the purpose of the care plan project

> *"We have to do it (care plan document) because it is a key performance indicator (KPI), but what is the purpose beyond that… and how can we shape it when we need to meet X, Y, Z in the document?"*
> *"I guess we have to play the game… it is simply a tick-box exercise" (noted in respect to meeting KPIs and care planning documentation)*
> *"How does it (care plan) look for individuals? What do they actually want out of it rather than us saying this and that?"*

The above frustration resulted from the team's inability to shape the process owing to restrictions placed by particular service indicators and measures. In this case, there was also team agreement that care plan documentation could look different for service users beyond a standardised format. However, the team felt they did not have the power to change this. More widely, across the teams, evidencing the impact of QI work was difficult:

> *"If someone came in from the outside and enquired what QI work do you do, I think we would be able to tell them what we had done,* ***but when they asked for evidence of impact, we would be struggling – all we could say is 'well it felt better to us, it seemed like it worked for us, so we are carrying on with it'****. I mean that is probably right, but, it is difficult to show the evidence, the proof behind that, you know, that is difficult to measure" (Emma, QI Fellow and Coach, Cranton)*

Evidencing impact of improvement is a crucial tenet of the CMS process – *how do you determine whether or not changes have led to improvement?* Concerns like Emma's (above) highlight the difficulties of evidencing more qualitative outputs. This further emphasises how objective and quantitative metrics return more favour. An example of this is reflected in how QI engagement was recognised as leading to better team cohesion yet this was not seen as a sufficient outcome and therefore not a sign of measurable success:

> *"****The benefits I see of teams embarking in QI are not just about the individual changes, it's also about the team coming together and building strong relationships, honesty, respect and wellbeing, a sense of self-efficacy*** *[…] It's all that stuff, which, probably is the most important things you need, but you probably don't get credit for and can't measure a great deal, apart from possibly the staff survey each year." (Thomas, Trust QI Facilitator and Coach, Dexton - Eastview CMS)*

It was noted earlier in this section (Ian, p.112) how a failure to uphold certain mechanisms of QI processes could introduce unintended variation. There was acceptance amongst staff that the process of measurement could be difficult. The account, below, reflects on one such meeting where the Westside team were exploring their options to yield feedback from service users and staff:

Reflection: QI Meeting 6 – Westside – Attempting to get feedback on how service users and staff feel in regards to current care plan documentation

> *The team had decided to get feedback from service users and staff in relation to what they felt about the current care plan document before the team could*

> *proceed with creating a new and improved document. However, there was notable confusion and uncertainty around how this could be achieved, particularly in terms of the design and methods e.g. quantitative or qualitative? the number of questions to be asked? what to ask? How to collect responses? How they would know whether the new document would be better? Staff found themselves out of their comfort zones with the task continuing to be side-lined. The solution was to arrange for a member of the Trust QI team to come and discuss some of the issues, resulting in significant time delays and progress disruption.*

The accumulated frustration and progress disruption experienced by the Westside team as they sought to get feedback was further captured in a conversation with their QI lead:

> *"People get frustrated with how long it takes to bring about change,* ***if we are kind of saying 'hold on, we need to collect some baseline data that we can evaluate against', and that drives them nuts having to wait and collect baseline data.*** *They (the team) just want to get on with it, and they find the whole concept of measurement and measuring what you do, very foreign and frustrating, and, in order to keep the staff engaged with the improvement work,* ***we'll frequently compromise on what data we are collecting.*** *" (Simon, QI Coach, Oston – Northside & Westside CMS)*

Measuring and evaluating evidence of certain improvement efforts could be construed as timely processes, whilst some staff accepted that they lacked the appropriate skill and knowledge around these components. Nonetheless, compromising elements of the CMS process to sustain team interest could be a further indication of poor fidelity (Dixon-Woods, 2019b). Many interview participants were quick to describe how QI, at large, represented a process through which service user outcomes could be improved. Certainly in the various discussions and interactions that took place, there was consideration of how QI could impact on service users (amongst other stakeholder groups). Some of this consideration can be attributed to the CMS framework which stresses the need to have a service user focus. At the same time, in the process, there was often concern over what data was actually being collected (and potential compromise of data) alongside the absence of regular service user input into the process. Subsequently, whilst discussions with staff often raised the service user experience aspect of quality, actions appeared to prioritise safety and clinical outcome metrics that were more readily measurable or what services were expected to meet.

The first part of this chapter has concentrated on the construction of QI and how interview participants interpreted their involvement in QI work. Having reflected on some of the main discussion items, the next section moves to focus on some of the challenges of QI as raised by personnel and captured through observations of the process in action.

8.2 The Ability to do Quality Improvement

> *"As we would say in CMS, every system is designed to deliver what it delivers and I think, you know, **we have a system that makes it difficult to do QI work**, so I think, you know, it is not the people, it is the system that creates this situation."*
> *(Simon, QI Coach, Oston – Westside & Northside CMS)*

Several interview participants, from QI coaches to frontline team members, spoke about QI in the wider context of day-to-day practice. Though certain benefits have been discussed in earlier sections of this chapter, frontline staff often raised concerns of being unable to devote time for CMS work amidst various other work commitments and expectations. Observations of teams also revealed their instability with meetings regularly cancelled and the attendance of staff varying between meetings. Some of the issues identified may not be solely restricted to CMS teams in this study as QI leads confirmed a widespread concern across the Trust.

8.2.1 Quality Improvement: A luxury

QI was often described as feeling like an 'add-on' or a 'luxury' by frontline staff members. The reasons for this was attributed to routinely stretched services with staff shortages and time pressures. This meant engaging with CMS work was not an immediate priority. Frontline staff and QI personnel explained how services were not necessarily measured against their commitment to QI which made it easier to prioritise other actions. A further indicator of (lack of) priority towards to QI may be observed in how engagement with CMS QI was not seen as a staff requirement. On a broader, organisational level, the absence of QI as a feature within the quality assurance framework may also diminish its importance:

> *"I suppose, one of the main barriers is the assurance framework, I think, that actually* ***when it comes down to it, the NHS isn't, the organisation isn't good or poor because of the QI work it is engaging in****, so I guess that's the first thing." (Ian, CMS Programme Lead, Cranton)*

Subsequently, a lower level of importance could result in 'bouncing QI off the agenda when push came to shove'. This is captured in Lauren's account:

> *"When the case load is really high and the waiting lists are really high,* ***it can sometimes feel that it [CMS] is an extra, and I know it feels awful to say that,*** *I know, I do believe in it all and stand by it, but sometimes, the clinical stuff becomes really stressful, the time it needs, and so the time for this (QI), yeah [sighs]" (Lauren, Staff member, Oston – Northside CMS)*

Members of the Trust QI team recognised that this view of QI was concurrent within other teams but it was their job to dispel this. For Nathan and Thomas, QI work was as important as the day-to-day treatment routinely delivered to service users:

> *"When you've got a service that is under pressure, the first thing to go, are what sometimes are seen as the 'luxuries'.* ***I say luxury in inverted commas, because for me, it (QI) is essential, but it depends****" (Thomas, Trust QI Facilitator and Coach, Dexton – Eastview CMS)*

> ***"I think once we have worked out that improvement work is just as important as the treatment that they do****, the care that they give to service user, it is just as important than that – it will always be seen as an added extra" (Nathan, QI Fellow and Coach, Dexton – Eastview CMS)*

The opinions expressed above may be viewed with some caveat. Thomas and Nathan are both in non-clinical positions and therefore away from the immediate pressures of care-giving. For Simon, a QI coach, prioritisation of QI was inherently intertwined with the supporting system and culture:

> *"**The system encourages people to be reactive rather than proactive**, so, on the ground… it doesn't enable space for people to spend time thinking about 'well, how can we do what we do better?' The priority is getting through the urgent to-do lists, so people find it, the stress of that demand means people find it difficult to justify the time to take out to do something that, you know, it is quite time-consuming…* ***if you are going to get a bollocking, it's probably because you haven't seen or you have taken too long with a patient, all those sorts of things. So nobody is going to be thinking – 'well somebody is going to be on my back because I haven't done QI work or I've not attended that meeting'****. (Simon, QI Coach, Oston – Northside & Westside CMS)*

Simon describes how personnel are less likely to be reprimanded if they are not engaging with the QI. Additionally, QI work continues to be seen as something that is additional to peoples' day to day operational roles. On several occasions within teams, progress was often delayed between weeks because of varied staff attendance, team members having to catch up, and the cancellation of meetings. This upheaval was not helpful considering the already limited time teams had for CMS improvement; usually one to two hours per month. Meetings were often cancelled in the Westside CMS and Eastview CMS teams. In the Westside CMS team, meetings were cancelled in advance, usually several days before. Whereas in the Eastview CMS team, several CMS meetings were sometimes cancelled on the day due to no team members turning up or numbers being deemed too few to resume. In this particular team, the absence of team members was a source of frustration for the Eastview QI coach. The following account reflects on action taken by the coach in response to low team attendance:

<u>Field Notes: Eastview CMS - Meeting 6 - Addressing the lack of attendance at QI meetings</u>

> *Frustrated with a series of cancelled meetings, the QI Coach contacted the service manager in regards to poor attendance at CMS meetings, stressing that this was a real opportunity for the service make improvements. The next meeting resulted in 14 staff members attending much to the surprise of the coach and more regular members; where meetings had previously taken place, numbers fluctuated between 6-8 staff members. This big turnout was certainly surprising and the room was not large enough to appropriately accommodate such numbers, many of which were new faces. It was clear, and many joked over the fact that they had only turned up because the service manager had sent an email around in regards to poor attendance.*

Whilst not privy to the exact nature of the communication between the QI Lead and Service Manager, it could be assumed that the team had received a warning in regards to their attendance. However, there is a delicate balance here in respect to what may constitute ‘authentic’ ownership of the process. On one hand, increased participation of members could lead to exposure to QI, while on the other, it may lead to an ‘empty’ ritual of engagement, where QI represents a tick-box exercise. Notably, the service manager was not present at any CMS meetings over the duration of the research although it is possible that this could be a result of shift patterns, which was cited as a reason for indifferent participation. QI theory underpinning the CMS process makes a clear distinction between stakeholders participating in the development and ownership of an idea as opposed to buy-in i.e. agreeing to an idea that has already been developed. This finding also links with an earlier argument raised concerning an over-reliance on QI coaches to lead work and the need for staff members to take on individual responsibility. In both Northside and Eastview CMS teams, it was noticeable that task outputs from meetings were often taken on by the same one or two members of the team despite the QI coach imploring others to take on responsibility. This was further surprising given that they were large teams, and where meetings took place they were well attended.

8.2.2 Permission for Quality Improvement

The above sub-section identified issues of priority, time and space for QI. These issues were closely linked with the notion of permission and team members feeling confident enough to devote time and effort to QI work. Thomas, the Trust QI Facilitator, highlighted this as the main barrier:

> *"Possibly the biggest reason QI doesn't happen is because people aren't enabled or feel like they have the time to be part of it.* ***My wish would be, within the NHS, there are lots of targets and 'CQUINS'… I'd like to see a CQUIN[6] that is just – every team has an hour once a fortnight to do QI****. Don't worry about the outcomes of it – just measure and record that everyone has that time, and trust by giving that… and good, meaningful stuff will happen" (Thomas, Trust QI Facilitator and Coach, Dexton – Eastview CMS)*

Thomas suggests identifying QI as a CQUIN, a type of healthcare performance indicator, could highlight the importance and seriousness of QI work and encourage staff to participate. This said, each team in this study had protected time for meetings and which often took place on a set date and time. To all accounts, team members knew well in advance when meetings would take place. A particular issue observed across teams were actions not being completed between meetings potentially suggesting that protected time for QI was limited to meetings only. Rachel, the Trust Continuous Improvement Manager, further expressed the need to enable staff:

> *"I think if you asked anybody in the organisation, 'do you want to improve the care, do you want to continuously improve the care we provide for our carers and service users etc.', if anyone was to put no, I'd be really surprised [laughs].* ***I think genuinely anyone, anybody, would want to, but being able to, or feeling able to do that, feeling able to have the time or whatever, and the permissions maybe,***

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[6] The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to link a proportion of providers' income to the achievement of quality improvement goals

> ***I think, there is still some way to go****” (Rachel, Continuous Improvement Manager and QI Coach, Cranton)*

In the accounts above, both participants highlight the need to support and enable front-line staff to participate in QI. Permission to undertake QI is linked to ‘psychological safety’, which directs attention towards the relational aspects of the QI process that include key features of reflection, communication and support (The Health Foundation, 2013; Batalden et al., 2016; O’Donnell, 2019). Psychologically safe spaces allow for interpersonal risk taking and reflects a team climate of interpersonal trust and mutual respect (Kaplan et al., 2014; Batalden et al., 2016; Jones et al., 2021). This said, it could be argued that perpetuating a notion of staff needing to be enabled by ‘someone or something’, may shift an element of individual responsibility and accountability away from frontline staff - to ‘kick-start’ their own QI journeys. A slight tension was visible in conversations with senior members of staff (Senior Executive team and Trust QI team) as they emphasised the Trusts’ ever-growing commitment and support for QI. They underlined how QI featured explicitly in key strategic documents and pointed to a host of trust-wide interventions such as QI learning days, CMS induction training and a growing centralised QI team. Senior staff indicated that permissions for teams to engage with QI were in place and that they hoped for more teams to adopt CMS improvement. Corresponding to Eastview CMS team’s poor engagement with the process (as described in the reflection point - p.125), Nathan, the team’s QI Coach, expressed his frustration despite appearing to have the support of senior management:

> *“I understand that I can’t expect to have ten people here every week, it is just a little bit annoying that some, you know, because, senior management know that we are here, they have encouraged us to be here, they want us to be here, you know, so,* ***it is just frustrating when you have to go back to the management and say ‘look, our numbers have dropped off again’. They [staff members] need to realise that they have to own this work****” (Nathan, QI Fellow and Coach, Dexton – Eastview CMS)*

CMS team members regularly spoke about the lack of time for QI work. This was somewhat contrasted in conversations with the Trust' Chief Executive and Deputy Medical Director whom both suggested that pinning the blame to issues of time was not ideal:

> ***"I think, the biggest challenge at the moment to CMS work, is the perception that people haven't got the time to do it****. I think, that is true in some areas, where it is extremely precious… but I think it is almost becoming a narrative within the organisation that we can't do QI because we haven't got time, and I don't think that is helpful to be honest, and I think we have to try and counter that narrative." (David, Chief Executive, Cranton)*

> *"****One of the barriers is as we've talked about, is the idea that people need extra time for this****. There needs to be a shift in the way we think about this, we can't give everybody an extra two hours a week to do QI [laughs], that's not the mechanism in which we do this. (Jane, Deputy Medical Director, Cranton)*

Questioning the narrative of more time needed, the accounts above are seen to attribute some share of team engagement problems with attitudes at the level of individuals. For example, Jane, the Deputy Medical Director, did not out rightly dismiss time as a limiting factor but called for a sense of realism given the various challenges faced by services (Dixon-Woods, 2019a). In her view, shifts in mentality and attitudes were also needed for QI to become a routine part of healthcare professionals' roles. This may require professionals viewing their roles beyond the traditional scope of training they may have received, to encapsulate principles of QI - *Is it about encouraging people to learn or developing staff who actively seek out that learning?* Davies et al. (2007 p.129) suggest reasons for non-engagement of staff in QI extend beyond time and resources with QI practice challenging strongly held beliefs that requires "substantial unlearning […] from cherished turf". At the same time, individualised blame over attitudes and behaviours may fail to hold supporting systems and structures to account. These are partly responsible for providing logistical support and creating 'psychologically safe' conditions. QI personnel did express leadership was important to enable a sense of ownership and togetherness in the QI process. Ian, CMS Programme Lead, stressed the importance of leadership in QI:

> *"Without leadership, QI is incredibly difficult and can be like, almost like, the problem is that, people can get very inspired when they come on the two-day QI course, and it's supposed to be that,* ***and then they go back to the workplace and feel that it's quite difficult to get going, and maybe because it's not a priority for the kind of leaders around them, or the people around them****, so you've almost built up motivation to a really high level, and then, they can't actually, or they don't have the opportunity to use some of the things that they've heard, or aren't enabled to do that, and therefore, actually, they get cynical." (Ian, CMS Programme Lead, Cranton)*

Effective leadership could help create momentum for QI with consensus amongst participants that this extended beyond senior level of leadership; for example, a frontline staff member taking the initiative and 'rounding the troops up' for QI. In a sense, less emphasis was placed on the 'heroic' leader to provide sole direction. Rather, a cohesive effort from other staff members across disciplines could be the key lever for change. Leadership is recognised as a key facet within the relational design of QI. At the same time, the role of middle management, seen by many as the first line of leaders, was identified as a gap where prioritisation of QI could come unstuck.

> ***I: In terms of the support for CMS work?***
> *N:* ***I want to say resistance but that isn't the right word…well, I feel the difficulty is, where the barriers are, is at middle management****. I don't think that is just about QI, it is more widespread in any organisation within the NHS, and anything you try to do, they are the stumbling block at the minute, because they, they are obviously in a vulnerable position because they are being told what to do by senior staff, and then, you know, staff below them are telling them what to do as well, so they feel they are being battered from both sides and not getting any support… and they feel vulnerable that way, so how do we tackle that, it's not even a brick wall, that… barrier, that is the barrier we need to tackle****. So it is that bit in-between and how we get through that wall, I don't know how we do that yet!*** *(Nathan, QI Fellow and Coach, Dexton – Eastview CMS)*

Middle management are caught at a delicate juncture of meeting top-down level expectations and being accountable to staff at the micro-level. The role of middle management has been divisive within the health service, with some seeing their roles as further bureaucratisation, and others, more sympathetic, recognising that they are often blamed for issues beyond their level. In respect to implementing QI, middle management have a key role to play given they have an element of control over resource allocation. Subsequently, this may also show that support for QI is not solely restricted to frontline staff. This support may extend to clarity over manager's roles and responsibilities in QI which extends beyond simply trying to 'sell' QI to teams.

8.3 Summary

This findings chapter has explored how personnel tended to construct QI in terms of an idea at first and then how they reflected on the realities of practice. It was important to recognise the shared and diverse understandings amongst participants as to what they thought was being achieved through QI work. This was helpful to build a picture of the current culture and practice towards QI in different teams across the trust.

Many participants spoke positively about the democratic design of the CMS process and the opportunity for teams to dictate their own improvements. QI as a process to attain superior outcomes for professionals, services and service users was also consistently expressed. However, a concern remained over how improvements could be evidenced, pertaining to what form of 'quality' was being pursued (which was not always clear) and frustration with data collection and measurement processes. Inefficiencies in data collection and measurement were linked to issues of time and a lack of skill. Nonetheless, admitting to compromising elements of the CMS process indicated poor fidelity, a cardinal sin of QI practice. The deliberative style of CMS meetings, based on effective meeting skills and team coaching approaches, were lauded as encouraging balanced participation. This said, a democratic impetus within meetings, which was widely credited by team members, appeared to be seen within choreography of encouraging wider staff engagement. Thus, reinforcing a narrative of QI as a space for particular professionals and teams and where QI becomes a process done ‘for’ service users ‘by’ professionals.

Pressures of time and requiring permission to engage with CMS were widely expressed as reasons for failing to engage properly with QI; this may be emblematic of the supporting context with QI not recognised as an absolute priority. Subsequent discussions highlighted the need for psychological safety and paying attention not only to the technical aspects but also relational dimensions of the CMS Process. The research findings also highlighted some tension with calls for more time and permission questioned by more senior members. A number of commissioned actions such as service-wide QI training were drawn on to signal the Trust’s growing commitment to QI. A gap in middle management in respect to driving and leading QI was highlighted although this was also mirrored by the need for individual accountability and responsibility for QI. This relates to attitudinal and behavioural changes where people may be required to reassess their roles to encapsulate principles of QI. Nonetheless, the failure to prioritise QI appeared to be caught up in a vicious cycle of blame.

This section has provided an overview of how QI was constructed, and subsequent chapters will now narrow this focus to concentrate on the role of the service user in QI. Understanding of QI, from its aims and principles through to QI language and methodology, may have significant ramifications for the role of the service user. The instability of the QI process and maintaining team engagement in the first instance, and as was observed, may side-line the involvement of service users to a secondary or even tertiary issue. Moreover, much of the discussion around QI appeared to largely revolve around a professional discourse: what professionals could do, what they could not do or how they could improve. This reinforced a vision of QI as a professionalised and formal activity, where QI is done ‘for’ rather than ‘with’ service users. The involvement of service users in QI is rather explicit. CMS guidance stresses the importance of utilising service user knowledge with a 5Ps phase forcing teams to consider their respective service user population as improvement discussions commence. The role of service users in QI is now considered further with more depth in the following chapters.

CHAPTER 9

The Construction of Service User Involvement and Co-Production

Chapter 9 introduces the second set of research findings which explore how processes of service user involvement and co-production were constructed, both in terms of familiarity with definitions and language, through to understanding the experiences of personnel involved in participatory activities. A particular line of enquiry was to explore how the language of co-production was understood and used, if at all. The chapter is broken down into the following themes with the hope of delivering a concise and critical examination of the discussion:

9.1 Collaboration as an Asset
9.2 The Language of Co-production
9.3 The Possibility of Power Exchange in Co-Production
9.4 Co-Production within 'The System'

The first section, **9.1 Collaboration as an Asset**, provides an overview of how the involvement of service users, in a rhetoric sense, was perceived within service improvement activities. This was from the perspectives of professionals and service user volunteers. The sections that follow provide a more in-depth analysis on the concept of co-production. In **9.2 The Language of Co-production**, a visible lack of clarity over what co-production entails in practice is highlighted with a number of participants describing the language of co-production as jargon. Here, the conflation of co-production with other forms of involvement is explored and what this means for practice and further development of the involvement agenda. The third section, **9.3 The Possibility of Power Exchange in Co-production**, as suggested by the title, explores the conception of power in service user and professional exchanges. The relation between power sharing and contemporary features of the healthcare system is explored in this section. The final section, **9.4 Co-Production within 'The System'**, explores factors present in supporting environments that may further influence actions and attitudes towards the involvement of service users.

9.1 Collaboration as an Asset

> *"Service user involvement takes more than going the extra mile. It needs to be a marathon" (Aisling, Service User Volunteer, Oston)*

Involving service users in QI, or certainly the principle of doing so, was characterised positively by all interview participants. This does not come as an immediate surprise given the well-versed healthcare rhetoric - 'Patients at the Centre' - that has come to typify coalition between professional and service users (Foot et al., 2014). Similar sentiments were repeated in a number of conversations. Justifications for involving service users in CMS work and QI were broadly similar to general reasons given for involvement across other areas of healthcare e.g. research. Professionals noted service users offer alternative insight and perspectives which they may be unable to capture and this could help result in better tailored care; this echoed the technocratic rationale of involvement (Martin, 2008a). Further justifications included service users having a legitimate stake in health services, which was underpinned by a democratic rationale. Service user volunteers, that were spoken to, drew on the strength and uniqueness of their lived experience when talking about their involvement. Eve, a service user volunteer involved with another CMS team, made a distinction between professional and experiential knowledge:

> *"**Bless their hearts, as much as they try, they can never step into that role of being in that situation [as a service user]** and that is a good thing, because we need them to be where they are, but at the same time, I think there is an opening up to say 'actually, how do these people feel?... and I do think that is where the service user experience is key" (Eve, Service User CMS Volunteer, Cranton)*

Adam, a staff member of the Northside CMS team, agreed that service user input was important as professionals could often find themselves holding a closed view:

> ***"I think without it, you get into a sort of a bubble, and you get into a real sight that we become so focused on the processes, the internal processes, that you can***

> ***lose sight of the wishes and desires of the service user**, and, so again, service users involved, it is essential for them […] to highlight the stuff that isn't working, so we can do something about that" (Adam, Staff Member, Oston – Northside CMS)*

The input of service users was described as bringing unique 'lay' knowledge into conversations and also highlight the end goal of work - *'why we are ultimately doing this?'*. In conversations with service users, motivations to participate (in involvement opportunities) were largely driven by a stance of *'power within'.* This aligned with a sense of altruism and obligation to contribute to the improvement of the very services that they used as Eve explains:

> *"It's good and positive to think that when I'm dead and gone, things will be better for people, and improved, and you know, that is what I believe." (Eve, Service User CMS Volunteer, Cranton)*

In addition, Aisling described involvement as an opportunity to honestly air their concerns. This, to some extent, emphasises the right of service users to exercise their voice:

> *"We want a positive input, we need to know that what we've got to say, is either important enough, or credible, useful, and **sometimes it is an opportunity to have a scream even if nothing comes out of it. People need to hear that scream."** (Aisling, Service User Volunteer, Oston - Northside)*

Aisling had become involved through her responsibilities as a carer and it was pertinent, then, that she felt her involvement resulted in better treatment for her son. Whether this was down to her physical presence at various exchanges or ability to share knowledge, was unclear. However, she did reflect on being quite confident and vocal – *"I make them listen"* – which she acknowledged that not every service user was comfortable with:

> *"Personally, I've always felt that when I have been involved, I have to say this, my son gets better treatment because **I come over as somebody possibly relatively knowledgeable, but it's not that I am knowledgeable about the clinical side of it,***

> ***I guess I have become now over the year, but I'm knowledgeable about the functional side of it****. So they have to listen because I make them listen… […] Being involved has strengthened me, enabled me, on top of perhaps my normal confidence, but the other side of the coin is that it has enabled me to support other people that don't have those skills." (Aisling, Service User Volunteer, Oston - Northside)*

Intrinsic benefits such as increased self-esteem, agency and confidence were expressed by service user participants as motivations for their involvement. Locock and colleagues (2016) describe how service users may draw upon varying categories of symbolic capital during their participation. Symbolic capital refers to the "perceived levels of status, prestige and respect held by individuals within and beyond immediate social networks" (Locock et al., 2016, p.3). Locock et al. (2016) identify two categories through which service users may use their symbolic power – 'illness experience' and 'technical illness knowledge' that is accumulated over time. Aisling (above) refers to this technical knowledge as she reflects on being knowledgeable about both the 'clinical and functional sides' of her son's diagnosis.

Perceived benefits of engaging service users described by both professionals and service users mirror much of what has been captured in the extant literature. These include technocratic and democratic justifications for involvement of service users. Service users' view on working with professionals contained narratives of hope and the potential of what could be achieved if this was regularly coordinated. As noted at the start of this section, it was unlikely that noticeable objection would be portrayed at the idea of involving service users, and certainly expressed in conversation; for example, the involvement of service users represents a normative good. This also, then, explains the somewhat vague title of this section - Collaboration as an Asset - given that collaboration, in the view of this thesis, remains a somewhat loose term, and one that may be used to indicate a degree of exchanges between service users and professionals. The involvement of service users, in an idealised sense, was positively discussed. However, involvement of service users may take place with different degrees of influence and power. The following sections now move to a focus on co-production and how it was understood and constructed by participants.

9.2 The Language of Co-Production

> *"I remember someone saying that we can't even agree whether it (co-production) has a hyphen or not, like that's how kind of confusing the word is to everybody!" (Maureen, QI Programme Lead, Sirville)*

Though the involvement of service users was positively characterised by participants, there was uncertainty in how co-production and associated 'co-' terms offered a new lens through which to approach the involvement of service users. This was slightly surprising as the majority of participants recognised these terms and also admitted to using such language interchangeably in conversation. The language of co-production and co-design was expressed more in conversations that took place with senior management staff and QI coaches when describing the relationship between professionals and service users. Members of the Trust Executive and Continuous Improvement teams spoke about how co-production corresponded to the Trust's vision and this had been relayed in a series of policy and strategic documents. Repeating that this language forms part of key statements and strategies echoes what Vennik et al. (2016) have described as an 'organisational logic'; co-production intertwines with the organisation's service user orientated vision. In conversations with frontline level staff, terms such as co-production, involvement and collaboration were used interchangeably. Frontline staff often quoted key characteristics such as honesty and trust to complement definitions of co-production where they were asked. It could be argued such values are required across the continuum of involvement and therefore this offered little clarity. It was more so visible how potential challenges to co-production were raised in a number of conversations with many sharing Lauren's view below:

> ***"I think it all means involvement really, there are these buzzwords that you hear all the time like co-production, and co-facilitation and all that stuff, they are kind of buzzwords which are quite popular at the moment I think.*** *The language is completely different but essentially it is just involvement, but yeah you see all these buzzwords, you hear them…co-production, co-design and then yeah you just start subconsciously using them" (Lauren, Staff Member, Oston - Northside CMS)*

A number of personnel, both professionals and service users, explicitly referred to co-production as jargon and a buzzword that appeared fashionable in the current climate. This seemingly reflected the NHS' apparent affinity for various acronyms and buzzwords as was described in Section 2.1. It is pertinent, then, that Lauren (above) notes how the ever-increasing popularity of co-production in the current discourse resulted in a subconscious pressure to use this type of language, even if not fully appreciating its value. In addition, differentiating between the concepts of co-production and co-design suffered from similar inconsistencies of clarity. The majority of participants described them as 'similar actions with different names'. Some QI coaches described co-design as a specific category of co-production, but failed to describe what this meant in practice. Given the uncertainty over language and the various connotations attached to different terms, there was some consensus that the actual intention behind engagement actions was what really mattered.

> *"I'm not particularly fussy about the word itself, because I care more about the fact that we're getting people kind of involved in shaping their own care, but just to say, actually a lot of people don't like the word co-production and co-design, and that's interesting in itself isn't it?" (Emma, QI Fellow and Coach, Cranton)*

Much of the uncertainty around co-production terminology appeared to stem from the wide array of terms that many participants had been exposed to previously. Joanna, a Participation Co-ordinator, summed this hesitancy by noting caution over 'new' terms possibly emerging in the near future:

> *"I think co-production is a new term for something and I think, are we trying to get away from patient involvement or some sort of involvement that has not worked in the past and so has got a negative connotation to it? … So now we're saying 'it has to be co-produced' you know. Again, it is all about, is coproduction – communication? Better communication? Hmm… […]* ***I'm just wary that it might be in ten years' time that we might be calling it something else, you know****." (Joanna, Participation Co-ordinator, Tanview)*

Similar trepidations over what co-production means or how it differentiates from other terms, though are, again, evident here - *'Is co-production better communication?'*. Characterisation of co-production as a buzzword was also associated with its recurrent use to describe a range of various professional and service user activities as Daniel highlights:

> *"I try not to use words like co-production, co-design anymore… because I think the problem with the word co-production is that like a lot of terms,* ***it has been used so much now, and to mean so many different things, we use it for everything that it has kind of been hollowed out of meaning****, so I think people probably use it sometimes without really thinking if it is the right thing or the appropriate term" (Daniel, Non-Executive Director, Cranton)*

This was a common theme. Co-production being used superficially to describe activities and processes that did not qualify in the core sense of the term. Daniel's account above resonates with Lauren's (p.136) in respect to the subconscious adoption of terminology that currently appears favourable amongst individuals, groups and organisations. However, there is a risk, then, that such characterisation amounts to a sort *false or faux-production* (McGrath, 2020). *Faux-production* is a result of trying to be seen to do the 'right thing', in this case co-production, but failing to appreciate the distinct principles and values underpinning it.

> *"I think, again, a lot of our, there is a lot of time that people talk about co-production because it is the right thing to do, and* ***they say they've done it, but they haven't, they haven't understood it, and it is a grey area****." (Levi, Engagement Manager, Cranton)*

The prescriptive nature of co-production as the 'right thing to do' (because everyone is doing it), similarly described in other conversations as services needing to sound 'cutting-edge', could emphasise a tick-box rhetoric of co-production. This is a further indicator of *faux-production.* Subsequently, the imperative to 'co-produce' may result in the co-option of the involvement process, that far from offering greater influence for service users, further perpetuates power asymmetries between professional and service users. In doing so, this can undermine the enterprise of both service user involvement and co-production whilst leading to disappointment and distrust for those expecting more from the process (Bovaird et al., 2019). This said, in the research, both Aisling and Eric, long-term service user volunteers also expressed frustration with the language of co-production:

> *"I get pretty cheesed off by all these different terminologies…co-production and what is the other one? Hmm… I just find 'partnership working' is what I'm happy with really.* ***I often find that with these things, they are quite political and they come from a groundswell of opinion out there, which is perfectly valid, their concerns are, but they've gone overboard with it.****" (Aisling, Service User Volunteer, Northside CMS)*

Similarly, Eric alluded to the possible tick-box rhetoric of co-production:

> ***"I feel like co-production is just one of those buzzwords now that is bandied about, and like inclusion.*** *I've heard it too often, to tick a box" (Eric, Service User Volunteer, Oston)*

It could be argued that such accounts (given by both staff and service users) do not offer a particular critique of co-production per se, but express a general frustration with terms that have preceded yet failed to realise their intention (Robert et al., 2015). Nonetheless, the enterprise of co-production, shaped by its radical and transformative potential, suffers as a result. Furthermore, Edward, a Lived Experience Educator and National Patient Representative, emphasised how being 'visible' in spaces of involvement did not also automatically guarantee co-production. He reflected on some of his experiences during the interview:

> *"[…] In NHS terms, you co-produce something by kind of wheeling people in at the last minute. I've been involved in research, QI, I've been asked to come in and speak, and been told to go and talk about whatever I want – well that,* ***there is still within some areas, there is a tendency towards tokenism still, whereas other people have a philosophical understanding and belief of the benefits you can get from co-production.****"*

> *"… My lived experience is a resource that can be used to help you do what you're trying to do or you can just,* ***it almost becomes MH porn [when used tokenistically]. It becomes voyeuristic and that's uncomfortable and it's wrong you know… there has to be a purpose to it."*** *(Edward, Lived Experience Educator and National Patient Representative, Cranton)*

Several key points are raised by Edward in this account. Edward's experience of being *'wheeled in at the last minute'* where his involvement and knowledge bears little resemblance to the discussion, questions the intention behind the invitation to participate. In this manner, 'getting a(ny) service user in' and calling it co-production exacerbates a tick-box rhetoric. Much like the issue of *faux-production*, then, this serves to maintain an ''appearance of inclusion" (Papoulias and Callard, 2021 p.4) with involvement resembling a 'window-dressing ritual'. More broadly, Edward's account highlights how 'spaces' of involvement and co-production can be manipulated. Enterprises of involvement and co-production are often described as creating 'spaces' for exchange – 'invited spaces' (Cornwall, 2002), 'knowledge spaces' (Gibson et al., 2012), 'a third space' (Rose and Kalathil, 2019). Cornwall (2002) describes how service users may be invited into participatory spaces with promise of power and voice. However, there is a possibility that these spaces are controlled by those with greater authority and power, limiting the emancipatory potential first premised i.e. there is control over who is invited and what can be discussed. Edward's view over the possible commodification of his lived experience – ''*it almost becomes MH porn, it becomes voyeuristic''* - reflects how the uniqueness of knowledge experience can be tainted by tokenistic practice. In this manner, then, service users remain tied to particular roles, identities and behaviours, which legitimise the actions of professionals, whilst failing to experience the agency that comes with involvement. As Carr (2019, p.1147) describes, lived experience knowledge remains "token lucrative commodities" at the will of those in power.

It was evident that the construction of co-production by personnel seemed to suffer from conflation with other participatory approaches. A number of participants described co-production as a buzzword, whilst others expressed a general frustration with the range of terms that had and continue to be used to describe the involvement of service users. There is a danger of assuming that the right words will be followed by the right actions (Beresford, 2005). This may be indicative of how personnel acknowledged instances where co-production is used because it is seen as ‘the right thing to do’ or this is what the Trusts’ ambition is. Williams et al. (2020b p.224) warn of “a problematic trend of viewing co-production as merely different in degree – but not in nature – from involvement practice”. This results in a lack of appreciation for the underpinning principles and values of co-production e.g. equality, reciprocity and sharing of power. The next section advances focus on the dynamics of power within processes of co-production.

9.3 The Possibility of Power Exchange in Co-Production

> *“Do you really think it is really possible for highly paid psychiatrists and well paid health professionals to co-produce with someone who has been on benefits for 20 years because their experience of hearing voices, and are poor, and they left school at 14 because they became ill, and they have no money, no confidence, no power or influence in the world?” (Daniel, Non-executive Director, Cranton)*

In the previous section, the potential co-option of language along with discussion of tokenism highlighted how the practice of involvement can be manipulated. These are, then, a further reflection of the wider power differentials operating within contemporary features of healthcare (Farr, 2018; Rose and Kalathil, 2019; Tembo et al., 2019).

Returning to the various definitions offered within the literature, it is the explicit commitment of sharing power and equality that, for many, separates co-production and co-design from other forms of participatory practice and service user involvement (Bradwell and Marr, 2008; Needham and Carr, 2009; Slay and Stephens, 2013). Discussion of power, although not always expressed in terms of sharing it, were raised in conversations with some interview participants as they linked co-production with the professional-service user relationship. Mention of power was less explicit in interviews amongst frontline staff, whom, instead, referred to characteristics such as trust and honesty to describe professional and service user relations in this manner; this could also indicate that power as a concept was not routinely reflected upon.

Where power sharing was explicitly mentioned, occasionally to indicate the definition of co-production, this was often paralleled with the realities of the system. Participants (both staff and service users) could be seen to construct and differentiate between two visions of co-production: 1) *'true co-production'*, a version which requires an explicit sharing of power (and closer to more radical definitions of power transformation), 2) an *aspirational* version of co-production (an almost 'co-production lite' variation), where services approach the involvement of service users with the best intentions of using 'co-productive' principles. *'True co-production'*, was seen as being somewhat unrealistic within the current healthcare system. Edward shared this view:

> *"I'm quite cynical because I think, what it means is dependent on the context of the person that is setting the project up in the first place.* ***We talk about co-production being as – involving and sharing of power – I don't believe that ever happens because the power ultimately remains with the person who has commissioned the project, paid for the project, the person that can take it away again. I think what involvement is able to do is kind of being able to wriggle around the kind of space it is allowed to wriggle around in.*** *In my experience what happens, is, when this is done at its best, everyone has the opportunity to speak, everyone feels like they are listened to,* ***there can be an attempt to negotiate some common ground, but ultimately the professionals decide****" (Edward, Lived Experience Educator and National Patient Representative, Cranton)*

There is a cynicism in Edward's view as he cites overarching professional control anchoring the co-production process; power dynamics between stakeholders will always remain unequal when someone has the power to "take it away again" (Rose and Kalathil, 2019). This distinction reiterates the capacity of professionals to shape, control, privilege and equally dismiss certain types of knowledge through the epistemic authority they possess – they ultimately have the 'power of decision' (Carel and Kidd, 2014). Healthcare professionals are epistemically privileged by virtue of their knowledge and expertise, and third-person objectivity, possessing culturally recognised attributes and competencies which entails a basis of professional power (Callaghan and Wistow, 2006; Carel and Kidd, 2014). Epistemic privileges are not only in the possession of professionals. Service users have particular privileges owing to being holders of unique experiential knowledge whilst persons invited into knowledge spaces have additional privileges. However, the epistemic privilege and status afforded to professionals is greater and therefore their knowledge is prioritised in practice. Subsequently, a view that 'true co-production' is unrealistic was closely allied with the structured and hierarchical set up of the healthcare system:

> *"I think in the NHS, **it is very difficult to, to do co-production to its core, you know, because you have those hierarchical, powers,** and you kind of have to, you know. That is how a health trust has been set up" (Michelle, Co-Chair of Service User Engagement Group, Cranton)*

The implication towards the hierarchical set up of the healthcare system points towards dominant discourses and systems that have historically given primacy to certain forms of knowledge over others. Professional knowledge has greater status and therefore maintains an upper hand. This said, it is also possible that the various responsibilities of staff that include provision of care, accountability toward peers and meeting particular service indicators, influences what and how much power professionals may be willing to share with other stakeholders (Gibson et al., 2012). This, for example, is captured in the following short quote: "It is good [to get them involved], but then if anything goes wrong, ultimately we are accountable so there is always that" (Joanna, Participation Co-ordinator, Tanview). Subsequently, then, professionals also find themselves in networks of power where they are answerable to peers positioned at different hierarchical levels.

Returning to the construction of a 'co-production lite' variation, some interview participants suggested this involved working alongside service users with acknowledgement of power dynamics 'hovering in the back'. Edward (p.142) alluded to this in his account above as he talked about a space for negotiation with recognition that power is ultimately held by specific individuals. Daniel and Levi (below) offered similar perspectives:

> *"I think we also need to understand that, and probably, we don't have to be happy with it, **but paradoxically, I think accepting that true co-production is probably almost impossible, may actually, if we accept that fact, it may take us near to***

> ***actually doing co-production, because we will be thinking about power imbalances*** *and we will be actually doing something that is necessary for true co-production, when we start to accept 'hang on, no, there is a problem here and it is in the structures and systems we work within'." (Daniel, Trust Non-Executive Director, Cranton)*

Daniel offered his view with a disclaimer that it may not be universally liked (seemingly from the perspective of service users) given some of the discourse around co-production originates from a position of equality, reciprocity and sharing of power (Needham and Carr, 2009). Glynos and Speed's (2012) distinction of 'choice-based additive' and 'recognition-based transformative' accents of co-production may have particular relevance to how participants constructed 'true' and 'aspirational' forms of co-production. Williams et al. (2020b p.227) offer a concise summary of these two accents. 'Additive' co-production involves service users in healthcare design but where service users experience little change to their roles. 'Transformative' co-production, which appeared to align more closely with participants' distinctions of 'true' co-production, signifies greater recognition, status and identity of the service user in service reform. Levi, an Engagement Manager, echoed hope for co-production but accepted that certain people will always have the most power:

> *"I think it's trying to make things a bottom up approach, so eventually it would be great I think, if services were designed in a co-produced way.* ***But I think it takes a long time and to me… co-production… it is recognising that service users have a voice that is just as valuable as clinicians, but we also have evidence and constraints put upon us by the government essentially and the commissioners, in terms of, money, resources, so it is about bringing all those together"*** *(Levi, Engagement Manager, Cranton)*

Levi reiterates the complexity of organisations, where power imbalances exist not only between professionals and service users but also between staff positioned at different hierarchical levels. There was consistent agreement across participants that transparency and honesty between stakeholders was required with much of this responsibility on the professional given that they were the 'paid' person in the relationship. This further emphasises the social standing of the professionals with issues of pay linked to economic capital and access to money and material goods (Bourdieu, 1987; Locock et al., 2016). Professionals have economic capital equating to greater status and privilege. Pertaining to honesty in co-production activities, Levi discusses how she sets parameters in any involvement or co-production activity:

> *"I think we need to be honest when we're co-producing if that is what we are calling it. I normally start with this thing now, so when I'm co-producing something, where I say this is the box – so 'we're not thinking outside the box –* ***this is the box we've got and we're working within the box and within these constraints, and what can we do within these constraints*** *– And I'm the one to put those boundaries down, and that's the way I work and that box would be different for every activity that I'm doing" (Levi, Engagement Manager, Cranton)*

Levi's justification for setting parameters may reflect what Carel and Kidd (2014) describe as the second component of epistemic privilege. This is where persons with authority are responsible for controlling and setting out the structures of participation. At the same time, and in contrast, it is possible that in calling for honesty and transparency, Levi is careful of managing her position of power and privilege as to avoid taking deliberate advantage of stakeholders with less power. Such reflection of power was not visible in the majority of interviews. Edward agreed that collaborative practice takes place in a tightly controlled spaced where there is an acceptable middle ground but which in his view did not qualify as co-production:

> *"What we're doing is, rather than co-producing****, we're finding that acceptable middle ground between the service user and the professional. We're finding what the service user will accept, or what they will tolerate, and what the professional will accept****. And that's what we are aiming for […] but that's not co-production as I understand" (Edward, Lived Experience Educator and National Patient Representative, Cranton)*

The arguments presented in this section appear to support the view that attempts to involve service users remain within privileged sites of knowledge generation. Boundaries and rules set in regards are controlled by professionals and this is legitimised through their epistemic authority and power (Rose and Kalathil, 2019). As Eric suggests below, these power dynamics may also operate unconsciously and which are reflective of current healthcare organisation where roles and responsibilities are routinely accepted:

> ***Interviewer: Why do you think that is then…the power dynamics that you noted?***
> *E: Well, not on purpose in the sense that you know, not in terms of like a conspiracy or ought like that, but unconsciously purposeful, right. Like the unconscious is really powerful, and* ***those power exchanges go on an unconscious level, of course and when researchers, clinicians are using the traditional research paradigms, the stuff they have been trained in, they are happy with the traditional way of doing things and the unconscious roles of power will go on, as they have always gone on*** *– that is safe ground for them. (Eric, Service User Volunteer, Oston)*

The description of 'safe ground' and finding comfort in traditional paradigms reflects how internalisation of attitudes and actions by professionals is likely to be shaped by the models they received training in (Carel and Kidd, 2014; Wardrope, 2015). The subconscious internalisation of professionals' position of power is evident in how greater value is ascribed to medical training, knowledge and skills (Nimmen and Stensfors-Hayes, 2016). Nonetheless, there was an acceptance amongst service user volunteers, that service user involvement, in any guise, depends in part to how much power professionals are willing to cede. Service users expressed a desire to be valued whenever they got involved. Although, it was unclear whether this was on an equal footing with professionals or to gain more equality than they had traditionally been offered. Both Eric and Aisling offered slightly contrasting views in regards to this:

> *"So we want to be valued equally, with them [professionals],* ***we want parity. I won't say that as survivors we know better than the specialists, but our knowledge is important,*** *and it's not just the specialists here, there are people working in local authority, and all those other stakeholders, who have a parity, and*

> *the survivor should be central to that, central in importance! I think that is crucial!" (Eric, Service User Volunteer, Oston)*

For Eric, equality and parity of power was crucial to his involvement. He was also passionate about organisations commissioning more survivor-led activities (where service users hold the majority of power), further emphasising why the discourse of sharing power held crucial symbolism. Aisling, on the other hand, was less forward in her need for greater power:

> *"That is perhaps another thing that I have no desire for, you know, desire to be powerful.* ***I think my power here comes from being honest, trustworthy, I give up my time happily… I don't think that I have equal power here, even if I co-produced until the cows come home […] So it's not that I don't want to be equal****. What I want is somebody that will listen to me, and that they will judge it on its merits… It's not, it has got to fit something" (Aisling, Service User Volunteer, Oston - Northside)*

Aisling viewed her power through a lens of being able to provide a voice and for this to be judged fairly. Her depiction of equal power was reflected alongside realities of the system – *"I don't think that I have equal power here, even if I co-produced until the cows come home".* This extends back to earlier discussion concerning the possibility, or equally, impossibility of transformative co-production within privileged sites of knowledge production. Aisling stresses this further:

> *"Somebody who comes here as a volunteer, to be involved in discussion groups or what not,* ***I think there are being unrealistic if they are talking about power and co-production. The equality and power comes with what they are offering, whether it is agreed or not, they are entitled to their opinion and it is giving them their voice, that is agreeing that they have the power****. I think it is the connotations around the wordage, and I try not to get too hung over these things." (Aisling, Service User Volunteer, Oston - Northside)*

The contrasting views offered by Eric and Aisling towards the exercise of power may be, in part, due to their different backgrounds, care needs, time assimilated into the organisation and so forth. Nonetheless, both imply the act of giving and sharing of power is within the responsibility of the professional. Much of this professional power, as has been described in this section, can be attributed to the epistemic authority and privilege given to professionals. This authority is granted pending intuitionally recognised medical qualifications and training which assign knowledge higher epistemic status (Carel and Kidd, 2014). This, for some, meant the potential for 'true co-production' was difficult given the current design and delivery of healthcare services. Instead, an aspirational version with co-productive principles and values was best to target. Having discussed the role of power in regards to service user involvement and co-production, the next section focuses on systemic features that were highlighted in discussions. These were reflected upon as participants attempted to explain the inclusion and exclusion of service users from spaces of involvement.

9.4 Co-Production and 'The System'

> *"I kind of wonder sometimes, it feels to me like, we're coming to a place where involvement is like a defensive move, trusts can't get caught out rather than embracing challenge, and embracing the possibility of new insight. The excitement of involvement, the radical potential of it, often seems to be lost in this mass of bureaucracy." (Daniel, Non-Executive Director, Cranton)*

Traditional hierarchical structures within supporting systems was cited as a central reason by participants for the difficulties faced in trying to involve service user groups. Structural deficits have traditionally been identified as barriers to service user involvement. Nonetheless, this further reiterates how creating communities and spaces are reliant on the design of social systems as well as overcoming individual epistemic challenges (Anderson, 2012; Fletcher and Clarke, 2020). In the research, for example, barriers to involvement were partly attributed to a defensive culture and workload pressures. As a result, preparation of involvement formats and allocation of time dedicated towards involving service users could be impacted.

i) A Culture of Defensiveness

A series of comments were made by professional personnel in respect to potentially 'airing dirty laundry' in the presence of service users. Subsequently, to avoid such situations, professionals could be cautious of what to reveal during their exchanges with service users. Nathan, a QI Coach, alluded to defensive behaviour and mechanisms as he spoke about the involvement of service users in QI:

> *"People are always, staff are always a bit cagey what they might say in front of service users, so that is the difficulty if you want to involve the service user." (Nathan, QI Coach, Dexton – Eastview CMS)*

Defensive behaviour was also associated with the possibility of 'getting things wrong' in full view of the service user. To avoid 'drawing attention', it was better to be safe and limit exchanges between professionals and service users. Reflecting on her professional experiences in healthcare, Michelle, Co-Chair of the Trust Service User Engagement Group, acknowledged a risk-averse healthcare culture which was likely to influence staff behaviour and actions:

> *"Do you not think that is because the NHS is risk-averse full stop. In some ways, it has to be because you're dealing with people's lives so you have to be I guess, but I wonder if my impression of the NHS is that when I've worked in partnership with them, is,* ***that kind of risk-aversion seeps into lots of stuff that they do, because there is always a fear of 'if I get something wrong you know****" (Michelle, Co-Chair of Trust Service User Engagement Group, Cranton)*

A degree of risk-aversion is expected in healthcare given the delicate nature of care giving. However, as Michelle suggests, this risk-aversion could spread into other areas of governance that includes the involvement of service users. In conversations, senior members of the Executive Trust team also acknowledged a defensive culture across services. This was somewhat surprising given that a culture of fear and defensiveness (at the frontline level) may be in part a result of the standards and expectations set by individuals at more senior levels.

David, Chief Executive of the Trust, further acknowledged that staff will naturally try to protect the reputation of the organisation:

> *"We have a tendency to protect the reputation of the organisation, and I think that is for, sometimes it is for negative defensive reasons, but also I think, it's also genuine in that, if you don't have a confidence in the service, you're not going to engage with the service, it's not going to benefit the service, and if the reputation is negative, than you will have less confidence to do that…there is this constant challenge around being open and encouraging of feedback and constructing negative feedback,* ***but I think we do have a tendency to try and defend the reputation, though it probably is a combination of service quality reasons but also self-defence really.****" (David, Trust Chief Executive, Cranton)*

Protecting the reputation of services helps to maintain a positive image to existing and new service users in receipt of care. On the other hand, defensiveness could be a consequence of negative service user feedback and critique. David continued to note how staff may feel scrutinised and demoralised when presented with negative feedback, perpetuating a culture of fear:

> *"It's extremely hard I think when people think they have done their best to be told 'actually, that wasn't particularly helpful' […]* ***I think, we're in a dynamic where all people in the service, frontline staff and managers are anxious about feedback and responding, because they are anxious it is going to be negative****…I've seen it" (David, Trust Chief Executive, Cranton)*

Nathan's assertion of 'feeling cagy' (p.149) and David's account above further illustrate how encouraging service user involvement can be approached with some hesitation. As to the case of co-production and co-design, where there is, in theory, a stronger defined role for service users, it is likely that this tension is further exacerbated. In the view of the Senior Executive team, any indication of a defensive culture, that could potentially constrain service relationships with service users, had to be challenged:

> *"But then* ***we can't expect people who have had a negative experience to necessarily do it in a sort of productive way. You know 'if you're pissed off because of this and that', then you're going to say 'I am pissed off because this, and this happened'****. […] Some of it will be negative because, inevitably, people's experiences will range… but we have to use that, don't we?" (David, Trust Chief Executive, Cranton)*

There was agreement that overcoming a culture of defensiveness and fear was not straightforward, but crucial nonetheless as this could mean missing out on a large pool of valuable knowledge. Rebecca, Head of Co-Design and Improvement at a local charity (working with the Trust), offered an equally pertinent critique of how the culture may be less conducive for external groups and individuals, that may include service users:

> *"I think health is more polarising than anywhere else because there is a view that doctors are geniuses, there is such an admiration for that profession… qualifications put them up a pedestal, which in a lot of contexts is absolutely right, they do know a lot of things,* ***but it's the same across all, where not only do the professionals struggle to accept that the patient is equal, but the patient struggles to accept that too*** *– "why are you asking me this, doesn't a doctor know?" (Rebecca, Head of Co-Design and Improvement, Sirville)*

Rebecca reiterates how dominant hierarchical perspectives – *''qualifications put them up a pedestal''* – may leave service users struggling to position themselves within a complex system like healthcare. As such, service users may adopt passive roles where they rely on healthcare professionals' skills and knowledge. Rebecca proceeded to expand on this:

> *"When I've done QI in the NHS, one thing I've found, I think that this is a massive barrier, is that,* ***there is a cultural thing of 'we're just so grateful for the NHS', that it is like blasphemous to say anything constructive or 'it would be better in this way', and I genuinely really think that is a challenge****. It's that people just assume, like, 'you've got to say thank you and be appreciative'" (Rebecca, Head of Co-Design and Improvement, Sirville)*

The above statement reflects how individuals and groups who see themselves on the 'outside' may be culturalised to act when entering healthcare services. For example, the practice of giving feedback may be approached with hesitation if there is belief that this is likely to affect care or damage the existing service user-professional relationship. Erosion of the service user-professional relationship was not a particular theme that was discussed at length. However, Nancy, a service user trained CMS coach, did allude to this during one such conversation:

> *"**They say, yeah, if you put in a complaint or criticise the service or staff – 'it won't affect you care' [sarcastically]. Excuse me, they are human, come whatever they say, it will have an effect!...** But I think as long as, with the CMS, as long as your criticism is constructive and things, that should be accepted" (Nancy, service user trained CMS Coach, Cranton)*

The preceding statements have illustrated how there is a disposition of hesitation when giving feedback as a service user or equally receiving feedback as a professional. This further reiterates how collaborative exchanges may not always lead to fair and critical dialogue. Nonetheless, it was apparent that it was the role of supportive cultures to bridge this gap and promote the positive act of giving and sharing feedback.

ii) Time for Co-Production

Structural factors such as time and resources were identified as key critical factors for successful involvement. Discussion here, then, also echoed some of the reflections that were presented in Chapter 8 and which concerned the ability of individuals to participate in QI practice. Ian addresses some of the faults inherent in the system:

> *"I think the other barriers are the structural deficits in terms of nursing shortages, doctor shortages and so, that actually, **we've designed ourselves into the system unfortunately, but we are, where we are, and they are really difficult, because if you can't run the service, how can you expect people to engage**, so I think that's another key barrier." (Ian, CMS Programme Lead, Cranton)*

Where services were seen to be 'doing' co-production, more widely across the Trust (with some particular examples given), this was described as services thinking 'outside the box'. In this respect, they were trying to make most of the limited resources available to them. Characterising co-production as doing something outside the box suggested that it remained a novel way of working rather than routine practice. Similar to a split view concerning the need for more time for QI work, Rebecca took a somewhat unsympathetic view of time issues limiting efforts of involvement:

> *"It's another thing that I guess I'm quite unsympathetic about…people are like 'well I just don't have time'…* ***bullshit you don't have time, you have time for a thousand management meetings, you have time for whatever you make a priority in work, that's the fact of the matter. The reality of it is, that it just doesn't feel enough of a big priority for some****, and that's why you feel like you don't have time." (Rebecca, Head of Co-Design and Improvement, Sirville)*

Rebecca likened the perceived issues of time to a lack of priority and value assigned to processes of involvement and co-production. Moreover, she constructed a parallel with her experiences of the social care sector emphasising how they had to adapt with even more limited resources than the health sector:

> *"There are a thousand things that if you look at it, […]* ***if you look at health compared to social care, they are much better resourced (in health), there's a lot more money in the healthcare system compared to social care, so I don't think it's a question really of people having no time, it's whether they really place it as a priority, I think that's a bigger question****. Although I don't only think this is unique to co-production, it's true of a lots of things" (Rebecca, Head of Co-Design and Improvement, Sirville)*

Her colleague, Maureen, a QI Lead, reiterated how the social care sector 'had to work co-productively' given the pressures they faced. Both were in agreement that many people perceive co-production as being something that is good for people. This said, they also suggest it is necessary for people, predominantly leaders, to recognise co-production as a ‘sensible business decision’. This perspective could potentially alter where involvement was placed in terms of priorities. It is also pertinent given that there is a suggestion that acknowledging the economic benefits of co-production (e.g. less wastage and cost-effectiveness) may hold even greater sway than appreciating the democratic and technocratic rationales underpinning the involvement of service users.

9.5 Summary

The rhetoric of involving service users in the design and delivery of services was characterised in positive terms. Technocratic rationales were drawn on to explain how the uniqueness of experiential knowledge could complement professional expertise. Service users could also be seen to draw on different motivations for involvement.

However, there also appeared to be significant tension concerning how collaborative approaches were characterised and to what extent methods of involvement could be recognised as co-production or co-design. The understanding of co-production and co-design was more visible in conversations with senior management staff where an ‘organisational logic’ (Vennik et al., 2016) was drawn upon. Such terms (co-production and co-design) were less visibly understood and defined by frontline level staff and where co-production, involvement and collaboration was used interchangeably. Many participants also described co-production unfavourably. Co-production was conflated with more traditional modes of involvement, seemingly suffering as a result given the radical nature of co-production could become co-opted. This was exacerbated by a widespread view that organisations and services often mislabel exchanges, where professionals and service users come tougher, under the banner of co-production. Co-producing with service users without appreciating the guiding principles and values amounts to *faux-production*. Enterprises of involvement and co-production are often described as creating ‘spaces’ for exchange (Cornwall, 2002; Gibson et al., 2012; Rose and Kalathil, 2019). Cornwall (2002) describes how spaces where service users are invited into may actually legitimise or mask overarching professional control. *Faux-production* is an example of this given service users may arrive with loftier expectations of their roles and responsibilities but only continue to resume traditional passive roles (Bovaird et al., 2019; McGrath, 2020).

The radical and transformative nature of co-production which is heavily aligned with language of achieving equality and sharing power was also widely contested. This is reflected in how participants categorised between *'true'* and '*aspirational*' visions of co-production. *'True co-production'*, representing a more radical view, was described as unrealistic, leading to several calling for (or accepting of) a version of co-production in which collaboration between professional and service user continued under the recognition of power differentials. Much of the discussion, here, incriminated a dominant professional discourse inherent in the system, through which the idea of power sharing was seen as untenable. Professionals, by virtue of their strong claims to authority and various responsibilities, were predominantly in charge of shaping the space of involvement. This mobilisation of power may occur on an unconscious level with professionals internalising attitudes, knowledge, beliefs and values informed by the environments in which they have trained and developed (Nimmen and Stensfors-Hayes, 2016). It was pertinent, then, and although only a small number of participants (including a service user), that the importance of reflexive awareness practice was raised. This was particularly visible when co-production was discussed in terms of acknowledging power dynamics and being honest and transparent with participating stakeholders.

There was widespread acceptance that actions and attitudes towards involving service users in the design and delivery of services had gradually improved over the past decade. Yet, the surrounding culture could be unsupportive of efforts to involve service users. This, then, could highlight broader systemic issues which impact opportunities to create epistemic communities and spaces (Anderson, 2012; Fletcher and Clarke, 2020). Participants alluded to a defensive, risk-averse culture, where services could be fearful of getting things wrong, staff are possibly wary of 'airing their dirty laundry' and the reputation of the organisation is trying to be upheld. Structural tensions inhibiting co-production such as lack of time and resources were also raised in discussions and for some, this reflected the priority attached to involvement of service user groups in QI. The various discussion points examined in this section offer further understanding of the context of involvement, and highlight deficits that can limit the ambition of co-production and co-design. Despite widespread positivity towards involving service users and collaborating effectively, it appeared that this was not a straightforward route, and rather, one tinged with hesitation and uncertainty.

CHAPTER 10

The Absence and Presence of Service Users in Quality Improvement

Chapter 10 introduces the third set of research findings. This chapter draws concepts of service user involvement, co-production and QI together through further interrogation of interview and observational data gathered from following three CMS teams. The main purpose of following these CMS teams was to examine the involvement of service users within CMS work being undertaken. In practice, the involvement of service users, both in terms of their presence in meetings and the use of their input captured through other means, could be best described as sporadic. This contrasted conversation that had taken place before the research commenced in which CMS teams had acknowledged the use of service user knowledge to help drive QI efforts. The research focus therefore moved to examine the lack of service users in the CMS process and to make sense of the various discussions taking place. It was evident that the respective health-related needs of the service user groups served by teams presented key challenges to their involvement. At the same time, however, the research findings highlight a lack of clarity over the roles of service users in addition to questioning the credibility of service user knowledge in the collective efforts of QI. To make sense of the intricacies observed in the research, then, this chapter is separated into two sections.

The first section provides insight into how service user involvement was organised in respective CMS teams before exploring how CMS teams perceived challenges of involvement. Here, the research explores a link between claims to knowledge and the appropriateness of involving service users in QI. This discussion is examined further by drawing upon the concept of epistemic injustice. The second section of this chapter focuses on some of the actions and discussions that took place in regards to the potential involvement of service users. Some of these were raised in response to the challenges highlighted, for example, the notion of having the ‘right’ service user for QI. In addition, the second section of this chapter also attempts to make sense of the various discussions that took place as some CMS teams increased their efforts to recruit service users.

Findings are organised under the following headings:

10.1 The Challenge of Service User Involvement

- 10.1.1 ‘Service Users in the Room’
- 10.1.2 Other Sources of Service User Experience Data
- 10.1.3 Service User Involvement and the Nature of Impairment

10.2 The Potential Selection of Service Users

- 10.2.1 The ‘Right’ Service User
- 10.2.2 Representation and ‘Representativeness’
- 10.2.3 Overcoming Challenges of Involvement

10.1 The Challenge of Service User Involvement

10.1.1 'Service Users in the Room'

This section offers an overview of CMS teams and their approach to the involvement of service users. Discussions that took place within teams and individual conversations signalled a desire for service user input within the CMS process. However, in practice, there was a lack of service user involvement in the CMS process. In the Eastview CMS team, no meetings included service users. Within the Westside CMS team, one meeting observed included a service user, whilst the team also remained fleetingly in contact with a service user volunteer through email. In the Northside CMS team, towards the end of the research, two service user volunteers were recruited as part of the team; two of seven meetings observed included service users. The absence of service users was not lost on teams. For example, Northside and Westside CMS team members often expressed frustration at not having service users present within meetings. This is captured in the comments below:

> ***Northside CMS: Meeting 4: Post-meeting evaluation phase***
> *"Bizarre how we can have CMS meetings without a service user and that worries me!"*
> *"Bizarre how there hasn't been any (service users) and actually how the conversations would be different"*
>
> ***Westside CMS: Meeting 1: Team discussion of current QI project - Improving care planning documentation***
> *"It's obviously for us (healthcare professionals) that will use it (care plan) - but it's also essentially for the patient, it's about them, so we need them here!'*

The Westside CMS team did have an arrangement in place which involved conducting CMS meetings at a participating service user's home. 'Home' CMS meetings, as they were described, represented novel attempts to engage with a service user and this was roundly credited in various Trust-wide communications[7]. This said, no 'home' CMS meetings took place over the nine-month study period. Therefore, whilst this arrangement was well-intended, the lack of meetings could question what meaningful impact this arrangement had. Nonetheless, having service users 'in the room' was characterised as gold standard practice. This is consistent with CMS guidance which states how involving patients in CMS improvement meetings are essential. For Jason, a Northside CMS staff member, the physical presence of service users in CMS meetings was instrumental to help maintain focus:

> *"**The CMS meeting is markedly different when the service user is there I would say, in that, people focus and attention is just more geared towards having the voice in the room**… I think it is more the way people speak in meetings, and it is, it reflects that someone is in the room… so even if they (service users) are not speaking, like it has a real observable impact on the way that people present their ideas and approach situations […] **we are so focused on details and processes within the service, you kind of get lost in that, and you stop thinking about the service user, so I think it definitely helps**." (Jason, Staff Member, Oston – Northside CMS)*

Similar views were expressed by other team members noting how the visible presence of the service user could result in a greater quality of communication. The presence of service users also seemed to suggest teams would have to be more prepared and focused in meetings. This was noticeable during CMS meetings where a service user had attended e.g. preparation of the meeting room (e.g. food and drink), all staff members ready with the meeting starting promptly on time, and CMS documentation (e.g. mission statements, global aims) all at hand. Several staff members echoed a preference of involving ex-service users or other volunteers whom the service did not have a current clinical relationship with. Probed further, staff were wary of causing further distress to 'already vulnerable' service users and therefore this preference was underpinned by a sense of protectionism. In addition, it was also seen as an opportunity to safeguard current professional-service user relationships:

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[7] The Westside CMS team delivered a workshop at the Trusts' annual health and safety conference regarding this arrangement, receiving much interest and support. This arrangement was also positively raised in conversations with senior members.

> *"I imagine staff are concerned that the demands on the service user of being involved in QI might have a detrimental effect on their well-being. They might have also built a relationship with that person when they worked with them, and so potentially that may be threatened." (Simon, QI Coach, Oston - Northside and Westside CMS)*

Sophie, a QI Coach of another mental health CMS team, also admitted to being cautious when trying to involve service users. A lack of clarity over how to negotiate service users' involvement was offered as a reason. It also further suggested that a 'protectionist' stance was not isolated to the CMS teams under study:

> *"**I've got to a point that I don't actually involve people who are acutely ill, but I used to**, and so it's just the boundaries of what to do, they are blurry and I don't know whether they'll ever be clear, but if there can be some clarity that would help, I don't know, but I tend to be wary now" (Sophie, QI Fellow and Coach, Cranton)*

Involving ex-service users may help navigate certain ethical issues e.g. care and legal responsibilities and therefore represents what may be considered a 'simpler' route for involvement. This said, service users in current receipt of services offer real-time feedback and are more likely to experience any subsequent changes that are implemented. Subsequently, this raises a paradox: whilst reasons of 'protection' may be for valid, it can be problematic if potential service users are excluded without asking them first or assuming they may not want to participate (Mulvale et al., 2019; Moll et al., 2020). Calls for further clarity from staff (as Sophie notes above) does however suggest a need for further organisational support and dialogue over how to engage service users in QI. This support could extend to helping staff make informed ethical decisions where they reflect on their ethical responsibilities along with the rights of service users to participate (Liabo et al., 2018). The Trust did have a dedicated Continuous Improvement Team with a remit for co-production and QI. Across the research period, this available channel of support was noted on several occasions by CMS teams and QI leads. The following field note provides reflection on one example where the Northside CMS team called upon support from the Improvement Team:

<u>Field Note: Westside CMS - Meeting 8 - Meeting with Cranton Continuous Improvement Team</u>

> *The Westside CMS team contacted the Improvement Team after struggling to decide how to gather service user views on care plan documentation. In a scheduled CMS meeting, a member of the Improvement Team worked with the CMS team to focus on opening dialogue with service users and also in the design of questionnaires that were to be sent out e.g. phrasing of questions, choice of language. CMS team members noted increased confidence remarking how additional help was required at times as this was not their 'usual' area of expertise.*

Despite strong assertions of service users 'in the room' as best practice and frustration expressed when meetings lacked service users, several conversations with frontline staff revealed that involving service users was not necessary ideal at all times. One of these occasions was when QI projects revolved around staff processes or internal systems:

> ***Interviewer: Do you feel there should be a service user in every meeting?***
> *L:* ***Yes, in a CMS I do… Actually hmm… it maybe varies a bit depending on what project we are doing as well.*** *The stuff that we are doing at the moment, maybe that would be really dry for them, for service users to be sitting on, because we're talking about the referrals process, it's for the greater good, but I think it is quite a dry topic and I wonder how much of that would go over their heads or whether it would be stressful for somebody […] but with the other projects, so the stuff that we were doing with the waiting rooms, it was absolutely key to have one, two service users helping. […] So yeah,* ***I think it is important, but I can see why some projects might be easier than others.*** *(Lauren, Staff Member, Oston – Northside CMS)*

Rather than being wary of opening up to service users, which could reveal issues within the service, Adam (below) noted awareness of trying to avoid tokenistic practice i.e. 'involving service users for the sake of it'. Although, this in itself may imply a lack of defined role for the service user in CMS work.

> *“(In reference to the team’s referrals project) I was apprehensive of having a service user there because* ***it might be seen as doing it in a tokenistic way, and actually it may cause someone a lot of distress for the sake of us just saying ‘service users are to be involved in that’****. I guess it is all about whether it is relevant, really (Adam, Staff Member, Oston – Northside CMS)*

Nathan, the Eastview QI Coach, was more explicit about the positioning and roles of service users in CMS work:

> *“****It is good to have a service user now and then, but I think, maybe, it needs to be planned within the process****, not necessarily ‘every four meetings we are going to have a service user involved’, but maybe plan when we do CMS, what is on the agenda and then we discuss whether it would be good to get service users involved in the next meeting. You know, so maybe that is when you would get a service user involved when we think it is an appropriate time to do it, rather than having them every week.” (Nathan, QI Coach, Dexton - Eastview CMS)*

Suggestions from staff team members over involvement taking place at an ‘appropriate time’ or seemingly questioning the ‘relevance’ of service users reinforced the control of professionals over the CMS process. Service users being involved on an ad-hoc basis is more characteristic of a consultative process i.e. the team ‘checks in with the service user’ to attain confirmation of something that the service user may have little comprehension. In respect to teams’ actions and conversations, then, it was apparent that service users were not recognised as ‘core’ team members. Subsequently, and as raised in Section 8.1.1, this perspective may limit opportunities for service users to access the ‘more impactful’ stages of the CMS process, which includes decision-making processes around design and implementation.

10.1.2 Other Sources of Service User Experience Data

In the absence of direct service user representation, CMS team members listed various sources of other service user experience data available to them e.g. Care Opinion, Friends and Family Test (FFT), suggestion boards, complaints and surveys. The Westside CMS team referred to how a previous CMS project - improvement of the waiting area - had emerged from their service user suggestion board. However, despite being aware of the various sources of data (routinely being collected by services), it was unclear how this data was built into continuous QI. This is something that was recognised by Ian, the Trust CMS Programme Lead, who suggested a disparity between the collection and meaningful use of data:

> *"I think we sort of have a process that meets the needs of collecting and responding to feedback, a complaint or suggestion, whatever, rather than generating that as an opportunity for improvement. I think we've made strides with that, but that could be better as well" (Ian, CMS Programme Lead, Cranton)*

It became apparent that using service user experience data was influenced by concerns over time and the required skill-set to respectably make sense of the data – *'the reality is that we are not trained in this level of analysis' (Comment by staff member at Westside CMS meeting).* Furthermore, it was unclear whose responsibility it was within teams to manage experience data. The challenges of incorporating service user experience data have been discussed at length in the literature (Martin et al., 2015; Gleeson et al., 2016; Flott et al., 2017). Sheard et al. (2019, p.51) report how organisational structures place intense focus on data collection at the expense of understanding the data. This means that service user feedback, whether positive or negative, is not processed even though they may have given their time and effort to respond.

On occasions, staff team members drew upon conversations or exchanges that they may have had with service users: for example, some Northside CMS team members were involved in a community research group. These exchanges could highlight service user concerns which the staff member would then recall and input during service development activities. Thomas, the

Trust QI Facilitator, emphasised the strength of using these exchanges as a conduit to inputting the voice of service users:

> *"I think it is everyone's role to put a service user voice in it.* ***Sometimes when we talk about the gold standard of having a service user involved in CMS meetings, we seem to minimise the fact that every member of staff has hundreds of interactions with service users throughout the day, so ask them – what do service users tell you about this? What things do you hear all the time?*** *I mean it's second hand knowledge, it's not ideal, but it's still bringing the voice into things. (Thomas, Trust QI Facilitator and Coach, Dexton – Eastview CMS)"*

Thomas appears to refer to what has been described in the literature as 'wild data' - "the informal, embodied and intuitive knowledge about patient's experiences that staff acquire during daily interactions with patients" (Montgomery et al., 2020, p.9). Wild data may counterbalance challenges of facilitating direct service user representation, constraints of time and capture data missed by more formal collection methods. Equally, the 'authenticity' of service user experience data may be questioned given it is not coming directly from service users. Using 'wild data' may raise questions about whether comments could get filtered e.g. negative and awkward comments. It also leaves open the possibility that data can be manipulated to advance particular ideas and mirror staff taken-for-granted practices. On a practical level, reliance of wild data could privilege the knowledge provided by certain members of staff e.g. those with frequent service user contact or members who regularly attend CMS meetings. It was clear that teams recognised various sources of experience data available to them, but lack of time and skill could be limiting factors in making sense of the data. Subsequently, despite the power of this data, it was not immediately clear how it could be used to drive QI.

10.1.3 Service User Involvement and the Nature of Impairment

The complexity of impairment needs across the respective service user groups presented clear challenges to their involvement in CMS teams. Attitudes towards the involvement of service users, then, although idealistic were, at the same time, sceptical. A visible theme throughout the data was service users' vulnerability to potential epistemic challenges of their knowledge. Rachel, the Trust Continuous Improvement Manager, queried the feasibility of involvement in a mental health inpatient environment like Dexton:

> *"If they're quite ill, it's not appropriate. I know clinicians are making them decisions, but actually, I'm no clinical person, but I guess if you're detaining somebody or whatever, how can they be fit to be involved? And do they really want to?" (Rachel, Continuous Improvement Manager, Cranton)*

Nathan, the Eastview QI Coach, also questioned the 'appropriateness' of involvement given the 'unpredictable' and 'vulnerable' nature of mental health within the Dexton service:

> *"**They are unpredictable, vulnerable service users that we have here**, so by that… you can't say every two weeks we're all going to sit down, and we're going to definitely have a CMS meeting. **That would be the most productive way to do it, however, because they are so unpredictable that is very difficult to do.** The service user might be well in the morning, but by lunchtime they might not be, something might have happened and so you have lost that service user.*
>
> *It's very difficult to shape services around what we perceive the problem to be… now you'll only get that by talking to the service user, **but are they so unwell and unpredictable that it probably isn't reasonable what they're saying"** (Nathan, QI Coach, Dexton – Eastview CMS)*

Nathan's characterisation of service users as unpredictable and vulnerable may be unintentional however some of this language resonates with the historical and often negative labelling of mental health service users. In the context of mental health, existing research documents how service users have been described as 'morally defective' and 'risky subjects' in spaces of involvement (Beresford, 2009; Lewis, 2014; Bee et al., 2015; Le Blanc and Kinsella, 2016). Nathan was not alone in questioning the service users' capacity to be involved, but a challenge nonetheless - *"are they so unwell that it isn't reasonable what they're saying"* -

appeared to raise broader concerns around the credibility and legitimacy of service user knowledge (Lewis, 2014). Questioning the credibility of service user contributions highlights epistemic challenges to their knowledge leading to the potential generation of testimonial injustices. In the above account, for example, description of 'unpredictability' and 'vulnerability' cast a shadow over the credibility of service users' knowledge and their ability to participate. Epistemic challenges (value of knowledge being provided) are particularly heightened within mental health services given negative stereotypes attached to a psychiatric diagnosis (Crichton et al., 2017; Scrutton, 2017; Newbigging and Ridley, 2018).

A view over the feasibility of involvement in QI was less pronounced within Oston-based Northside and Westside CMS teams. This is possibly because service user involvement was supposedly embedded in other areas of the service. It may also be that traumatic brain injury conferred different features (to mental health) resulting in issues of capacity or ways of involvement being less difficult to navigate. However, as the account below suggests, questions over the capacity of service users to understand the QI process also persisted here:

> "*There is a sense that service users might struggle to understand the complexities of the service and the CMS process, the methodologies, the details and that… within that environment, having more of a say and more power within the decision-making process**, they might influence decisions in a direction that some staff might feel aren't the right directions for the service, because they haven't got a good understanding and necessary knowledge of the complexities of the delivery of a service"** (Simon, QI Coach, Oston - Northside and Westside CMS)*

Difficulties pertaining to understanding CMS processes and technical QI language have been documented in the literature. This said, there also appears to be a suggestion that involving service users could result in a loss of control over projects – *"they might influence decisions in a direction that some staff might not feel are the right direction for the service"*. This resonates with what Bergerum et al. (2020) describe as a 'tug of war' in QI between whose knowledge (professionals or service users) takes precedence. Questioning the intellectual capacity of service users' nonetheless highlights challenges to the knowledge they hold. The challenge presented above, not in isolation, seemingly questions the participation of service users on the grounds of possessing insufficiently articulate knowledge (Carel and Kidd, 2017). It was also evident, then, that professionals saw themselves as possessing the 'expert' knowledge in these settings. This was further indication of their epistemic authority and privilege.

Both Nancy and Eve, long-term service users of other community mental health services, were involved with other respective CMS teams. These teams were not followed and therefore it was difficult to ascertain the level of involvement. Nonetheless, their involvement indicates that they were in receipt of some epistemic privilege as they had been granted access to share their experience and knowledge, whilst being involved with professionals. Yet, in response to what she saw as barriers to service user involvement in CMS QI (acknowledging that this was relatively low across the trust to her knowledge), Nancy noted negative staff attitudes towards service user knowledge was still evident in places:

> ***Interviewer: What do you feel are the main barriers to getting other service users involved in CMS work?***
> *N: Well apart from the fact that the assumptions that 'we don't understand' 'we are not reliable', 'we don't have time', 'it takes a long time to get them involved because we have to explain everything'… well it's on you [professionals] to change that! (Nancy, Service User trained QI coach, Cranton)*

Phrases like 'we don't understand' or 'we are not reliable' again echo staff doubts over the intellectual capacity of service users. This may further illuminate the power of negative stereotypes where service users may not be taken seriously. It is also pertinent here, then, that Nancy refers to the responsibilities of services to provide service users with the necessary tools to share their knowledge. In doing so, she raises how service users are also at risk of hermeneutical disadvantages due to the lack of resources available to allow them to articulate their knowledge (Hutchison et al., 2017). Fricker (2007 p.1) explains how hermeneutic injustice corresponds to "flaws in shared resources for social interpretation". A lack of time, a prominent issue discussed across previous chapters, is also an indication of hermeneutical challenges. This leads to insufficient interaction with service users and limited space to make sense of service user experience data. Grim et al. (2019 p.165) describe how lack of time is emblematic of poorly fitted formats within organisational structures that fail to give primacy to the collection or use of service user knowledge. A perception-based view linked to a complex label of mental health was reflected upon by Daniel:

> *"I do think the issue around… you know, there probably is still a perception – 'well there is no point in involving him because he is hearing voices, so'.* ***That idea that the whole person's potential to contribute to the world is wiped out by a set of experiences. I mean, yeah, I think that is still probably a shadow.****" (Daniel, Non-Executive Director, Cranton)*

Both Nancy and Daniel's reflections emphasise the deep-rooted tension between who is heard and how, and this raises the notion of prejudice and credibility. Testimonial injustice may result from an identity prejudicial credibility deficit (Carel and Kidd, 2014; Naldermici et al., 2020). As a result of a psychiatric or life-limiting diagnosis, an individual's credibility as a knower may be dismissed and subsequently the individual is stripped of their agency. Subsequently, opportunities for involvement may be reduced. Testimonial injustices may be further perpetuated by the internalisation of views - 'difficult', 'unpredictable', 'vulnerable' – from service users themselves (Hutchison et al., 2017). During conversations with service user volunteers, they often, although in jest, characterised themselves as being 'difficult'.

> *"We are difficult clients when we first come here [laughs], we don't want to be here, we are confused, we don't know what day it is […] You're working with such damaged individuals [laughs], because we are easy to upset sometimes I suppose, we can upset other people sometimes" (Eric, Service User Volunteer, Oston)*

> *"…because we're a difficult bunch of people… carers particularly [laughs]." (Aisling, Service User Volunteer, Oston)*

Nancy, a service user trained QI Coach, for example, described herself as a ‘nuisance’:

> *“… they told me that I was like a Yorkshire Terrier with a bone [laughs]. I would not shut up until something was sorted out, whatever it might be!” (Nancy, Service User trained QI Coach, Oston)*

In these conversations, there was honest self-reflection about the personal challenges that each person had faced with their ill-health or in their caring responsibilities. Nonetheless, internalising views of being ‘difficult’ or ‘damaged’ may perpetuate existing hierarchies and the taken-for-grantedness of the dominant professional perspective - *‘professional knows best’* (Hutchison et al., 2017; Godrie et al., 2020). Carel and Kidd (2014) describe this as ‘self-censoring’. The broader harm is that this could potentially influence the confidence of service users to participate, resonating with potential ‘imposter phenomenon’ and service users downgrading their own abilities and knowledge (Carel and Kidd, 2014).

10.2 The Potential Selection of Service Users

> *“On the issue of representativeness, I mean, we could spend the rest of our days trying to ensure that bodies are representative, but that is no excuse for them to be wholly unrepresentative!” (Daniel, Non-Executive Director, Cranton)*

This section attempts to make sense of the discussions and actions taken by some teams as they increased efforts to involve service users in the QI process. In discussion, issues of selection, representation and professionalization were raised and these are discussed in a broader context.

10.2.1 The ‘Right’ Service User

Discussion over the selection of potential service users mirrored discourses of ‘appropriate’ and ‘right’ service users for QI. This contrasted earlier discussions with CMS teams, where the process was described, in democratic terms, as being open to ‘anyone’. Staff members of the

Westside CMS team spoke favourably about how their participating service user, Jan, was a confident individual and it helped the team that she came from a previous healthcare background (although her career had ended prematurely because of ill-health):

> *"She has a background in the NHS, she is a really bright lady, confident, very physically impaired, but she said she fancied a project […] and she probably has an idea of some of the inner workings and whatnot [from her prior experience]" (Ruth, Staff Member, Oston - Westside CMS)*

Referring to Jan's knowledge of 'the inner workings and whatnot' seemingly suggested a good fit for QI. Identifying service users based on 'advantageous' characteristics was more evident within the Northside CMS team as this team had a larger pool of volunteers to select from. Both a previous service user who participated and a new service user recruited towards the end of the research were described as possessing significant managerial experience (in a non-healthcare background) that entailed heightened credibility. This credibility related to understanding and a sense of 'comfortableness' with the systems-orientated process of QI. In conversations, it also emerged that the Northside CMS team had a previous negative experience of involving a service user in the CMS process, and where the service user was asked to step down. As a result, the team could be seen to approach the selection process with some caution:

> *"We did have problems… we picked somebody who it turned out, wasn't very suitable for that role. They had other medical problems, mental health problems, which in the end meant that they really struggled with the idea of reaching consensus and decision-making by consensus. They very much felt that, because of the things that they thought weren't always agreed on, that in some way, they had an expectation, as a service user, they would come in, and whatever it was they said, that would happen…* ***their perception was that their voice wasn't being heard, and that was based on the fact that we didn't always agree to do the things that the service user was saying we should."*** (*Simon, QI Coach, Oston – Northside & Westside CMS)*

Two notable tensions are raised as Simon describes, what he considered, an unpleasant experience. The complexity of impairment - *''they really struggled with the idea of reaching consensus''* – and a lack of clarity over the roles and expectations of involvement. The team's negative experience appeared to explain some of the reservations within the Northside CMS team as they discussed the selection of potential service users.

> *"That previous experience is possibly something that might be brought up as a reservation about doing it, so, we know,* ***we would need to give the staff some confidence around the selection process, that we, I think we are a lot more aware of the features in a service user that is necessary in order for them to be able to actively participate in the CMS****." (Simon, QI Coach, Oston – Northside & Westside CMS)*

It became clear from the discussions taking place in meetings that staff were close gatekeepers of the selection process, deciding who should be approached and involved. This further indicates their epistemic advantages as decision-makers of the process (Carel and Kidd, 2017). The following research field note captures a discussion that took place as the CMS team went through a volunteer list whilst deciding whom to approach and invite:

Field Note – Northside CMS Meeting 3: Discussion of potential volunteers for CMS involvement

> *"Hmm… (that service user) could be a double edged sword"*
> *"I don't think he'd like this"*
> *"Don't know whether this is for them"*
> *"I think she struggles with decision-making"*
> *"He could be good… I also think he has a professional background"*

The above range of comments that have been presented summarise much of what has been discussed up until this point in this chapter. For example, questioning the decision-making capacity - *''I think she struggles with decision-making''* - highlights the complexities of the condition but which also raises doubts over their subsequent capacity to be involved. Assumptions are made around whether a particular individual would or would not like this opportunity to be involved (with the professional ultimately making this decision). Concerns over impairment impacting involvement may be well-intentioned. However, at the same time, the description of a particular service user as – ''*they could be a double edged sword*'' - suggests hesitation to involve someone who could potentially affect group dynamics. Again, this is pertinent given the team's previous negative experience with a service user. Nonetheless, these comments suggest there were expectations of 'appropriate' and 'acceptable' service user behaviour which could reflect normative expectations of collaboration (Lewis, 2014). In this respect, involvement in QI is conditional with certain forms of communication or etiquette, which closely align with professional forms of communication and interaction (Lewis, 2014; Carel and Kidd, 2017; Brosnan, 2019). Carel and Kidd (2017 p.342) describe this as *strategies of expression* where groups are excluded from participatory spaces because "their characteristic expressive style is not recognised as rational or contextually appropriate".

An ideal form of service user behaviour and correct forms expression can exclude certain groups from these spaces: these are likely to be those with limited agency. Both Eva and Nancy, service users involved in other CMS teams, noted how they were approached to take part on the basis of having an extended history with the service and were seen, in their own words, to be 'good fits'. Nancy had also been supported to train and become a fully qualified CMS coach. She acknowledged her extensive professional and volunteering background (e.g. service user governor, staff recruitment panels) that spanned over two decades. In all respect, she could be identified as a 'confident' service user that reflected this 'ideal' service user behaviour.

It also emerged from conversations with CMS team members that a certain level of confidence to engage and contribute to conversations with staff was seen as a prerequisite for any involvement: it was highlighted here that service users were to be involved in wider service design and development rather than their own care. Confidence can reflect age, social status, previous work background, volunteering experience. However, the broader argument is not that a level of confidence is not required; this is needed to express thoughts and interact with professional peers in a team-based environment (Martin and Finn, 2011). But, rather, whose responsibility is it to become confident? Lack of confidence and self-esteem are obstacles for many vulnerable service user groups and without hermeneutical resources and adequate arrangements for their involvement, further exclusion of these groups is risked (Beresford, 2013a; Scholz et al., 2019). This is not helped by presumptions about certain characteristics of ill-health that suggest an inability to participate as has been described in this section.

10.2.2 Representation and 'Representativeness'

The research findings described in the above section highlight how teams showed preference for service users with favourable features for involvement in CMS work. It was reasoned that the selection process was a tightly-controlled practice that may lead to the inclusion of some individuals and the exclusion of others. At the same time, there was a concern in teams and also more wider within the Trust around issues of representation:

> *"I do think there is a problem with usual suspects, but I don't think the problem is with the people though. I think, it's the fact that the organisation finds that easy to do, and I also understand why the organisation finds it easy to do, because involving people is hard,* ***but obviously it means if you do have the same people turning up all the time, the views you are likely to be able to get hold off and hear are likely to be more limited than if you had a more diverse body****." (Daniel, Non-Executive Director, Cranton)*

Daniel raises concern over being reliant on 'usual suspect' groups. These groups have been described as possessing 'preferential' characteristics sought by professionals, leading to suggestions that service users become desensitised into the organisational way of thinking (Beresford, 2013a; Moll et al., 2020). For services, choosing these individuals may reduce time and resource-costs with training and prior administrative checks already undertaken. Jane, the Trust's Deputy Medical Director, further described how these groups may represent 'safe pairs of hands' (Hogg, 1999) but what was needed was for services to be challenged:

> *"We have that problem here in the organisation.* ***We have people who are, who we know, who will say yes, who we almost know are going to play the game, and do what we want because they are culturalised to behave like we want them to behave****, and that causes completely missing the point, because what we really need is people who will challenge us" (Jane, Deputy Medical Director, Cranton)*

A label of 'usual suspects' can be somewhat unfair as this almost reprimands service users for putting themselves forward rather than the service being reliant upon them (Beresford, 2013a; Maguire and Britten, 2017). This, to some extent, is observed within the accounts of Daniel and Jane as both suggest contextual challenges within organisations i.e. matters of ease, time and sharing similar views could influence who is selected. This latter idea of sharing similar views could relate to professionals relying on service users to 'legitimise' their decisions (Harrison and Mort, 1998). The notion of 'usual suspects' was also reflected upon by Eric, a service user volunteer, who described his own route into involvement as taking an unusual path:

> *"There are quite often the same usual suspects that are involved, in whatever…that is usually someone who is a retired captain, squadron leader [laughs], someone in a senior position, ex social worker, you know what I mean"*
>
> *"I would like to see more of those service users who have come, not just from the gutter, but close to that, you know what I mean, that have come under the stone […]. Not just those service users that are quite confident anyway because of the background they have" (Eric, Service User Volunteer, Oston)*

The above range of statements describe how representation remains a pertinent tension in the selection of service users. It is also important when the discourse of involvement, co-production and QI revolve around an equitable and democratic rationale. Some CMS staff were conscious about achieving representation but this was not helped, in their words, by service users unwilling to participate – ''*the reality is that we're not inundated with service user volunteers for this type of work''*. There is some conflation here given that staff expressed service user preferences which imposed a narrow selection process. In a slightly contrasting manner, and although cited in a small number of interviews, some caution was observed regarding the unrepresentativeness of involved service users on the basis that they could only share their own knowledge. This is captured in the respective accounts presented below.

> *"Occasionally we have had a service user in here and it has been really good when they have been here,* ***but they only see it from their point of view, whereas, the staff see it from maybe four or five points of view****, so having more service user involvement, whilst good, you can't get focused on one service user's needs, you don't want to run the project, or do the improvement based on one service user's needs, even though they might be fully engaged, ultimately they can only see it from their point of view." (Adam, Staff member, Oston - Northside CMS)*

At the same time, Simon, spoke about how some conversations would need to take place if service user numbers were increased in CMS meetings:

> *"If we were to have more service users in here, I mean they have different voices, they don't all have the one voice, they often have different opinions****, but I don't know how challenging the staff would find that, to have more equality in terms of the make-up of the meeting, in terms of the numbers if people in there, the proportion of service users compared to staff****." (Simon, QI Coach, Oston - Northside & Westside CMS)*

The above pair of statements highlight the intricacies of collaborative working, whilst to some extent, further reiterating that professionals see themselves as the 'expert' knowledge holders. In addition, it could be argued that these statements show signs of "acute hypocrisy" Martin (2008b p.1758). Martin (2008b) describes how professionals may allocate a single space for service users in teams but then their 'representativeness' is questioned as they can only represent a singular view. Challenges to representativeness have been recognised as ploys to maintain control and defend existing power relationships (Beresford and Campbell, 1994; Martin, 2008b; El Enany et al., 2013). This, to some extent, is reflected in Simon's assertion of relinquishing equality in the make-up of the meeting. There was a conscious view that 'representativeness' was near impossible to attain even if a select group of service users were present: “any individual claim to belong to or represent the public will face some opposition from other categories of actors” (Contandriopoulos et al., 2004, p.1590). Nonetheless, this chimes with Daniel’s opening quote at the start of this sub-section (p.170): *“we could spend the rest of our days trying to ensure that bodies are representative, but that is no excuse for them to be wholly unrepresentative!”.*

Within the literature, challenges to representation are closely tied with the tension of ‘professionalization’. To some extent, this was apparent in the conversations that concerned talk of representation. For example, Jane described a concern over selecting service user volunteers *‘who we almost know will play the game’* (p.175) and which could manifest as a professionalised form of lived experience:

> *“One of the problems or challenges that we have is, representation, and breadth of representation. […] Again it’s very easy to end up with a professional lived experience user [laughs]” (Jane, Deputy Medical Director, Cranton)*

Participants associated a ‘professionalized’ lived experience with the selection of known individuals and groups. Service user identities as ‘lay’ contributors may come under challenge as a result of their background, experiences and training they may have received within the involvement role. However, as has been revealed in this chapter, services can be complicit when they look for features beyond the ‘lay’ knowledge of service users. In this respect, there was a certain paradox to how teams and participant interviews characterised the involvement of service users. For example, some staff in the Northside CMS team spoke positively about their new service users’ previous managerial experience and how it could contribute towards the CMS process going forward. At the same time, concerns were aired that this possibly did not reflect the wider service user subgroup as the comment below indicates:

> *“I guess the thing is, sometimes… our last volunteer,* ***he had such a wealth of knowledge, he had business experience, like strategic experience****, he brought, sometimes it felt like he thought that was his role, it was kind of like a business consultant to the group, which isn’t, which is of course is valuable,* ***he came up with some good ideas, but at the same time, it was like, but you’re also here to***

> ***represent patients and service users, kind of, that professionalized view that he had, wasn't reflective**." (Jason, Staff Member, Oston – Northside CMS)*

Where service users holding little knowledge may be seen as a limitation, too much knowledge may be seen as 'professionalized' and not representative (Thompson et al., 2012): this is akin to a 'Catch-22' situation (Learmonth et al., 2009). This is not to say that service users' input was not helpful and this was certainly welcomed but the knowledge they shared could be questioned. Regarding recruitment of service users, there was no current arrangement in place (within CMS teams) to introduce the CMS process to service users although this idea was welcomed e.g. QI introduction training. Equally, it was unclear whose responsibility this was to coordinate and there was acceptance that this would take considerable time and effort. An introduction to QI may help familiarisation with the concepts, principles and language of QI. It was difficult to determine the impact of service users in meetings (when present) as they were either one-off meetings or the CMS process was relatively new. However, it was noticeable that a lot of technical terms and acronyms were used and, on occasions, service users would temporarily stop the meeting to ask for clarification.

Opportunities for service users to be introduced to QI (through the introductory two-day course that was delivered to staff) was a particular recent ambition for the Trust. Nancy was a service user trained QI coach however she noted that this idea was first proposed by herself after being regularly involved in CMS meetings. When asked about the potential for further developing QI training for service users, Ian was hesitant over whether this could lead to the incorporation of more 'professionalized' views:

> *"The particular service users who are involved in CMS are almost professionalised in a way. **I think there are a number of barriers, to a service user, becoming a CMS coach. They would have to have the special set of conditions really, they'd have to want to do it, and they'd need some means to be able to do it, would we employ them? And then that changes the whole dynamic**, I think, it would have to have a special set of circumstances." (Ian, CMS Programme Lead, Cranton)*

Reflecting on the possibility of more service users becoming coaches, Ian, questions whether this would force a change in dynamic (in the relationship between service user and service) and how this would be facilitated in respect to terms of employment and payment. Nancy did not receive extra payment in the role (bar travel reimbursement), but it is easy to see how this tension may play out given that professionals are being paid for carrying out the same activity. More pertinently, the above reflection casts a doubt over the identity of the service user and questions the 'layness' of a participant. 'Lay' people are assumed to retain the 'ordinary' norms and values of the society. On the other hand, the 'lay' expert may acquire norms, assumptions and value that resemble more professional ways of thinking (Hogg and Williamson, 2001; El Enany et al., 2013).

Ives et al. (2012) argue that providing training to service users can limit the 'layness' of people's experiences and knowledge. A counter-argument is that this 'layness' will always remain, and rather, training allows service users to develop skills such as confidence and teamwork. The absence of these skills has traditionally led to the exclusion of particular service user groups (Staley, 2013; Hutchison et al., 2017). There is a further argument to suggest that training equalises some of the power differentials as it provides stakeholders with the tools and skills to participate effectively. Beyond this, there are broader questions concerning whom is able to access these training opportunities and whether this could be further caught in a vicious cycle of exclusion i.e. leading to an increasingly stratified service user movement (Friesen et al., 2019). Nancy, for example, in her own words, was well assimilated into the organisation, had access to staff intranet and was involved in a number of roles. On the other hand, service users may not be aware of these training opportunities or feel that these opportunities are designed for them (Beresford, 2013a). This belief could further reiterate how service user groups may be at hermeneutical disadvantage.

10.2.3 Overcoming Challenges of Involvement

Amid the challenges of involving service users in QI, some participants highlighted the need for broader support mechanisms in order to diversify the 'constituency' of users involved. These type of reflections were predominantly offered by members of the Trust's Continuous

Improvement Team and service user volunteers. Recruiting more diverse groups is only possible if disincentives to involvement are recognised. Practical barriers to involvement may affect representation given they can limit access of some groups e.g. timing of meetings, transport, travel costs. Nancy identifies some of this her reflection:

> *"Professionals expect the service user to come to them, they do all the travelling, but many service users can't, for many reasons, and it is very difficult for them to get to a meeting, so they've got to invent or think of different ways to get service user involvement in, to stop the service user necessarily having to spend a lot of time travelling […]* ***I feel there is still very much a thought of 'well they have to come to us, into our meeting, and behave the right way'****" (Nancy, Service user trained QI Coach, Cranton)*

The arrangement within the Northside CMS team (as described in Section 10.1.1), which saw the conduct of 'home' CMS meetings, resembles an example of thinking 'outside the box'. Email contact was maintained amidst the challenges of engaging in-person. However, it was difficult to carry out collaborative work in this way and ended up being more a process of staff informing the service user about any progress the team had made. In addition, the technical language and acronyms used in meetings may help maintain the visage of professional activity; this was also described in Section 10.1.3. Tailoring language (or the lack of it) may potentially emphasise who belongs or who does not belong in these spaces. These were challenges that the Continuous Improvement Team were acutely aware off:

> *"****We want people to come, and when they do, we've got piles of papers that we then whizz through acronyms and so then how welcoming do we make it?*** *How accessible are we? You know, do we hold our meetings in places where it is easy for people to come? At times they can come? – I don't think we particularly great on thinking about that." (Rachel, Continuous Improvement Manager, Cranton)*

All service user participants expressed sympathy for the pressures faced by staff. However, a lack of attention towards structural deficits and incomplete examination of formats used to engage service users (as Nancy and Rachel discuss above) may indicate the value that is attributed to involving service users in QI. More broadly, this may have implied messages of power:

> *"I think building and spaces send messages to people, and they are implicit, they are implied messages about power, and who belongs here and who doesn't belong here." (Daniel, Non-Executive Director, Cranton)*

Ideas around access and design of involvement spaces place attention on the spatial arrangement – 'place and space' – to create environments which place value on meaningful service user involvement and co-production. Alongside this, calls for a renewed relationship between service users and professionals were offered by participants with lived experience of ill-health. This targeted the individual-interactional level where professionals were expected to continually reflect on the power differentials operating within their areas of work. Eric went as far as suggesting staff training on power dynamics:

> ***"I think, I'd like to see more comfortableness with each other, but, that involves addressing some uncomfortable things for some of these*** […] *there is an onus on a paid practitioner to let everyone feel comfortable to inter group, and that is really difficult to do.* ***So I think staff, practitioners, should have some training around power dynamics, and, group settings, before they embark on that, because it isn't easy for service user****, you can't just decide to, but all too often that is what people do" (Eric, Service User Volunteer, Oston)*

The need to reflect on power differentials was less visible in conversations with frontline teams. However, two senior members of staff did appear to suggest that personal and role reflection was vital:

> ***"We are culturalised as professionals to take control and to claim power****. Different professionals more so, but relinquishing that power doesn't come*

> *naturally to us at all, and **that's why I think this concept of continual challenge, renewal of challenge is so important**." (Jane, Deputy Medical Director, Cranton)*

Given the previous analyses of epistemic injustice, it may be, then, that these suggestions and reflections resonate with the notion of 'epistemic humility' (Buchman et al., 2017; Grim et al., 2019) or what Brosnan (2019 p.11) suggests as the need to develop 'epistemic receptivity' during practice of service user involvement. This is similar to critical reflexive practice where professionals, as the more dominant actors, reflect upon their methods of working, biases and assumptions and some of the barriers faced by service users (Grim et al., 2019; Moll et al., 2020). Such reflexive practices also require emotional work and this complements emotional labour that forms part of the practice of service user involvement and co-production work. Whilst acknowledging service user input as vital contributions to knowledge generation, reflective practice also helps to anticipate and prepare for potential challenges that may result from working with vulnerable service user groups. This, then, ensures relational safety for all stakeholders involved (Mulvale et al., 2021).

10.3 Summary

This chapter has built on previous findings sections to draw concepts of service user involvement and co-production together with QI. Whilst individual and team discussions signalled a desire to increase service user input into QI, in practice, involvement could be best described as sporadic.

A clear struggle to involve service users in meetings was observed and complexity of care needs was identified as a key barrier. In the absence of direct service user input, staff recognised the value of using other sources of service user experience data. However, the time and skill to interpret this data often failed to match the pace of data collection. The use of 'wild data' – staff drawing upon daily and informal interactions with service users – may offset some challenges. However, it should be considered that this represents second-hand knowledge. Where QI projects concerned staff processes and systems, there was uncertainty over how service users can contribute and assumptions existed around whether they would want to in the first place. This, for example, was indicated in discussions of service user involvement taking place at an 'appropriate' stage or when 'relevant'. Nonetheless, it was up to professionals to dictate when involvement was appropriate or relevant. Furthermore, the perceived lack of technical proficiency and knowledge (service users) could mitigate against participatory parity for service users which strengthened the specialised and esoteric nature of QI work.

Determining an appropriate time to approach service users was seen as challenging with concerns over disturbing clinical relationships. However, the capacity of service users to be involved was also raised on several occasions. Here, the generation of potential epistemic injustices, largely testimonial, could became visible, whereby the credibility of knowledge provided by service users could be disputed. In relation to QI, this was driven by doubts over whether service users would be able to understand the various processes and systems to make a meaningful contribution. However, in some conversations, hesitation around involving service users was underpinned by potentially losing control of the CMS process. Persons living with ill-health are especially vulnerable to testimonial injustice (described by Kidd and Carel (2021) as pathocentric injustices) because there is often a presumptive attribution of certain characteristics that negatively affects their perceived credibility. Healthcare professionals exercise their authority (and epistemic privileges) by deciding what degree of credibility to assign to individuals and groups.

A perception-based view on a person's ability to contribute likely determines who is granted access to spaces in order to be heard. Given this identity credibility deficit, recruitment and selection of service users was driven by perspectives of the 'right' service user. Through various discussions and exchanges, it was apparent that selection of service users could be driven by preferential features (such as confidence) with a professional background often seen as beneficial. Naturally, this could affect the representation of service users in QI. There was widespread recognition that lack of representation continued to underpin efforts of service user involvement, including and extending beyond QI. Yet the notion of representativeness, as characterised by some, was also somewhat paradoxical. Service users could be characterised as being only 'one' voice or 'too professional' yet also be seen unrepresentative as virtue of their backgrounds. Such findings find resonance with claims that professional challenges to representativeness and legitimacy may be seen as ploys to keep control over processes (Beresford and Campbell, 1994; Martin, 2008b; El Enany et al., 2013).

This chapter concluded by exploring some of the spatial features of involvement. The design of formats used in participatory spaces relay implied messages of power over who belongs in these processes. Participants described the need for greater focus on developing features such as access and meeting design which may increase the reach of potential service users. This should be done, as some participants noted, in tandem with renewed attention on the service user-professional relationship and one which requires “a disposition of epistemic humility “(Grim et al., 2019 p.171). Simply put, this requires professionals to engage in reflexive practice where they are continually reflecting on the power dynamics in operation. This is particular pertinent to the environment of QI, as it could be surmised that the process remained a very much tightly-controlled professional activity, starting from the design of the process through to the selection of service users. Even where the involvement of service users is approached with well-intention, a lack of clear roles and responsibilities (for service users) or restricting involvement to particular phases of the process, only serves to legitimise the practices of those embodied with greater authority and power.

CHAPTER 11

Discussion

This chapter reviews the empirical findings presented along with the existing literature and the research aims and questions of this study. In doing so, this chapter aims to identify the similarities and differences between my study and extant research before highlighting where my research contributes additional insight.

My research has focused on three key areas: service user involvement, co-production and healthcare QI. This research has commenced at a time when increasing attention is being placed on the role of service users within the design and delivery of healthcare services (Renedo et al., 2015; Robert et al., 2015; Batalden, 2018; Palmer et al., 2019). The impassioned plea for healthcare QI to acknowledge co-production (Batalden, 2018) as part of a forward-looking ‘third era of medicine’ (Berwick, 2016) calls for practice of service user involvement, co-production and QI to shift to the centre-stage. The linked aims of QI can be summarised as ‘the combined and unceasing efforts of everyone’ to deliver high quality care and services (Batalden and Davidoff, 2007). Subsequently, this highlights how successful QI relies upon collaboration between multiple stakeholders, that include service users. There are various definitions of QI. In this research, QI is understood as a specific and localised service development exercise which applies systemic change methods, tools and theory, and through which best practice solutions are implemented (Shah, 2021).

My research took place across two services (based in the same Health and Social Care Trust) that use CMS QI methodology as part of their QI efforts. In both settings, services are delivered to groups that may be considered particularly vulnerable: people living with traumatic brain injury and people living with mental ill-health requiring inpatient rehabilitation services. This thesis acknowledges that vulnerability is often misaligned with damaging and patronizing narratives which imply personal weakness or shift blame onto service users for making ‘poor’ choices and behaviours (Brown, 2013; Liabo et al., 2018; French and Raman, 2021; Røhnebaek and Bjerck, 2021). In respect to participation in healthcare research and QI, vulnerable service user groups face several social and structural obstacles that include challenges of access, communication and knowledge recognition. A number of these obstacles are, in part, a result of embedded power differentials. Power plays a fundamental role in enterprises of involvement and co-production (Arnstein, 1969; Carr, 2007; Rose, 2018). A central principle underpinning involvement and co-production is to allow service users to exercise their rights and powers through mechanisms of 'choice and voice' (Boyle and Harris, 2009; Dent and Pahor, 2015). Co-production is described using language of equality and reciprocity, and seen by many to disrupt existing power structures operating within healthcare (Sanders and Stappers, 2008; Needham and Carr, 2009; Slay and Stephens, 2013; Lambert and Carr, 2018). It is for this reason that co-production is recognised as being more transformative than other participatory methods.

Reviewing the Research Questions

This research study was driven by the aim of answering the following questions:

Research Question 1:
How are the concepts of service user involvement, co-production and quality improvement constructed and understood by key stakeholders?

Research Question 2:
How do the processes of quality improvement initiatives shape the roles and contributions of service users?

My research has focused on exploring the space of QI rather than on the outcomes of QI. Through the research, I explore how concepts of service user involvement, co-production and QI are understood by different stakeholders and observed QI practice to examine how service user involvement is discussed, and enacted. This combination of conceptual understanding and observation of practice has allowed critical examination of the role of service users in QI. It has captured the expectations of service user involvement in QI but also the reality of service user involvement in practice. This research exploration has been further strengthened through cross-examination of findings with key QI theory and the lens of epistemic injustice. Given that QI calls for the convergence of multiple actors with different backgrounds, experiences and knowledge, recognising the dynamics of collaboration is central to understanding the role of service users and their involvement (Donetto et al., 2015; Nimmon and Stenfors-Hayes, 2016; Ocloo and Matthews, 2016; Farr, 2018; Mulvale et al., 2019). The collaborative process is imbued with power dynamics that assigns credibility to certain forms of knowledge. This research, then, pays attention to processes of knowledge recognition and mobilisation in CMS QI, unpicking what this means for the involvement of service users.

In this discussion section, I turn now to reflect on the research findings and examine where my research supports, extends, or counters existing research. The research findings were separated into three distinct chapters – Chapters 8, 9 and 10. Chapters 8 and 9 addressed the first research question concerning how concepts of practice were understood and reflected upon. Chapter 8 explored how participants constructed the concept of QI, from why they felt they were involved in CMS work through to what was being achieved. In a similar vein, Chapter 9 examined how the involvement of service users and co-production was constructed with focus on intention, language and differentiation between concepts. In Chapter 10, research findings were presented to explore how service users were excluded from QI practice and how their involvement was operationalised.

11.1 The Construction of Quality Improvement

The intention of QI work was constructed positively by participants. QI was described favourably as an opportunity through which to achieve better outcomes, improve standards of care and lead to more efficient system performance. Certain benefits of the CMS process identified in the research include the ‘bottom-up’ democratic design which was believed to level out hierarchy and encourage team communication (Williams et al., 2009; Gerrish et al., 2018; Abrahamsson et al., 2020). There was evidence of the two larger CMS teams (Northside and Eastview) comprising of a diverse team of professionals that included non-clinical staff. A particular criticism of QI practice is how senior level staff have taken much of the control and responsibility in service improvement (Dixon-Woods and Martin, 2016; Jones et al., 2019). More diverse QI teams are able to draw upon a wider range of skills, networks and perspectives (Rowland et al., 2018; Locock et al., 2020). Nonetheless, some of the positive rhetoric espoused in discussions contrasted what was observed in practice. The strength of forming more diverse teams, as discussed, was difficult to examine in my research given the instability of CMS teams and which subsequently curtailed team progress. The instability observed across CMS teams could be largely attributed to the priority and value attached to CMS work. The degree of engagement with the CMS process differed across teams. However, there was a consistent view of needing greater support for QI work which entailed more favourable conditions for this work to be undertaken. Subsequently, the research findings reveal QI is not always afforded priority or value for several reasons that include the combined effects of structural barriers, organisational complexity and varied attitudes.

11.1.1 Priority towards Quality Improvement

Disruptions to the CMS process in the settings I researched, including frequent cancellation of CMS meetings, suggests possible de-prioritisation and poor fidelity to QI. As discussed in Section 5.4, poor fidelity can be a major problem in the implementation of QI methods, and a potential indicator of the priority and value assigned. Fidelity is “the degree to which a method is carried out in accordance to the guiding principle of its use” (McNicholas et al., 2019 p.356). A worrying admission made by CMS teams that saw the exclusion of key processual steps (to sustain stakeholder interest) is an indicator of poor fidelity. The CMS process is designed to take a long-term focus to service improvement, where tasks such as collection of baseline data and evaluation of current practice are crucial to determining what solutions need to be implemented (Gerrish et al., 2018; Shah, 2020). A particular concern highlighted in my research is where this compromise of steps includes the collection and use of service user experience data. The absence of experience data leads to gaps in knowledge, prioritisation of professional concerns and has broader implications for the value of service user knowledge and their role within the QI process; this is explored later in Section 11.4 together with an evident skill gap amongst frontline staff. Poor fidelity reduces the effectiveness of QI efforts and increases the likelihood of ‘cargo-cult QI’ (Dixon-Woods et al., 2011). The concern here, and further observed in the research, is that teams, although well-intentioned, implement quick solutions which fail to be evaluated. Failure to evaluate changes can result in the introduction of unintended variation which can create further problems.

My research suggests that poor levels of fidelity can, in part, be explained by incomplete understanding and stakeholder ownership of QI as identified when interviewing frontline team members and observing practice. Differentiating between service development approaches is important as it allows teams to appreciate the distinct intricacies of QI e.g. PDSA cycles, data analysis. It may also help teams appreciate where QI is the most suitable approach to tackle a project and where it is not (Al-Surimi, 2018; Backhouse and Ogunlayi, 2020; Dixon-Woods et al., 2019a). For example, in the research, the Eastview CMS team spent their allocated CMS meeting time designing a brochure for new residents. However, given this project did not require CMS tools or principles, and nor did it constitute a service development exercise, there was visible misuse of precious QI time. QI targets positive change in specific areas of a service’s operations rather than the generation of new knowledge which is more characteristic of research activities. Although there is some overlap, failing to recognise these differences can lead to a mismatch in expectation about what QI is, what it can achieve and how. Where expectations are not met, frustration can emerge leading teams to revert to ‘old’ established methods that potentially reduce the effectiveness of QI work (Portela et al., 2015; Backhouse and Ogunlayi, 2020).

A specific design feature of the CMS QI approach is the team-coaching model where a trained QI coach provides direction to CMS teams: this was identified as a strength across teams. However, the presence of an 'expert' was also shown to have an unintended consequence of creating team members' over-reliance on the expert's knowledge, interpretations and decision-making: *"they need to realise that they have to own this work" (QI Coach).* My research raises a potential concern that team members may show less urgency towards utilising their own knowledge and personal development. This can further result in deterring stakeholder ownership which constitutes a key principle of CMS team development. Subsequently, a paradox is noted when coaches are viewed in practice as primary knowledge-holders and are entrusted with decision-making responsibilities, as this interpretation of their role directly contrasts with the democratic principles that underpin the QI process.

The current discussion has identified how low levels of priority were observed in team engagement with QI despite the positive intention of this work being noted. It was also evident, then, that as a result of low priority attached to QI, key elements of the CMS process could be compromised. The next section continues this discussion by examining the key factors underpinning low levels of fidelity and priority. The supportive context of QI is discussed and how this may contribute and shape stakeholder engagement in the process.

11.1.2 Psychological Safety in Quality Improvement

In contrast to the positivity expressed by QI personnel regarding the purpose of QI, the research findings suggest that QI continued to be viewed as an 'add-on' and 'a luxury' for frontline teams. Several challenges reported in this research regarding team engagement with QI resonate with existing research: concerns over time, lack of resources, shift patterns, workload pressures, organisational complexity and competing priorities (Dixon-Woods et al., 2012; Dixon-Woods and Martin, 2016; Alderwick et al., 2017; Williams and Caley, 2020). It was initially surprising to learn in my research that team members felt the need for permission to prioritise QI. This is because each CMS team undertakes a self-evaluation to establish their capacity prior to committing to the process. Paradoxically, the decision to adopt QI methodology is to overcome some of the very challenges that in this research were found to inhibit engagement with QI. For example, one aim of QI may be to streamline local work processes thereby reducing time and resource wastage. This can result in greater pooling of resources which can be allocated for other areas of service development or for day-to-day care. Observing CMS meetings across the duration of the research, it was noticeable how responsibilities for carrying out meeting actions were often taken on by the same individuals. Moreover, given time and workload constraints, these actions often remained incomplete between meetings which further delayed progress. The combined issues reiterate the need for stakeholder ownership and the importance of dividing the workload across team members as to successfully conduct QI work and maintain a democratic stimulus.

The feeling of need for permission to undertake QI can be linked to ‘psychological safety’ (Deming, 1993; O’Donnell, 2019; Jones et al., 2021). Psychological factors (e.g. human behaviour) are fundamental, yet under prioritised, principles of successful QI (Davidoff et al., 2015). O’Donnell (2019 p.171) describes psychological safety in QI as where individuals should engage with QI practice without feeling that they are doing something unexpected and for which they may be challenged. Psychologically safe spaces are formed from strong organisational support and a renewed focus on the context: investment in time, resources, organisational commitment, QI maturity, learning capabilities and strong leadership. Reflecting on my research, I suggest the view that frontline staff felt they needed permission to undertake QI in combination with varying degrees of engagement indicate CMS teams felt the absence of psychological safety. I further argue that a lack of focus on the relational aspects of the QI process, which include reflection, communication and provision of support, was visible. This potential ‘blind spot’ in preparing for and sustaining QI work, is perhaps not surprising if, as Jones et al. (2021) argue, a focus on the relational aspects of QI has lagged behind more technically-orientated developments.

The tension identified in this research regarding the delineation of responsibilities between senior members and frontline teams also reflected an unstable context for QI work. A key driver of relaying the importance of QI work is through organisational commitment. Organisational commitment to QI is visible through inclusion in strategic documents, trust-wide communications and deployment of resources and support. In this research, senior members of staff echoed the Trust’s strong commitment to QI and similarly pointed to its inclusion in strategic documents. At the same time, then, they also appeared to direct some blame for QI struggles to CMS teams themselves. For example, in response to the admission for more time and resources (frequently highlighted by frontline teams), senior members of staff suggested that attitudes and behaviours needed a shift in line with unrealistic aims of simply granting more time for QI work. In a sense, these arguments suggested the need for frontline teams to believe and buy in to QI work first and foremost.

A number of QI leads echoed hope for a mentality shift amongst frontline teams to achieve an ambition of QI becoming 'everyone's business'. This mantra is not new. Attributed to Deming's (1993) maxim that "quality is everyone's responsibility", QI strategies, trust policies and plans often open with such powerful statements. There is widespread acceptance that access to greater resources is likely to result in the provision of higher quality care. However, as Dixon-Woods (2019a; 2019b) warns, a realistic perspective must be taken amidst healthcare services continuing to experience setbacks and cuts across various areas. In theory, QI is tasked with minimising this gap by optimising the use of available resources. In this research, the perceived lack of recognition of senior management support for QI by stakeholders at the micro-level suggests possible difficulties with downward-communication. However, this difficulty may not be peculiar to QI, but indicative of the wider structures and systems across the organisation.

Section 11.1.2 has emphasised the importance of psychological safety in QI. Contextual issues raised here, along with those identified in Sections 11.1. and 11.1.1, resonate with findings of the existing literature. The interplay between improvement interventions and their context is a fluid interaction and, as such, each can influence the other directly and indirectly in multiple ways. My research emphasises that understanding is key to the sociocultural exercise of QI along with the necessary relational and technical expertise for those involved in QI. The findings from this research found relational aspects of the CMS process to receive low priority and therefore subsequently argues for greater attention and development in this key area. Psychological factors are key tenets of QI practice which is clearly relayed in communication, frameworks and guidance manuals; for example, it is often cited that 'QI is 20% technical and 80% human' (Godfrey, 2013). There is a broader analysis that QI work, which challenges traditional divisions of labour, remains relatively new for certain groups of stakeholders who have traditionally been left out of these exchanges e.g. non-clinical healthcare professionals, junior members of staff, service users. Targeting a relational focus, then, may build understanding, enthusiasm, commitment and ownership, all issues that were identified in my research.

This section, as a whole, has addressed the construction of QI by personnel involved in leading, coordinating and participating in QI. A series of challenges have been identified which direct further attention towards the complexities of QI in light of the broader expectations of healthcare work. In respect to local practice, the research findings report a lack of attention over the relational aspects of the process. This possibly could explain the lack of engagement and ownership observed in my research, and also how frontline staff and QI coaches noted issues of time and permission as limiting factors to engagement. At the same time, my research argues that clearer understanding and differentiation of QI (from other service development activities) is needed in order for the process to be given adequate space and time. This space will help ensure that key steps of the process are not compromised and time is not misused which remains precious. Similar to the examination undertaken in this section, the following section in the chapter turns to exploring how concepts of service user involvement and co-production were constructed by stakeholders.

11.2 The Construction of Service User Involvement and Co-Production

In Chapter 9, the research findings illustrated how the rhetoric of involving service users in QI was enthusiastically reflected upon by senior leaders, frontline staff and service user volunteers. However, my research questions the extent to which collaborative approaches (and their differences) were adequately understood across participants interviewed. My research findings argue there was little awareness and difference between the categorisation of service user involvement and co-productive activities. In this respect, the research reflected what Williams et al. (2020a p.2) term as “cobiquity”, whereby “an apparent appetite for participatory research practice and increased emphasis on partnership working, in combination with the related emergence of a plethora of ‘co’ words, promotes a conflation of meanings and practices from different collaborative traditions”. In my study, the involvement of service users in the design and delivery of services was offered with technocratic and democratic justifications (Martin, 2008a). Senior trust members' also articulated an 'organisational logic' (Vennik et al., 2016) in which co-production was a central part of policy (as indicated by inclusion in strategic documents). Yet, the research found co-productive relationships were not always articulated in terms of sharing power and working with service users to design and implement solutions. Given the absence of these key processual features, this research questions whether the democratic objectives of co-production were truly understood.

11.2.1 Differentiating between Participatory Approaches

As shown in Chapter 2, various concepts and terms have been used to describe the involvement of service users e.g. consultation, collaboration, PPI, co-production and co-design. Distinguishing between these different participatory forms is important as all, in theory, promote "engaged scholarship and collaboration" (Pinfold, 2015 p.22). Involvement of service users can take place with different degrees of influence and power (Arnstein, 1969; Slay and Stephens, 2013). My research suggests oft-quoted descriptions of co-production as jargon and 'just another term' indicated a lack of clear difference between co-production and more traditional approaches such as PPI. The resultant conflation, even with the best intention, means distinct principles underlying methods risk not being realised in practice. Williams et al. (2020b p.224) warn of "a problematic trend of viewing co-production as merely different in degree - but not in nature - from involvement practices". For co-production, this risks the dilution of power redistribution, which I argue is a fundamental motive behind the increased emphasis on such methods in the first place.

The study also found evidence of terminology (including co-production) being used interchangeably when discussing potential involvement of service users and ambitions of QI. The use of co-productive language, despite reservations and vague understanding, reflects how 'fashionable' terminology can be used to maintain an image of inclusion (Locock and Boaz, 2019; Papoulias and Callard, 2021). In addition, some service user volunteers and lived experience professionals recounted personal experiences of tokenistic practice that took place under the guise of co-production. Such practice, then, to all extent, may be seen as a sort of false or *faux-production* (McGrath, 2020), where co-production is adopted because of its popularity and 'brand name'. It may be further possible that using the language of co-production was congruent with the organisational line of co-producing with service users i.e. 'this is what we should be doing'. However, I argue this can also result in co-production being merely seen as a tick-box exercise where the underlying philosophy and emancipatory values fail to be realised in practice (Ward et al., 2009).

There is a broader tension concerning the potential co-optation of co-production: 'whether one is really doing co-production and co-design?' (Crimlisk, 2017; Moll et al., 2020). A disconnection between what is proposed and what actually takes place in practice raises ethical issues (Pratt, 2019). Service users may arrive with expectations of greater influence (as indicated by the language of co-production) but are left frustrated when they see the resumption of the status quo of knowledge mobilisation that favours professional expertise (Bovaird et al., 2019). This is likely to be symbolic of tokenistic practice and can result in negativity towards the enterprise of involvement where power asymmetries are in full effect. There was evidence in my study to suggest negativity directed towards co-production was partly attributed to the association with 'past' phrases and terminology e.g. PPI. However, I suggest, that this was not in opposition to the values and principles of co-production as it could be argued that the concept had not been given sufficient space and time to be truly understood. Williams et al. (2020b) describe how conflating the failings of other participatory approaches with co-production could result in the emancipatory and transformative potential of co-production being scrutinised through no fault of its own.

The above discussion has raised the importance of understanding and differentiating between different participatory approaches. Conflation of different terms and approaches, the belief that they represent similar intentions, may mean the respective underpinning principles fail to be realised in practice. It can also be misleading and disrespectful for service users that are involved if their involvement does not match with what has been proposed. The degree of influence and power within involvement exchanges can vary. However, co-production is embedded with stronger values of sharing power and equality with service users. The following section explores the conception of power as discussed during the research.

11.2.2 Power in Service User Involvement and Co-Production

A key principle of co-production is an ideal of sharing power between professionals and service users (Needham and Carr, 2009; Slay and Stephens, 2013; Green and Johns, 2019; Tembo et al., 2019). Recognition of power differentials in the professional-service user relationships was varied. Senior staff members and persons with lived experience did refer to dynamics of power, power asymmetries, power sharing and so forth. This type of language was less visible in discussions with frontline staff and it was pertinent, then, that it was at this level where conflation between different participatory approaches was predominantly observed. Failure to recognise power dynamics operating between groups may indicate hermeneutical knowledge gaps in understanding. This finding is particularly pertinent given CMS QI operates at the frontline level and it is also the location where sharing of power with service users is intended to take place: *how can co-production take place if it is not understood properly by the different groups involved?*

Where discussed by interview participants, the possibilities of sharing power appeared idealistic. Several participants delineated between what they described as ‘true’ co-production (‘real’ sharing of power) and a more ‘aspirational’ vision of co-production. The latter interpretation, although well-intentioned, remains in control of the professional due to their authority, expertise and power that has been authorised by the system (Carel and Kidd, 2014; Rose and Kalathil, 2019). Pertinently, Farr et al. (2021), in a review of co-production in health and social care research, also grapple with deciding where activities involving service users resembled ‘true’ co-production.

The possibility and potential to share power in participatory practice has been deliberated in the literature with the idealistic characterisation largely attributed to structural, institutional and hierarchical constraints within the system (Madden and Speed, 2017; Green and Johns, 2019; Paylor and McKevitt, 2019; Tembo et al., 2019; Rose and Kalathil, 2019). Seemingly, then, in my research, the possibility of co-production was contrasted with the impossibility, or certainly, the impossibility of a ‘true’ transformative vision of co-production. Rose and Kalathil (2019 p.8) interrogate the possibility of co-production in mental health services, describing how current configurations of healthcare “demarcate elite sites of privilege in knowledge generation”. In conversation with two professionals, both with lived experience of mental health, the impossibility of co-production had been accepted. Meanwhile, other QI staff appeared to imply this view through emphasising their responsibility over the welfare of service users and final decision-making: *“It is good [to get them involved], but then if anything goes wrong, ultimately we are accountable so there is always that” (Participation Co-ordinator)*. For ‘true’ co-production to inform practice, professionals will have to relinquish some of the power they hold, but this can be a misconception as not all power needs to be shared. Moreover, relinquishing power is not straightforward as professionals also find themselves entrenched in hierarchies and structures with imposed expectations and targets. Such discussion further resonates with the need for psychologically safe spaces in QI. Relational support needs to be provided to staff so they proactively seek exchanges with service users where values of honesty, openness and transparency are developed.

11.3 Summary of Research Question 1

The purpose of the first research question was to explore how concepts such as involvement, co-production and QI were understood and constructed by personnel:

How are the concepts of service user involvement, co-production and quality improvement constructed and understood by stakeholders?

This line of enquiry was important given that understanding may influence how involvement, co-production and QI is approached and implemented in practice. Several key findings have been identified. In respect to QI, findings raise important tensions regarding understanding of QI, stakeholder engagement and priority attached to QI, inadequate structural arrangements and attitudinal barriers to QI work. My research findings suggest relational aspects of the QI process, in particular, along with systemic issues, need to be prioritised to improve understanding and commitment of stakeholders involved.

In respect to service user involvement and co-production, my research identified a conflation between different participatory approaches. This conflation was more pronounced at the frontline level which could be a cause for concern as this is where service users first become involved. Addressing gaps in understanding and recognition of power differentials is vital. Consistent with the literature, my research findings question the potential to share power with service users under the current configuration of healthcare and QI in complex settings such as mental health (Rose and Kalathil, 2019; Tembo et al., 2019; Farr et al., 2021). However, this is as much to do with structural barriers that pose obstacles to this way of working. The following section focuses on the second research question and explores the involvement of service users in the CMS QI process in more detail. In doing so, Section 11.4 draws together the construction of concepts and researcher observations of QI practice to explore how service user involvement in QI was discussed and enacted in practice.

11.4 Position of Service Users in Quality Improvement

My research findings resonate with the characterisation presented in the literature review that service users are seen as ‘passive sources’ of data rather than ‘active participants’ in QI. I argue, through my research, that the professional stronghold over the QI process limits the potential role of service users in shaping and influencing QI. My research described QI practice, to modify a popular healthcare phrase, as a process being done ‘for’ rather than ‘with’ service users: *“they tell us what is wrong and we do our best to improve it” (CMS staff team member)*. Following discussions raised in previous sections, I suggest the passive role of service users in QI clashes with ambitions of co-produced QI. This, in part, I attribute to deeply entrenched power asymmetries and epistemically unjust practices, that fail to acknowledge or accommodate knowledge provided by service users.

It was highlighted that CMS QI guidance is clear about the need to involve service users throughout the process and encourage, where possible, their involvement in CMS meetings; although this is not the only method to engage with service users. Reflecting on the observations and discussions that took place within the research, the desire for involvement surpassed actual involvement in practice reflecting the old adage of ‘rhetoric vs reality’ (Faulkner et al., 2015; Ocloo and Matthews, 2016; Madden and Speed, 2017; Beresford, 2019). The findings from my research suggest the instability of CMS teams (e.g. staff engagement, frequent meeting cancellations) is likely to have impacted efforts to involve service users. For example, teams were possibly wary of inviting service users amidst their own failures to engage with the process. However, before this, I question whether CMS teams saw service users as core members of the QI team. The first part of the CMS process involves the organisation of a ‘core’ team with team composition expected to reflect a diversity of stakeholder groups that includes service users (Abrahamsson et al., 2020). Instead, it appeared greater concern was assigned to making sure a range of staff were represented in this ‘core’ team, whereas service users were to be involved as and when required: *they were not fully-fledged team members per se*. Lack of service user involvement has broader implications for team diversity. Locock et al. (2020) describe how lack of service users in QI teams can be missed opportunities for skills, knowledge and experience. Moreover, my research findings suggest that the involvement of service users in CMS work was not readily identified by staff as a critical success factor in comparison to contextual structures and organisational arrangements.

This is not to say that CMS teams were totally unaware of the absence of service users. The lack of service users was emphasised at times by staff with some acknowledgement that their involvement fell short of the ideal. However, this reflection bore striking resemblance to what Broer et al. (2011 p.214) described in their study as a “panoptic function”. People are aware that they are being observed (‘in the panopticon’) and therefore adjust their behaviour and conversation to reflect certain norms like the expectation of service user involvement. Subsequently, the ‘panoptic function’ might have emerged where staff were motivated to show their ‘consciousness’ of involving service users in light of my presence as a researcher investigating these exact issues. Relatedly, staff would also often mention service users being involved in ‘other’ areas of the service (where research access had not been granted) or in previous CMS projects, conveniently before my research began. In their study, Papoulias and Callard (2021 p.5) describe how the “location for PPI was a constitutive elsewhere” with perceived involvement cited in areas where the authors lacked access or ethical clearance. In my research, from discussions that took place with CMS team leads, it could be assumed that service users were involved in other areas of service; exact details of their involvement were unclear. Nonetheless, it appeared that this wider involvement of service users in other areas could almost mask the lack of service users in the CMS processes of teams.

My research locates some struggles of service user involvement in CMS QI to the absence of a well-developed structure. Although emphasising the involvement of service users throughout, the CMS process is not designed as a specific service user-centred QI approach like EBCD. Relatedly, my research findings which documented a skill gap amongst frontline staff in regard to involving vulnerable service user groups resonates here. Upon reflection, I suggest there is a lack of supporting guidance in the CMS framework as towards the ‘how’ of involvement rather than the ‘why’, which was more clearly communicated. Without clear rationale of the roles and responsibilities of service users, their involvement can easily slip into tokenism or no involvement at all. In the absence of guidance, staff have to rely on their previous experiences of involvement which maybe insufficiently tailored to the specific requirements of QI. A lack of empirical guidance for involvement in CMS QI has also been reported by Bergerum et al. (2020 p.9). The authors describe how CMS team members were left “occupied with considering how to balance roles and relationships, how to achieve mutual learning, how to measure the impact of patient involvement and how to match the knowledge of patient needs to the resources within the patient processes”.

The passive role of service users, as this research argues, is also further demonstrated in staff discussions of involvement taking place at ‘appropriate’ stages of process. This almost exclusively meant involvement of service users being limited to the early stages of the CMS project. Limiting the involvement of service users to earlier stages of the process risks mirroring more consultative exercises. This is particularly problematic if the ambition is, or if services believe, that they are co-producing QI with service users. Access to more ‘impactful’ stages of the QI process that include decision-making responsibilities, implementation of QI solutions and evaluation, arguably activities more in line with co-production, is restricted for service users. There is a simpler argument that greater authenticity is achieved where collaboration and involvement of different stakeholder groups is embedded from start to finish.

My research also revealed how the ‘relevance’ of service users could be questioned by teams leading to a further reduced role for service users. The relevance of service users tended to be constructed in two main ways: 1) service users’ ‘disinterest’ in professional-facing issues and/or 2) service users having too little knowledge about particular issues (concerning professional practices, diagnostic conversations and process-driven activities). Abrahamsson et al. (2020), Bergerum et al. (2020) (both focusing upon CMS QI) and Vennik et al. (2016) report similar findings in their respective studies that also span different contexts and regions (UK, Sweden, Netherlands). Vennik et al. (2016 p.162) describe a reduced role for service users may be legitimate “when keeping the time investment of both staff and patients in mind” (p.162). Although, I argue that this view may be challenged on the basis that everything, in theory, should be ‘on the table’ and assumptions concerning knowledge gaps (of service users) should be examined. Nonetheless, I argue that it is professionals who are responsible for dictating the ‘appropriateness’ and ‘relevance’ of involvement of service users, and it also by this process that service users are excluded from types of decision-making. Put simply, then, the involvement of service users in QI remains at the will of the professional.

It is acknowledged that certain critical factors need to be taken into account when deciding the level and mode of involvement e.g. nature and complexity of impairment (of the service user group), project objectives, resources available. It may not necessarily always be feasible to share power and responsibility. This said, involvement has often too frequently taken place at the level of feedback with a one-way transfer of information between service user and professional (Tritter, 2009; Ocloo and Matthews, 2016). In their respective studies of QI practice, both Boaz et al. (2016) and Locock et al. (2020) describe how the involvement of service users was restricted to early stages of the QI process. Boaz et al. (2016) report that some resistance came from service users themselves as they believed only professional staff possessed the technical expertise to implement QI solutions. A technical perception of QI exists, relatedly attributed to the origin of QI and subsequent industrial techniques, tools and language. A technical description of QI was raised in conversations with some service user volunteers. Seemingly, my research findings question whether such a technical perception of QI acts as a deterrent to service users as they decide whether they would want to be involved. This however is first dependant on how the opportunity to get involved in QI is advertised, if at all. The absence of service user involvement in the CMS process across teams, whilst supposedly embedded in other areas, also further reflects this argument. Certainly, the research findings suggest cautiousness around involving service users is heightened within the specialised and esoteric nature of QI work.

My study found limited evidence of CMS teams using other sources of knowledge (e.g. service user experience data) to support QI work. Collection of data through various platforms was acknowledged but concerns over time and the skill to make sense of data in the absence of adequate training were identified as barriers by participants. These findings are not new. Martin et al. (2015) and Weich et al. (2020) report how frontline staff may lack confidence, authority and the necessary resources to help turn experience data into meaningful improvement. In agreement, Sheard et al. (2019) also highlight the importance of staff realising the value of feedback and sufficient organisational support for teams to work on improvement. Failure to utilise experience data impacts negatively on service users who have given their time and effort to share this information. More insidiously, the collection of service user experience, then, represents ‘nice to haves’ (Weich et al., 2020) collected merely to meet regulatory purposes. Greater direction is required on how to make sense of experience data which may subsequently require additional training for staff and streamlining of data collection platforms. It may also help to look beyond the notion that the service user has to be present ‘in the room’ for service users to be heard and their knowledge to be used (French and Raman, 2021).

In this section, I have described how the role of the service user was passive within processes of CMS QI. Several factors were highlighted including the absence of a well-developed structure along with professional concerns over relevance and appropriateness of service users to the QI process. Decisions regarding the involvement of service users, as has been demonstrated, remains in control of the professional. In the next section, I advance this focus through examining how the complex nature of impairment may also or is perceived to affect the involvement of service users in the QI process.

11.4.1 The Nature of Impairment and Involvement

As was described in Section 4.3, people living with brain injury or mental ill-health can have characteristic cognitive, psychological, emotional and behavioural effects that impact their every-day functioning. Consequently, service users’ functional ability and capacity to participate in QI at times may be temporarily reduced. This said, my research findings revealed a noticeable lack of clarity over how to negotiate and manage the involvement of service users from these groups. A shared concern expressed by QI coaches and frontline staff was the potential negative impact of involvement on service users’ well-being and having to make difficult decisions regarding service user capacity. A ‘protectionist’ stance taken by healthcare staff and equating involvement with risks of overburdening people has been reported elsewhere (Liabo et al., 2018; Borgstrom and Barclay, 2019; Amann and Sleigh, 2021). Existing research reports how service user involvement may evoke negative emotions and recalling of unpleasant experiences amongst service users (Beighton et al., 2019; Isham et al., 2019). In contrast, involvement may be an important step in recovery for some service users (Borgstrom and Barclay, 2019; Sangiorgi et al., 2019). These are apt concerns which emphasise that facilitation of involvement is not straightforward and, in particular, requires careful ethical attention.

Given potential concerns of involvement raised in this research, ethical attention, I suggest, extends to careful management of the relationship between service user and professional. This will help provide clarity over boundaries, responsibilities and terms of involvement, whilst using tailored tools can also foster effective communication. Paying ethical attention and ensuring means of access (physical, communicative, cultural) are vital considerations when involving vulnerable groups as facilitating their involvement may require more time, resources and, on occasions, creativity (Beresford, 2013a; Liabo et al., 2018; French and Raman, 2021). Burgess and Choudary (2021) describe how meaningful involvement and co-production with vulnerable service user groups can only be achieved through a long-term approach with supporting material, relational and symbolic resources in place. Similarly, Miles et al. (2018) call for the adoption of a ‘slow co-production’ approach to accommodate the changing temporalities of health experiences which may be particularly pertinent to the population of this research study. Such examination places further spotlight on the current organisation of healthcare, and whether current resourcing levels are adequate to support the development of meaningful relations between service users and professionals.

Making decisions regarding the capacity of service users to be involved can be tricky for professionals given their responsibility towards patient care and safety. It is possible that professionals were erring on the side of caution in the research (and therefore avoiding involvement) but this ultimately leads to unexamined exclusion of groups where determining capacity is not straightforward (Sangiorgi et al., 2019; Moll et al., 2020; French and Raman, 2021). This may point to a need to recognise capacity as more fluid and time-specific rather than as existing as a binary state. It is argued that services often underestimate service users’ insight and capacity for decision making and that this may exaggerate imbalances between service user knowledge relative to the knowledge base of professionals (Grim et al., 2019). Bergerum et al. (2020) describe how decisions regarding capacity of service users to participate represent another ‘tug of war’ between professionals and service users. In their study, Borgstrom and Barclay (2019) noted how people in the receipt of palliative care services wanted to get involved despite the burdens they faced and this contrasted what professionals tended to assume. A failure to initiate dialogue with service users and offer a range of options to participate, that includes engaging service users in decisions regarding capacity, further exploits the very voices deserving of recognition (Liabo et al., 2018; French and Raman, 2021). Pertinently, Dietrich et al. (2017) describe how vulnerable service user groups have been generally approached and treated in the way that well-meaning others think best.

Discussion over the ability of service users to get involved amidst the complexity of their impairments in my research also resonated with what Beresford (2013a p.24) describes as a 'hierarchy of impairment'. Individuals with multiple impairments and high support needs, reflective of the study population in this research, are perceived to have limited abilities and are primarily focused on getting better from ill-health; from a professional viewpoint these challenges posed further obstacles. I argue, then, that staff concerns over whether service users would actually want to get involved in the first place could be somewhat misplaced. Some service users may not wish to participate but intimidating formats or lack of appropriate platforms also pose obstacles. Assuming or failing to ask service users whether they would like be involved in the first instance may also be considered disrespectful. Given that my research has documented other reasons for CMS teams approaching involvement with some hesitation (beyond the complexity of impairment), it does question whether expressions of carefully managing impairment shows genuine consideration for service user well-being or to prevent service users getting 'too' involved i.e. service users having greater control over direction of QI projects, which was, for example, raised by teams' QI coaches. It may also simply be that teams saw challenges as being insurmountable and therefore preferred to err on the side of caution or avoid.

In my research, I observed occasions where plans were made to involve service users in the Brain Injury service (Oston). One CMS team recruited two service users towards the end of the research whilst another CMS team arranged to hold CMS meetings at a service users' home. Both would then indicate an openness to service user input and therefore contradict the above claim of using a 'protectionist' stance to maintain control. However, my research also suggests the 'potential' involvement of service users could represent 'an imagery of inclusion' (Papoulias and Callard, 2021). During the nine-month study period, only one 'home' meeting was organised and this was later cancelled as the date approached. Email communication had been established with the service user (over the period of the research) although this contact remained irregular. This discussion reflects broader issues around access and the type of formats used to involve service users. Increasing attention is being placed on the location of involvement – 'place and space' (Palmer et al., 2019; Burgess and Choudary, 2021). Traditional meeting spaces may be intimidating and driven by a pre-defined agenda that tends to favour 'good communicators' resulting in exclusion of certain groups (Thompson et al., 2012; Beresford, 2013a). Changing the location of meetings, for example, can be more difficult within inpatient settings (like Dexton) given service users are residents. Service activities are held on the same site where people reside and receive treatment, and therefore may not represent ideal conditions. However, this may also mean adjusting formats that are utilised to yield feedback. Across CMS QI practice observed in this study, CMS work was largely conducted as formally structured meetings.

This section has summarised several central issues identified in the research that impacted efforts to involve service user groups in QI. Some staff noted concerns over whether involvement would cause further distress to service users with mental health and brain injury respectively. As a result, involvement could be avoided under reasons of 'protectionism'. Others also pointed towards the lack of clarity and guidance of how to involve service users and to negotiate challenges of capacity. This, then, seemingly also reflected skill and knowledge gaps. Making informed decisions regarding capacity are important in determining how service users may be involved. Though such decisions can be difficult, the argument presented here is that involving vulnerable service user groups requires time, resources and ethical attention. This support will encourage dialogue with service users and place greater attention to the formats and spaces used to involve service users. Deficits in supporting structures and resource allocation are key barriers to service user involvement, but nonetheless, service users remain excluded from practice that may unintentionally reinforce existing inequalities (de Freitas and Martin, 2015; Mulvale et al., 2019). The following section, now, turns to summarise research findings concerning the careful selection of service users and examines the repercussions of this on the enterprise of involvement in QI.

11.4.2 Selection, Representation and Professionalization

The selection and recruitment of service users is a key aspect of involvement and co-production processes. Participatory practices are often underpinned by a democratic rationale of making involvement opportunities as broadly and fairly accessible; this can be seen as a sign of equitable practice (Verschuere et al., 2018). Nonetheless, challenges to the representation of service users in involvement are by no means new with my research echoing some of these. On one hand, senior staff reflected on their over-reliance on particular groups of individuals, whilst on the other, discussed how any potential service users have to be a 'right fit' for teams. The methodological and technical process of QI, as opposed to the wider generalizable aims of research, may be identified as a reason for selecting service users with particular characteristics and qualities. These qualities often revolve around being 'strong characters', 'well informed' and 'confident' (Peat et al., 2010; Armstrong et al., 2013; Wiig et al., 2013).

However, I argue that given the settings in which this research takes place, adopting strict selection procedures can exclude groups of service users on the basis of lacking preferred ways of communication; that is, communication which is compatible with professional dialogue. This puts service user groups where, for example, it is not straightforward to determine capacity, at a disadvantage. This disadvantage could be considered an example of 'consent bias' (Shepherd, 2016). In the absence of support to help develop the confidence and self-esteem of service users, lack of involvement may be unfairly seen as the 'problem' of the service user as they have to 'prove' their competence and involvement to the 'selectors' (professionals) (Potter, 2010; Montenegro and Cornish, 2019; Scholz et al., 2019). My research documented examples where service users internalised negative views of being deemed 'difficult' and 'challenging'. This can further perpetuate the taken-for-grantedness of the dominant professional perspective (Hutchison et al., 2017; Godrie et al., 2020).

A pertinent finding of the research was how some frontline staff reflected on the potential loss of control over the CMS process if a number of service users were to participate at the same time. This discussion was comparable to what Martin (2008b p.1578) has described as "a sort of acute hypocrisy". Staff challenged the "representativeness" of one or two services users participating on grounds that they could only represent their own views. At the same time, teams were complicit in limiting recruitment to one or two service users with potential concern of losing control over the CMS process. This example of acute hypocrisy indicates how power dynamics are in play in spaces of exchange. Moreover, a paradoxical situation emerges where the lived experience knowledge of service users, that is largely welcomed, is assessed against more 'wider' and evidence-based forms of knowledge (Mazanderani et al., 2020). An argument may also be made that the number of professionals participating in meetings is rarely questioned, and neither is their 'suitability' and 'relevance' examined (Happell and Roper, 2006). This division can illuminate an 'us and them' mentality where there is one rule for service users and another for professionals.

The identification of 'suitable' features for service user involvement which gives staff greater confidence in the selection process interconnects with 'appropriate' service user behaviour that reflects normative expectations of collaborative working (Lewis, 2014; Brosnan, 2019). In this respect, service users involved reflect 'a safe pair of hands' (Hogg, 1999). There was further evidence of teams being wary of dissenting voices and negative feedback. For example, One CMS team, was cautious in their selection process after a previously negative experience of involving a service user. It could be argued that it is the responsibility of services and professionals to overcome their professional discomfort, and encourage inclusion of individuals who may not necessarily share similar views. My research findings suggest that the various issues raised and observed regarding selection procedures in QI reinforce a separation between professionals and service users, limiting the view of service users as credible and equal partners.

Section 11.4.2 has summarised how issues of selection and representation were raised in discussions of service user involvement. Though certain attributes and characteristics favour the involvement of a narrow group of service users, others remain at a disadvantage. Greater disadvantages are experienced by service users where ill-health affects every-day functioning; this was the case for groups in this study. More broadly, the research findings illuminate the power dynamics at the heart of selection processes given professionals carefully manage and decide which service users are involved.

11.5 Summary of Research Question 2

The purpose of the second research question was to draw the understanding of service user involvement with practice observations to examine the space of QI for service users:

How do the processes of quality improvement initiatives shape the roles and contributions of service users?

The discussion within this section has highlighted several tensions regarding the involvement of service users in QI. In the research study, service users remained passive sources of information with limited roles. Individuals living with mental health and brain injury are considered particularly vulnerable owing to the complex nature of their ill-health. It was evident that their lack of involvement in the CMS process was influenced by issues of ‘protectionism’ and skill gaps in professionals i.e. negotiating demands of capacity. These groups of service users could be further disadvantaged by selection criteria where professionals identified opportunities of involvement for the ‘right’ service user. Efforts to involve service users remained unassisted by the absence of a QI-specific framework for involvement. This is despite the purpose and intention of service user involvement (‘the why’) being made clear. At the same time, concerns were also expressed by professionals that extended beyond the complexities of ill-health. These concerns revolved around the ‘appropriateness’ and ‘relevance’ of service users in particular QI projects. The involvement of service users was further contested over a loss of professional control over the CMS process highlighting how professionals carefully managed the process to uphold their power.

To summarise, then, exploration of the second research question contributes to existing research through providing further examination of the barriers that exclude service user groups from spaces of QI. Several tensions identified may be similarly viewed across other areas of healthcare. Yet, my research findings also provide evidence of how QI specifically in its mechanisms and specialised concentration can limit space for service user involvement. The issues raised in this section are underpinned by dynamics of power and continues, then, to question the potential of co-production of QI with vulnerable service user groups. The following section examines the findings from my research, notably the role of the service user, through applying an epistemic lens and highlights how practice of QI can raise several epistemic challenges.

11.6 Theoretical Contributions and Implications

This section discusses the findings of the research in relation to theories of knowledge recognition, vulnerability and power within QI. A fundamental component of involving service users in the design and delivery of services is the degree to which their experiential knowledge is recognised and valued as credible sources of information.

11.6.1 Epistemic injustice, Involvement and Quality Improvement

My research suggests current mechanisms in the organisation and practices of QI are epistemically unjust that can lead to the generation of epistemic challenges. These challenges, I argue, lead to service users encountering epistemic injustices when within the process there is an unexamined privileging of certain forms of knowledge, language and communication which align with the dominant biomedical belief model. Features of contemporary healthcare practice also contribute to epistemically unjust practice. Pressures of time, resource shortages and competing priorities limit efforts to listen and create relationships with service users. Ultimately, the generation of epistemic injustice impacts upon the ability of service users to be meaningfully involved in QI with broader ramifications for the potential of 'co-produced QI' with service users.

Though highlighting the importance of their knowledge, service users, I argue, were not regarded 'essential' in the collective efforts of QI. The findings from the research suggest service users were given more passive roles and this is consistent within normative practice of service user involvement in QI (Robert et al., 2015). To this effect, Crichton et al. (2017 p.67) posit how healthcare professionals have tended to "…regard patients as objects of their epistemic enquiry rather than participants". My research findings highlighted significant professional control over the QI process which shaped QI as an exercise being done 'for' the benefit of service users rather than 'with' them. The limited involvement of service users contrasts ambitions of co-production and QI which is based on a vision of meaningful collaboration 'with' service users.

My findings draw attention to team members' perceptions of service users providing limited information of value to professional concerns of service improvement. It is argued that where service user's knowledge is sought out and shared, professionals hold the licence and authority to determine how this knowledge is applied in practice: "service users' capacities may be reduced to attending only what stems from the perpetrator's [professionals] perspective" (Pohlhaus Jr., 2014 p.105). Therefore, the assertion of involving service users at 'appropriate' stages in the QI process, as observed in my research, reflects this statement where professionals dictate terms of involvement. The failure of frontline staff to recognise power asymmetries and how their actions may reproduce them when constructing involvement and co-production can also produce epistemic challenges within processes of QI (Grim et al., 2019). McKinnon (2016) describes this as 'epistemology of ignorance' where given the dominant group (professionals) are seeking the views of the non-dominant group (service users) they should also be wary of the power differentials that may affect how different views and experiences are communicated. That is in addition to challenges of unstable organisational infrastructures which are often identified by professionals as the main reason for non-involvement of service users (Grim et al., 2019).

The selection of service users premised on 'suitability' i.e. the 'right' service user, brings light the intimate relation between credibility deficits and excesses (Hutchison et al., 2017; Naldemirci et al., 2020). Service users identified as having 'suitable' features are granted credibility excesses which are rooted in "the social imagery that plays a crucial role in instituting and maintaining epistemic injustices" (Medina, 2011 p.32). Put simply, the design of QI favours 'appropriate' behaviours and certain ways of communication, inadvertently reducing opportunities and disadvantaging individuals lacking this style of expression. The majority of service users unsurprisingly lack training in relevant medical terminology and are unlikely to have extensive professional medical experience. As a result, they encounter potential participatory prejudices leading to credibility deficits and a deflated epistemic status (Hookway, 2010; Brosnan, 2019; de Boer, 2021). Vulnerable service user groups are already facing hermeneutical challenges in respect to confidence and self-esteem. Further dismissal of certain individuals due to their expressive styles or behaviours, a type of hermeneutical injustice in itself, leads to hermeneutical double injury (Carel and Kidd, 2017; Kidd and Carel, 2017).

Individuals living with psychiatric impairments and brain injury are particularly vulnerable to pathocentric epistemic injustice as a result of stereotypes attached to their condition (Scrutton, 2017; Crichton et al., 2017). Krahn (2015) describes how individuals living with brain injury have been described as the 'walking wounded' due to the perceived 'invisible' nature of their impairment. At the same time, hierarchy, fixed role dynamics and agential limitations are visible features of mental health services that have resulted from socially sanctioned professional power (Berzins et al., 2018; Newbigging and Ridley, 2018). My research revealed somewhat dismissive attitudes towards the ability of service users to participate as equal partners given the nature and complexity of their impairments. Hookway (2010 p.152) describes how service users are often thought to lack the ability to make reliable assertions. The exclusion of persons based on their 'unpredictability' or their knowledge being too difficult to make sense highlights how testimonial informational injustices may be generated (Carel and Kidd, 2014; Crichton et al., 2017; Kurs and Grinshpoon, 2018). The 'unstable' service user clashes with traditional expectations of a 'credible epistemic agent' - someone who is calm, rational and objective (O'Donovan and Madden, 2018). As to concerns of protecting vulnerable service users from the impact of involvement, these decisions are intimately made and are not straightforward. Zarroug et al. (2016), for example, question whether it is epistemic injustice or the safety of patients that should be prioritised first. However not inviting service users, assuming their lack of disinterest or failing to hold dialogue first about how service users should be involved, may be seen as potentially generating participant-based injustices (Hookway, 2010; Grim et al., 2019). Service users are excluded from the process or are restricted access to certain stages based on staff assertions of protection and safeguarding. This, I argue, may be in part a failure to recognise service users as full collaborators.

Previous studies have described how epistemic injustice is a valuable concept to understand how service users face barriers during the uptake of healthcare services (Carel and Kidd, 2014; Blease et al., 2017; Hutchison et al., 2017; Knowles et al., 2021b). These studies have been mainly focused at the individual level of care where discussion takes place between healthcare professionals and service users regarding symptoms, diagnosis, and treatment choices (Carel and Kidd, 2014; Schön et al., 2018; Grim et al., 2019). My research broadens the application of epistemic injustice to explore the integration of service users into QI. A key difference to the involvement of service users in QI is that they are expected to work collectively with professionals to design services rather than their own care, with a remit of creating value in multiple areas: better service user (and population) outcomes, better professional development and better system performance (Batalden and Davidoff, 2007; Williams and Caley, 2020). Recent commentary emphasises the strength and importance of 'patient knowledge' in QI, which has traditionally been under-utilised, and how there should be synergy between this type of knowledge, professional knowledge and improvement knowledge (Batalden, 2018; Gustavsson et al., 2022). Furthermore, a democratic rationale underpins the rights of service users to be involved in decisions regarding the healthcare they receive and services that they use. This considered, the various ambitions underpinning involvement, co-production and QI can be recognised as attempts to enhance epistemic justice in practice through encouraging the utilisation of multiple and diverse forms of knowledge in the design and delivery of services (Glass and Newman, 2015; Groot et al., 2020; de Boer, 2021).

The findings from this study add support to existing research which suggests integration of service users in QI is not happening at the pace which is espoused in policy and system-level documents. Moreover, QI provides an arena in which multiple forms of epistemic injustice may play out. I argue the specialised and esoteric nature of QI work along with entrenched pathocentric injustices encountered by vulnerable service users combine to produce limited spaces and roles for service users in QI. This research observed marginal participation with service users having few entry points or resources, both which are controlled by the professional. Subsequently, if service users are to be involved, they do so with 'hermeneutical disadvantage'. Other contemporary features of healthcare organisation such as lack of resources and investment, that readily apply to other areas (e.g. individual care, healthcare research), are also complicit in the generation of epistemic injustice.

Viewing the practice of service user involvement and QI through an injustice lens adds to current discussion by directly linking mismanagement of service user knowledge and poorly facilitated involvement practice to damage and injustices caused to service users. Knowles et al. (2021b p.10) describe how epistemic injustice is "'high stakes', deliberately provocative, and forces those with power to be aware of the risks of their actions". I argue, then, that the concept of epistemic injustice is particularly pertinent to the practice of QI where the output of this work is inevitably going to impact service users. Exploring, for example, how credibility indicators are unfairly applied to service users may highlight how the potential for service users to be involved in QI is undermined despite the rhetoric of their importance. This also enables recognition of who is considered knowledgeable, who is not, and the types of knowledge that are undervalued. Reflecting on the concept of justice in QI work, the democratic rationale of involving service users may become more visible and influential whereby there is a turn towards understanding how service user experience and knowledge can inform service development. By raising awareness of epistemic injustice, QI practice may strive towards solutions which aim to be driven by positive epistemic values (Moes et al., 2020) and ensure important discussion about whose benefit this work is being carried out for. This section has raised how practice of QI raises epistemic challenges but also how the concept of justice can be linked to the democratic ambitions of co-produced QI. The following section focuses on epistemic authority that is granted to professionals which may in part explain how they sustain control over large parts of the QI process.

11.6.2 Epistemic Authority and Privilege

Professional control over the CMS QI process can be attributed to the epistemic privileges afforded to them by virtue of their training, education and expertise (Wardrope, 2015; Byrne, 2020). The dominant biomedical model ascribes value to treating ill-health based on objective evidence with target-driven healthcare cultures traditionally leaving little space for the input of service users. For example, authority and power that arrives with this privilege is reflected in how the selection and recruitment of service users is informed by particular metrics of competency and behaviour that is congruent with professional norms and expectations (Kidd and Carel, 2017).

A more delicate question concerns the extent to which this epistemic authority is warranted and how it can affect opportunities for service users to get meaningfully involved (Carel and Kidd, 2014). There are several instances when professional authority is warranted. Professional authority is epistemically warranted when making capacity judgments of service users (Blease et al., 2017; Byrne, 2020). Yet, this authority becomes unwarranted when it is presumed that the service user is in a state of permanent irrationality and therefore not consulted again. This unfair admission results in the generation of injustice. To some, professional control of the QI process may be justified through the argument that professionals possess the correct technical knowledge and understanding of the system. However, involving service users or emphasising QI work is co-produced when involvement has only served as a symbolic token is an indicator of epistemic injustice. Once more, there is unfairness in the process with service users in the receipt of injustice (Fletcher and Clarke, 2020). A vital point to remember here is that the drive for greater service user involvement and co-production has emerged from widespread acceptance that healthcare has relied far too much on one source of knowledge – third-person, evidence-based professional knowledge. Moreover, it is not guaranteed that service users have epistemic privileges even after being ‘invited in’ to participate. Service users may be consulted but lack substantive critical powers to enforce discussion of certain issues or topics (Lewis, 2014; Brosnan, 2019). The likelihood is, owing to hermeneutical challenges and how spaces are designed and managed, that service users are likely to proceed with discussions that have originated from more dominant groups, whom are deemed socially as the ‘most knowledgeable’.

As to the intentional nature of epistemic injustice, several theorists agree injustice predominantly results from structural deficits and hierarchical features of the healthcare system (Carel and Kidd, 2014; Wardrope, 2015; Fricker, 2017). However, Fricker (2017 p.58) also warns that “non-deliberateness does not entail non-culpability”. Relatedly, factors such as lack of time, resources and skill gaps point to fragmented systems that limit the ability to involve service users even if healthcare professionals are well-intended and passionate about involving service users. Nonetheless, professionals may be seen as being unwillingly unjust. As reported in the research findings, a lack of knowledge and competency around involving vulnerable service user groups, and insufficient guidance on how to involve them specifically in QI, may be seen as hermeneutical gaps in training and education that influence the approaches, attitudes and actions taken by professionals.

The argument presented here does not aim to dismiss professional authority or disparage medical knowledge. This type of knowledge is valuable and as Wardrope (2015 p.350) acknowledges, “experts do exist […] which legitimately privileges them in some domains of inquiry”. Yet, the intention is for the value of professional knowledge to be recognised within a wider community that accounts for all forms of knowledge which includes lived experience knowledge provided by service users. Paying attention to epistemic factors of knowledge recognition in QI, that includes reflecting on one’s own position, I suggest, may help alleviate injustices or at a minimum, make professionals and services aware of them in their conduct. The next section introduces the concept of epistemic humility which calls for personal and collective reflection, and through which some of the epistemic deficits of service user involvement can be addressed.

11.6.3 Towards Epistemic Justice – Epistemic Humility in Practice

In this section, I argue that more informed and just QI practice entails a level of professional epistemic humility (Buchman et al., 2017; Grim et al., 2019; de Boer, 2021). Epistemic humility calls for recognition of ones’ own judgements, privileges and epistemic capacities all whilst being conscious of perspectives offered by other stakeholders involved in the same exchange (Buchman et al., 2017). Understanding the value of service user knowledge followed by credible attempts to integrate this into practice would resemble such humility. The concept of epistemic humility, I argue, is not too dissimilar from critical self-awareness or critical reflexivity, which equally challenge subconscious beliefs and acknowledges the power imbalances in relationships. The need for critical reflexive practice in healthcare research has been previously expressed (Brosnan, 2019; Moll et al., 2020; Farr et al., 2021) and conscious of the overlap, I suggest similar attention within the context of QI.

I argue that epistemic humility goes beyond expressing benefits of service user involvement and towards attaining a deeper appreciation of the existing power relationships and asymmetries between professional and service user groups. Through this, an ‘epistemology of ignorance’ is avoided (McKinnon, 2016). As I argued earlier: *how can co-production truly happen if it is not understood properly by all involved?* Beyond recognition of power differentials, reflexive work should also target a focus on the emotional and relational aspects of the involvement process. Mulvale et al. (2021 p.10) describe this relational focus within involvement exchanges as the “art of co-design”. Focusing upon the emotional and relational aspects of collaboration engenders greater openness and a shift in mind-set towards service user knowledge and its vital contribution for QI (Buchman et al., 2017; Grim et al., 2019). It is also vital in helping to anticipate and prepare for potential challenges that result from collaborating with vulnerable service user groups and where relational safety can be provided for all stakeholders involved (Mulvale et al., 2021).

It can be argued that the emotional and relational features of QI work have always been explicit. Deming’s (1993) System of Profound Knowledge, which informs QI methodology, highlights the importance of embracing a psychological view to better understand how people converse, collaborate and work together. This said, the limited attention to psychological factors is unsurprising given Davidoff et al. (2015) evaluate how the role and value of theory in QI work is seriously under recognised. Batalden (2018 p.2) describes how service users and professionals should be “held together by knowledge, skill, habit and a willingness to be vulnerable”. I suggest there is a particular need for professionals to share their vulnerabilities given that service users routinely share these as a result of living with ill-health. Furthermore, my research findings highlighted how healthcare professionals described a culture of fear and defensiveness as they discussed the potential involvement of service users and responding to feedback. Moreover, staff hesitation and lack of clarity were observed regarding attempts to involve service users. This thesis argues that it is these exact spaces where being open and vulnerable as a professional is needed, and which is likely to strengthen transparency and honesty in service user-professional relationships (Knowles et al., 2021a; Tembo et al., 2021). There is a balancing act that requires professionals to be vigilant in protecting vulnerabilities and navigating formal accountability, while simultaneously empowering service users to get involved in QI; this requires transparency, flexibility and creativity.

I have argued that taking an emotional and relational focus, which primarily operates at the individual-interactional level, may help limit instances of individual testimonial injustice and particular hermeneutical injustices (de Boer, 2021). However, a sole focus on individual-level factors presents a narrow view of implementation, particularly where there is a network of challenges that also operate more broadly. Failure to provide the necessary contextual support can lead to hermeneutical gaps whereby the risk of generating further epistemic injustices increase. The creation of psychologically safe spaces is an example of addressing both individual and structural barriers as this not only provides professionals with confidence, but also means that service users can develop agency and strengthen their contribution to key discussions informing QI.

11.7 Summary

This chapter has reviewed the empirical findings of my research alongside the existing literature in an attempt to identify similarities and differences between my study and extant research. The discussion in this chapter was presented by first answering the research questions of the thesis before moving onto offering the theoretical contributions of my research.

The first research question concerned the understanding of service user involvement, co-production and QI. My research findings suggest relational aspects of the QI process need to be prioritised along with tackling structural barriers that pose limits to engagement. Targeted understanding of the rationale of co-production and QI, whilst making engagement opportunities more accessible is likely to increase the commitment of individuals and groups involved in QI work. In respect to the understanding of service user involvement and co-production, my research identified a conflation between the different participatory approaches through which the value of underlying principles may be lost. Consistent with the literature, my research findings also question the potential to share power with service users under the current configuration of healthcare in complex services such as mental health (Rose and Kalathil, 2019; Tembo et al., 2019; Farr et al., 2021).

The findings from exploration of the second research question contribute to existing research through further examination of the barriers that exclude vulnerable service user groups from practice. Several issues have been highlighted and these largely characterise service users as remaining passive sources of information with limited roles to play in QI work. It was evident that some of the struggles of involvement could be attributed to the difficulties of navigating the complexities of ill-health. Skill and knowledge gaps across professionals further contributed to this challenge. Service users could be further disadvantaged by narrow selection criterion with professionals identifying a ‘right’ type of service user, where they were to be involved if at all. At the same time, there were concerns expressed beyond the complexities of impairment that included the ‘appropriateness’ and ‘relevance’ of service users to particular QI projects. The involvement of service users was further contrasted with a potential loss of professional control over the CMS process illuminating the power dynamics operating within these processes. Subsequently, through the discussion, it became visible how QI specifically in its mechanisms and specialised concentration can also limit space for service user involvement.

The theoretical contribution of this thesis is offered in relation to knowledge recognition, vulnerability and power within involvement and co-production practices of QI. Applying an epistemic focus, my research suggests that the specialised nature of QI work along with features of contemporary healthcare practice pose considerable epistemic challenges to service users and their ability to participate in QI. These challenges, I argue, lead to service users encountering epistemic injustices when within the process there is an unexamined privileging of certain forms of knowledge, language and communication. By paying attention to epistemic factors of knowledge recognition in QI, that includes critical reflection at an individual and collective level, may result in more epistemically just conduct and practice. The creation of psychologically safe spaces is also vital and these may address hermeneutical deficits in the organisation of services that currently act as barriers for service user involvement. As knowledge and power are intertwined, access to knowledge production is essential for service users to be meaningfully involved in QI. Through their involvement, it is possible that asymmetric power relationships may be addressed.

The next chapter now turns to summarising the reflections offered within this thesis. It reflects on the ambitions of service user involvement, co-production and QI, pulling together the various discussions that have taken place in this thesis. After reviewing the key discussion points for a final time, implications for practice are offered along with reflection of the study limitations of this thesis.

CHAPTER 12

Conclusion

This conclusion chapter brings together the various strands of research discussed within the thesis. A summary of the chapters in this thesis are offered along with clarification of the contributions of this research. This is followed by reflection on the strengths and limitations of my study before concluding with a review of the research implications and offering directions for future research.

The aim of the study was to explore the space of QI in order to better understand the facilitators and barriers to involving vulnerable service user groups in CMS QI. The research took place across two settings where the respective service user populations may be considered particularly vulnerable: people living with traumatic brain injury and people living with mental ill-health requiring inpatient rehabilitation services. In this research, QI is understood as a specific service development exercise which applies systemic change methods, tools and theory, and through which best practice solutions are implemented. The objectives of this research were produced in collaboration with a QI partner organisation that is responsible for driving the development of CMS QI in the healthcare trust where this research took place.

In the research, a two-pronged approach is taken and this is reflected in the ordering of research questions. To gain a better understanding of the space of QI, I first sought to understand how the different concepts and methods of practice were constructed by those involved in these very processes i.e. What did stakeholders feel was the intention behind QI? What did service user involvement, co-production and QI mean to different stakeholder groups? This line of enquiry was important given that understanding of these concepts may influence how service user involvement, co-production and QI is approached in practice. It was also pursed in light of the conceptual and language challenges reported within the literature. The second part of this research was to draw together the understanding and framing of these concepts with observations of practice to examine how service users could be involved, or, excluded from QI practice. In conducting this exploration, my research has also paid attention to dynamics of power that underpin the relationship between service users and healthcare professionals. This is pertinent given that QI calls for the convergence of multiple actors with different backgrounds, experiences and knowledge. The concept of epistemic injustice was considered useful to explore how varying claims to knowledge come to dominate QI practice.

The following research questions guided the exploration of my research:

Research Question 1
How are the concepts of service user involvement, co-production and quality improvement constructed and understood by key stakeholders?

Research Question 2
How do the processes of quality improvement initiatives shape the roles and contributions of service users?

The research investigation was led by the following interlinking aims and objectives: 1) Compare ambitions of service user involvement and co-production in QI against what is happening in reality, 2) Explore how understanding of concepts translates into approaches adopted in practice, 3) Describe the various processes and structures influencing practice, 4) Assess the influence of organisational context (vision, infrastructure, culture, commitment) within QI, and 5) Examine the relationships and spaces in which dialogue and learning takes place.

Through the use of multiple methods, the first three objectives informing the exploration of this research were met. A narrative review of the literature along with analysis of key documents (that included QI guides and frameworks) enabled recognition of the ambition for service user involvement in QI, and how this has emerged and developed. This was further explored in relation to the research site, with analysis of strategic documents and discussions with senior level staff (including members of the continuous improvement and involvement teams). Assessing the reality of service user involvement and co-production in QI was aided through observations of practice, with comparison achieved between what was being said and what was being seen. The utilisation of QI theory assisted in making sense of the QI process, with regard to aims, design, capacity and involvement of stakeholders. Likewise, the understanding of concepts (involvement, co-production, QI) and how they translated, or were visualised, in practice (the second objective) was also realised through interviews with different professional groups. Explicit questions were asked about different participatory approaches, perceptions around terminology and language, whilst reflections on experiences of involvement were also gathered. Here, for example, I document how co-production can be conflated with other forms of participatory practice resulting in a failure to realise the key underpinning principles and values. The third objective relating to the identification of structural and processual features was met in a similar fashion, with discussions and observations of QI meetings highlighting a range of individual and structural barriers to involving service users. Cross-referencing these findings with the concept of epistemic injustice enabled deeper interrogation of issues, providing insight into how processual features and structural barriers affect the practice of involving service users in QI.

The fourth and fifth objectives were partially met. A review of key strategic documents alongside discussions with different stakeholder groups (ranging in seniority) provided some exploration of contextual influence on QI (objective four). However, this examination was conducted at a surface level, and wider exploration was required. In respect to the fifth objective, the work conducted to explore the aforementioned objectives helped further understand the space of QI in terms of expectations and actions in practice. In addition, the dialogue between professionals was captured and examined. However, the examination of relationships and the various dialogical exchanges taking place (which would have enabled understanding of the different forms of knowledge) between participating servicer users and professionals was not achieved. This was largely down to the absence of service users in CMS meetings, and therefore such reflection was difficult to capture.

12.1 Summary of Chapters

In this section, I provide an overview of each chapter within my thesis, highlighting the different strands of the research covered and through which the intention of my research becomes clear.

In Chapter 2, I made visible the different arrangements for involving service users in healthcare practice before introducing the concept of co-production and charting how it has become increasingly prevalent within healthcare discourse. I show how co-production tends to be recognised as an egalitarian way of thinking about power, resources and partnerships, and therefore offers a different way of working from conventional knowledge production. Whilst co-production may be described as a set of activities, it is above all a values-based approach that represents a key mechanism in the transformation of modern day healthcare services to one that aligns more closely with the needs of service users. However, I also highlight a number of current challenges associated with co-production. ‘Conceptual fuzziness’ surrounds the understanding of co-production in the absence of a clear and agreed definition. More pertinently, the realities of sharing power have been deliberated in healthcare systems with a history of entrenched power asymmetries.

In Chapter 3, I reviewed the historical and political backdrop of the service user involvement agenda, illustrating how this has been influenced by consumerist and democratic ideologies. Whilst the policy atmosphere appears supportive, I argue that a raft of policy changes has made service user involvement difficult to implement. For instance, I highlight a mismatch between the urgency espoused within policy ambition and the inadequate allocation of resources to implement policy. I show how current policy ambitions espouse egalitarian and democratic values of co-production, which may explain the popularity of co-production in the development of healthcare services.

In Chapter 4, I examined the rationale of service user involvement before contrasting this with the key challenges and tensions reported in the literature. I highlight how service user involvement is viewed as a strength because of the unique first-hand experiential knowledge that can inform discussion. In theory, merging multiple sources of knowledge leads to better informed and transparent decision-making. Yet, this is not a straightforward endeavour as competing tensions and structural issues constrain practice. Some of these tensions make visible the challenges of sharing power between different stakeholder groups and also how power might be manipulated by more dominant and powerful groups.

In Chapter 5, I discussed how healthcare organisations are increasingly adopting various QI methodologies and tools to combat performance gaps and increase the quality of care being delivered. Taking influence from industrial practice, QI in healthcare attempts to narrow the gap between current practice and the best possible practice. Several QI methodologies exist, and in this chapter, I introduced the CMS approach to QI. I addressed how a commonality across the different QI methodologies is the need to prioritise context and provide supportive conditions for successful QI. Furthermore, I also show how the role of the service user has become increasingly prominent within the practice of QI, but this is an area of research which remains somewhat underexplored.

In Chapter 6, I advanced a focus on issues of power that underpin spaces of involvement and are visible in professional-service user relationships. I argue that fundamental to the involvement of service users in the design and delivery of services is the degree to which their experiential knowledge is recognised as credible sources of information. However, the organisation of healthcare contributes to knowledge asymmetries through the selection and privileging of certain types of knowledge. Subsequently, I drew upon the concept of epistemic injustice to explain how inequalities in knowledge production and mobilisation materialise. I suggest epistemic injustice is a useful lens through which to explore issues of service user involvement and co-production in QI given that the underlying rhetoric calls for multiple forms of knowledge to be represented in practice. The absence of epistemic justice may affect how service users are involved within the co-production and co-design of improvements.

In Chapter 7, I described the methodological choices and the analytical process navigated through the study. Considering the aims and objectives of this research along with my philosophical assumptions, a qualitative case study approach was selected. My research was interested in understanding how different stakeholders made sense of the various concepts before observing how service users were actually involved in practice. Subsequently, a number of complimentary research methods - interviews, observations and analysis of documents – were selected to enable the research questions to be answered. Data was analysed using an inductive thematic approach with higher order themes cross-referenced to key discussions in the literature, QI theory and the framework of epistemic injustice. The chapter concluded by providing a review of the ethical processes navigated in the research before highlighting some of the challenges experienced whilst in the field.

In Chapter 8, the first of the research findings chapters, I highlighted how QI is not always afforded priority for several reasons that include the combined effects of structural barriers, organisational complexity and varied attitudes. Structural barriers may not be peculiar to QI, but rather indicative of the wider structures and systems across the organisation. Nonetheless, the findings suggest that the psychological domains of QI work need greater priority than is currently assigned. Developing psychological safety and strengthening relational dimensions of the QI process is likely to have a positive effect on the success of future CMS QI work.

In Chapter 9, I observed how co-production can be conflated with other forms of participatory practice. I argued that as a result of this conflation, underpinning principles and values of participatory approaches may fail to be realised in practice. Failing to recognise dynamics of power is equally damaging for the enterprise of involvement and co-production. Where power sharing was discussed in regards to working with service users in QI, there appeared to be an acceptance that this could be difficult, or near impossible, given the current configuration of healthcare and complexity of services.

In Chapter 10, I report how there was a limited role for service users in the QI practices of CMS teams. Whilst the instability of respective CMS teams contributed to this, I argue that there were several issues raised by personnel and observed in practice that suggested a limited role for service users. I highlight how complexity of service user impairment posed challenges, with staff expressing concerns of potentially overburdening service users. In respect, however, there was a lack of clarity and guidance on how to negotiate issues of capacity with service users. I also suggest that the absence of a well-developed structured for

QI-specific involvement meant teams were left unaware of how to involve service users. Beyond issues of impairment complexity, I suggest that teams were also wary of relinquishing some control to service users. Combined with questioning the relevance of service user involvement in certain projects along with discussions that identified a controlled selection process, I highlighted the power differentials underpinning QI efforts. This, I suggest, could lead to unjust practice and disadvantage certain service user groups from participation, where potential epistemic injustices could be generated.

My research findings show how QI in its current mechanisms can limit the space for service users to be involved in this type of work. The specialised and esoteric nature of QI work may result in staff cautiousness over how service users can be involved, whilst a lack of clarity over roles and responsibilities also suggests that the involvement of service users in QI may not be understood, prioritised, or even, appreciated. Subsequently, the issues raised in my research question the potential for co-produced QI with vulnerable service user groups, whilst an epistemic lens has been applied to examine how formats and practices may disadvantage service users from being involved. These form the basis of my research contributions which are further clarified in the next section.

12.2 Thesis Contribution

The research findings from this study highlight how the role of vulnerable service users in the collective endeavours of QI can be limited. This limited role does little to shift the role of service users beyond that of passive sources of information, rather than creating opportunities for active participation as is the ambition of QI. To a certain extent, in this study, the unstable context within which CMS teams found themselves is likely to have affected efforts to involve service users. Nonetheless, through my analysis, I identified how conceptualisations of the involvement process and stakeholders' knowledge and competency levels are also factors in limiting the participation of vulnerable service user groups in QI.

My research makes two main contributions in regards to the role of vulnerable service user groups in QI. The first contribution of this thesis is to link the limited role of service users to epistemically unjust mechanisms in the organisation and practices of QI. That is, certain forms of knowledge, language and expertise are preferred at the expense of others, and these often mirror the dominant hierarchical constructions within healthcare practice. I argue the relevance of viewing QI practice through a lens of epistemic injustice as to make clear the processes of knowledge production and mobilisation. Recognition of epistemic injustice is important if service users are to be meaningfully involved in discussions regarding the design and delivery of healthcare services, that includes the practice of QI. It may be argued that enterprises of service user involvement and co-production are designed to enhance testimonial and hermeneutical practice (Glass and Newman, 2015; Groot et al., 2020; de Boer, 2021). Therefore, I also argue that exploring how knowledge is produced and mobilised entails greater understanding of the relational dynamics needed when working collaboratively as is expected within these exchanges (Groot et al., 2020).

The second contribution of this thesis follows by questioning the extent to which genuine co-production can be achieved within QI work given the current configuration of mental healthcare settings and the professionalised nature of QI work. My research is not alone in documenting struggles to involve service users throughout the QI process. I argue the restriction of service users to particular stages of QI rather than throughout, does not reflect co-produced or co-designed practice, even though this language may be used to describe practice. The generation of epistemic injustice impacts upon the ability of service users to be meaningfully involved in QI. Until injustices are recognised and addressed, the potential for QI to be co-produced with service users might be limited.

12.2.1 Service User Involvement, Quality Improvement and Epistemic Injustice

My research links the passive role of service users in QI to epistemic politics and the recognition attributed to their knowledge. Given the complex settings in which this research has taken place, recognising the knowledge provided by service users is vital if they are to be seen as credible partners in QI. At the same time, QI is a collective and specialised process which has tended to be in the control of professionals.

My research suggests current mechanisms in the organisation and practice of QI are epistemically unjust, whereby service users may encounter potential epistemic injustice. That is, the knowledge of service users is undervalued, afforded less credibility and even invalidated in some instances within practices of QI, where healthcare professionals hold authority, control and power. This authority is bestowed by virtue of professional knowledge receiving greater epistemic status and credibility. The hierarchical organisation of services, structural issues such as lack of time and resources, gaps in learning and skill, and ill-fitting formats are also complicit in the hermeneutical marginalisation of service user groups from the very spaces that call for their involvement. These challenges, I argue, lead to service users encountering epistemic injustices when within the process there is an unexamined privileging of certain forms of knowledge, language and communication which align with the dominant biopsychosocial model.

This thesis has advanced focus on the epistemic dimensions of knowledge generation, extending the application of epistemic injustice to settings of healthcare involvement, co-production and QI. The concept of epistemic injustice has been applied across a range of settings to analyse interpersonal relationships in care-giving. Within healthcare, the concept of epistemic injustice has been applied to areas largely concerning shared-decision making and individual care and treatment. As such, my research represents a new area of development and inquiry. This thesis argues for attention to epistemic factors of knowledge recognition in QI, which may help to surface, detect, communicate, and potentially alleviate injustices. It is only through understanding how epistemic injustice operates to limit the knowledge of marginalized groups being represented, that action can be taken to reverse this, and to incorporate service user knowledge in a more equitable and meaningful manner. Thus, concentrating on making QI practices epistemically just may entail greater integration of service users into QI. The involvement of service users, then, would align more closely with the democratic ambitions espoused in healthcare policy where the service user has a prominent role to play in service improvement.

12.2.2 Service User Involvement and Co-Production in Quality Improvement

The second chapter of this thesis documented how ‘co-’ approaches are shaped by a set of distinct principles and values that includes sharing of power and democratisation of knowledge generation. In Chapters 9 and 10, I presented research findings that show how power asymmetries are not always recognised, the sharing of power in QI collaborative exchanges is a challenge, and co-production of all stages of a QI project can be difficult. The setting where my research has taken place, a Mental Health Trust, makes the common difficulties associated with co-production even more difficult. The intensified difficulties, I argue, are often located with the complexities of services users’ impairments and the prevailing dominant discourses that operate within these clinical areas. As reported in this research, people ‘on the ground’ arrive at the QI process with different forms of knowledge, skills and experiences, whilst some staff and service users also encounter uneven access to resources that ultimately limit their opportunity to participate. These new findings add to the view in the extant literature that the design and complexity of health services remains a key challenge for successful QI. Furthermore, the rationale of involving service users in QI requires further consideration.

i) Reflecting on the ambition: The Co-Production of Healthcare QI

Batalden (2018) describes how coproduced healthcare services are an inherent property of any care system and which will always involve service users. However, there is an ambition for a more active and meaningful role for service users in healthcare service design and delivery. This idealised role for service users represents a transformative ambition for QI practice, whereby service users contribute to 'health-making' as opposed to professionals 'making' healthcare. Under a transformative ambition, the status of service users and professionals change as a result of being involved in a collaborative process (Williams et al., 2020b). This positional shift for service users is targeted through moving from an 'oversimplified' product dominant logic to a service dominant logic (Batalden, 2018). Couched in marketing language, a service dominant logic acknowledges that service users are both 'consumers' and 'suppliers' of healthcare, and this should be seamlessly reflected in the creation (and sustaining) of effective service user-professional relationships.

The practice of QI is underpinned by a broader asset-focused aim – creating value with service users – and therefore driven by both a technocratic and democratic rationale (Batalden, 2015; 2018). As has been described, a technocratic rationale identifies the instrumental value of different knowledge forms to create more efficient services; in QI, this encompasses the interconnectivity of the three knowledge domains: professional, patient and improvement knowledge (Batalden, 2018). Whereas democratic arguments are based on communicative and consensus-oriented rationality, with emphasis on stakeholder participation in decision-making and representative inclusion; this entails transition to more equal power relations between service users and professionals. The purposeful staging of QI with various reflective points to gauge stakeholder perspectives and gain consensus over decision-making may reflect such democratic ideals.

I argue that in practice, involvement of service users is largely perceived to serve technocratic aims i.e. the involvement of service users is recognised as potentially improving the effectiveness of services and organisational processes for which QI has been introduced. Though a technocratic ambition remains a valid motive for the involvement of service users, tensions identified over the selection of service users, concerns over representation – raising questions over equity – and the failure to articulate power dynamics to explain service user-professional relations, suggest a democratic deficit. Moreover, concerns identified in my research relating to defensive behaviour amongst professionals and organisational conditions (e.g. permission and time to engage with service users) also point to inequitable service design, that belies a potential loss of the democratic rationale underpinning efforts. Democratic rationales confer closer examination of the relational process of involvement. Yet, attempting to capture and measure outcomes such as communication, teamwork and equity - factors relating to the process of co-production and QI - are not straightforward and typically harder to link casually to co-production and QI. In contrast, outcomes informed through a technocratic rationale may be more measurable, and therefore these tend to be prioritised within improvement.

Co-production is intertwined with democratic and egalitarian values, and attempts to redress power asymmetries (more visibly than traditional participatory approaches). If such values and focus is absent, questions understandably arise over the possibility of co-producing QI. My research argued that service user involvement remained within privileged sites of knowledge generation, raising important questions about the extent to which genuine co-production can be achieved within QI initiatives undertaken in mental health care settings. Even where the usefulness of service user's experiential knowledge may be recognised, it is still unclear how this knowledge can be used for the more 'impactful', decision-making stages of the QI process. The findings of this research support observations made by Rose and Kalathil (2019) and Farr et al. (2021) whom also question the possibility of co-production in mental health services and health and social care research respectively. QI aims to implement rigorously-evaluated solutions to solve local problems in care pathways or service operations. I suggest it is this specialised focus, which prioritises certain forms of knowledge over others, that can further explain why the potential for co-produced QI remains difficult. In addition, there are features of mental health practice that exacerbate power asymmetries and epistemic injustices which also duly need to be considered.

However, I argue that the ambition for the co-production of QI is not unrealistic, but rather that barriers obstructing this potential should be addressed in order for a democratic impetus to be strengthened within service improvement. Williams et al. (2020a) describe how a democratic ethos – based on fairness, transparency, equity – is premised on a basic aim. Broadening what is understood by value creation may help increase awareness of the democratic rationale of co-production in QI. Greater focus on the process of QI and the engagement of service users may help this endeavour and increase the democratic impetus to service improvement: the process being as important as the outcomes that are produced. Placing value on the space and process of QI will enable better insight into, for example, how projects have been decided, the transparency of decision-making and the management of different relationships (including negotiation of power dynamics). This extends to provision of support – organisational and professional - to service users that will allow them to feel that their involvement is valued and that they can impact decisions regarding the design and delivery of services (Verschuere et al., 2018).

To summarise, there is a need for QI in mental health services to recognise various epistemic dynamics and their influence on the QI process. The current configuration of mental health services along with the conduct of QI, which is dominated by professional control and decision-making, leaves little room for service users to be involved meaningfully. Where involved, the research findings show there is tight control over who is involved, whilst the terms of involvement are also dictated by the professional. Subsequently, then, the possibility of co-produced QI remains questionable until overarching practices, systems and structures are reconfigured. This then, for example, requires involving service users in a way that moves beyond consultative modes, recognising power differentials and creating more inclusive spaces where opportunities are created for service users. Actions, attitudes and behaviours informed by epistemic humility and reflexive practice will aid in this endeavour. Broadly, this may help move beyond sole concentration on professionally-highlighted concerns to an appreciation of multiple forms of knowledge and where there is greater clarity over how service users may be involved and to what extent. At the same time, co-production is not the only possible, or the most appropriate method. This considered, the extent to which service users are involved should reflect the nature of the improvement task. Subsequently, greater consideration of the rationale for co-production should be undertaken before proceeding. This would help avoid ‘cobiquity’ (Williams et al., 2020a), where practice is labelled ‘co-production’, but which lacks the fundamental underlying principles. Having clarified the key contributions of this thesis in the discussion above, the following section now focuses on the strengths and limitations of the research, where issues of study design and conduct are addressed.

12.3 Reflections, Strengths and Limitations

My research fulfilled its objective to provide more detailed examination of how the CMS QI process operates in services delivered to vulnerable service user groups, and how these groups may be involved or excluded. I used a range of methods which enabled a more robust explanation of the research area. I also interrogated the research through viewing power dynamics underpinning the QI process, which I believe is also a particular strength. This said, my study must also be viewed alongside some potential limitations: a single trust, a sole focus on CMS QI methodology, size of data set collected including number of participating CMS teams, meetings observed and stakeholder interviews.

My study has taken place in a single UK-based Healthcare Trust where CMS represents the trust-wide methodological approach to QI. Subsequently, the particularities of this single case possess a number of specific characteristics which may differ in other settings. In defence, my research originated from a collaborative award produced between the partner Trust and the University of Sheffield: the partner's request of the research was to learn more about the integration of service users in CMS QI. Chapter 5 highlighted how there are several QI methodologies being used in healthcare and therefore it is possible that these propose alternative methods of working that affects how service users may be involved. In respect then, it may be difficult to directly generalize the results of my research to other contexts. At the same time, I acknowledge Stake's (2011 p.18) argument that case study inquiry is "carried out so that certain audiences will benefit – not just to swell the archives, but to help persons toward further understandings". As has been discussed, the research study emerged in collaboration with a QI partner, whom wanted to learn more about the intricacies of service user involvement in the CMS QI process as this was a strategic ambition.

I adopted the position of 'outsider' in the research, only accessing case sites for meetings and to conduct interviews. Being an outsider, I found, allowed me to maintain distance, avoid group biases and navigate complex group dynamics whilst in the field (Hellawell, 2006). To some extent, my position may have become 'more insider' owing to the relationship developed with the collaborative partner. I attended several partner-hosted QI events, conversed with experts and shadowed QI staff as a means of orientation into CMS QI. Throughout the research, I maintained contact with the Trust QI lead and respective team coaches, which was helpful to 'open doors' and provide valuable sources of information (Buchanan et al., 1988). Naturally, I appreciate being an insider (i.e. a healthcare professional in one of the studied teams or a QI expert) may have enabled a different vantage point, influenced by working within the system and having access to a network of established contacts.

Several challenges were encountered in the research, and whilst some have been drawn out as findings, they are also equally reflective of the messiness of conducting doctoral and organisational research. Buchanan et al. (1988 p.54) describe how research plans succumb to "the practical realities, opportunities and constraints presented by organisational research". The number of CMS teams (n=3) participating in the research may be considered small however only a few teams across the Trust involved service users. As a result, team selection also reflected pragmatic decisions. For example, one CMS team dropped out unexpectedly after pausing their CMS work due to internal staff commitments. Realities of practice that included cancellations and rescheduling of meetings resulted in fewer meeting observations and difficulties in building rapport with some team members for purposes of individual interviews; this was particularly evident within the inpatient rehabilitation CMS team. To some extent, combining interviews with observational practice helped to counter-balance such challenges.

The number of service user interviews was lower in comparison to professionals particularly during the team-based phase. The rationale behind team-based interviews was to learn about experiences of participating in the CMS process however service users were rarely involved. Nonetheless, my exploration of service users' experience of the CMS process and working in service user-professional teams is limited. This is a point of personal frustration given the study design and the careful plan to address ethical issues in order to access and speak with service users. A study extension was submitted to compensate for fieldwork challenges and create more opportunities to engage with CMS teams. Unfortunately, teams paused their CMS work at the onset of the COVID-19 pandemic, and given the study timeline, research was brought to a close.

12.3.1 Reflecting on the Theoretical Contribution

I argue that the concept of epistemic injustice is particularly pertinent to the practice of service user involvement and QI where the output of this work is inevitably going to impact service users. Exploring, for example, how credibility indicators are unfairly applied to service users may highlight how the potential for service users to be involved in QI is undermined despite the rhetoric of their importance. This also enables recognition of who is considered knowledgeable, who is not, and the types of knowledge that are undervalued. Reflecting on the concept of justice in QI work, the democratic rationale of involving service users may become more visible and influential whereby there is a turn towards understanding how service user experience and knowledge can inform service development.

In highlighting the contribution of this thesis, I am acutely aware that the research findings presented have been predominantly shaped by discussions with professionals and informed by researcher observations of practice. In the vocabulary of epistemic injustice, the research findings have been informed by the 'testimonies of the hearer' i.e. professionals whom have traditionally held power and authority within participatory spaces. In contrast, there is limited understanding of the experiences of service users – 'the speakers'. Conceding the absence of a strong service user voice in this research is important as it is these groups that experience the actual injustices that have been raised in the discussion.

From a justice perspective, there is acknowledgement that service users should be involved and heard, particularly when research itself is about better understanding how participatory spaces facilitate service user involvement. Valuable research judgements have been made in this thesis, for example, the lack of service user involvement suggesting service users remain passive sources of information, which contrasts the rhetoric of QI. However, beyond the involvement of service users on grounds of justice, the insight of service users in such discussions is extremely valuable to provide exact learning over what it means to be involved, or how best to be involved (including the support required). This could be particularly important when discussing how greater diversity can be achieved in participatory spaces, where individuals from different backgrounds can be involved. Within this, there is recognition that failing to understand inequalities in ‘credibility and intelligibility’ between diverse groups, can ultimately reproduce existing inequalities. Where involved, greater understanding could be yielded from examining the types of knowledge informing QI practice. Such analysis would pinpoint how service users are contributing whilst appropriating the correct terminology to these efforts. That is rather than the adoption of language which is not underpinned by what is taking place in reality; it is neither possible nor desirable to share power and responsibility equally between service users and professionals in all situations. There is a need to understand how ‘patient knowledge’, both works alongside and affects professional and improvement knowledge, to support QI.

Understanding the predicament of service users would help identify the exact nature of injustices experienced by personnel and the impact of these. This helps move forward from discussion of ‘potential’ or ‘pre-emptive’ injustices that may arise from professional attitudes and behaviour, or structural mechanisms. In this thesis, different forms of injustice (e.g. testimonial, hermeneutical, participant-based) have been described with each type of injustice characterised by distinct aetiology. Mapping out these forms of injustice against the lived experiences of service users (in involvement spaces) would thus enable greater understanding of the various inhibiting mechanisms (individual and structural), and which types of injustice may be more discernible in the practice of QI.

12.4 Summary

This section has summarised the strengths and limitations of the study. I have also reflected on the theoretical contribution in light of fieldwork experiences. As illustrated, many challenges relate to methodological design and also bring fore considerations of conducting doctoral research with external organisations. The combination of methods used in my research helped to minimise the impact of such challenges. Furthermore, a particular strength of my research is the focus on power and epistemic factors of QI practice, a developing field in itself. The findings of this thesis make several inferences concerning the practices of service user involvement and co-production in QI. Whilst some directions for future work have been discussed, the following section attempts to summarise the implications for practice.

12.5 Implications for Practice

i) Healthcare Professionals

From reviewing and discussing the findings of the research, I highlight the need for service providers and professionals to assign greater value and legitimacy to service users and their input. The onus is placed on professionals given their system-sanctioned authority and hold of control, not to mention how service users have traditionally been negatively impacted by power asymmetries. In Section 11.6.3, I suggested greater appreciation of service user knowledge may be achieved through epistemic humility, akin to critical reflexive practice, where there is acknowledgement of one’s own judgements, privileges and epistemic capacities. This reflexive practice also forces understanding of different perspectives and through which accommodating this knowledge might become easier.

Encouragement of epistemic humility and reflexivity may be facilitated through professional training and education (eventually becoming a part of clinical practice) for current, new and trainee staff that includes healthcare students. Far from simply being a “technical skill included in the curriculum” (Naldermici et al., 2020 p.12), professionals should be empowered to believe in the values of this practice. Reflexive practice also ties in with greater appreciation of the emotional and relational aspects of service user involvement and co-production; co-production techniques themselves do not guarantee collaboration in the absence of reflection and dialogue (Knowles et al., 2021a; Tembo et al., 2021). Emotional labour, in particular, is important to build, manage and sustain key relationships, whilst creating space for fair and authentic dialogue between stakeholders. On this note, Farr et al. (2021) discuss how emotional work in co-production is both underappreciated and under-resourced. Involving service users is not straightforward and does not always tally with ideals of ‘well-ordered' practice. Thomas-Hughes (2018) describes how reflection and honesty forces the 'messiness of co-production' to be visible, from which better understanding, depth and rigour is achieved. Batalden's (2018 p.2) assertion that service users and professionals should be "held together by knowledge, skills, habit, a willingness to be vulnerable" is pertinent here. This reiterates how the 'messiness' should be appreciated and reflected upon through the process of involvement.

A number of concerns identified in my research point to the 'how' of service user involvement and co-production in QI. This was both in terms of involving vulnerable service user groups and integration of involvement within QI practice. My research reported that whilst guidance for involving service users in CMS work was clearly visible, guidance over how to facilitate this involvement was less visible. Professionals have to support service users whilst also managing institutional policies and practices. Therefore, one implication for practice is that support and education (for staff) focuses on providing greater clarity and appreciation of the key issues pertaining to ethical responsibilities, communication and access. These issues can be daunting to tackle for professionals, and in light of the challenges, many may err on the side of caution. One practical recommendation is to adopt action planning that coordinates greater integration of service users from specific areas and to develop better insights into the particular practices of QI most appropriate to that context. Having context-situated expectations, roles and responsibilities is likely to help as it provides clarity over where service users have been involved in the process and how they have contributed. Advanced planning could help make QI more accessible in terms of methods of engagement where, for example, communication and language is carefully monitored and tailored to encourage collaboration.

A particular challenge highlighted in my research was the ability to get service users 'in the room'. In such cases, service user experience data collected through alternative formats (more direct and unstructured forms of feedback) possess high explanatory power. The research findings, however, revealed insecurities of dealing with service user experience data with issues of skill, confidence and time. Nonetheless, if experience data has already been collected but remains unused then this is unethical practice; service users have given up time and effort to provide feedback on the proviso that this will be utilised in some form or at least acknowledged (Sheard et al., 2019). Certainly, then, support for frontline teams in utilising different data is essential, more so given that this data is being routinely collected. The centralised service user experience team will have an important role to play in providing this support given their expertise, as will, nominated service user experience leads within teams and services. Sheard et al. (2019) highlight key conditions for responding to patient feedback that includes structural legitimacy (professionals feel that they have the autonomy, ownership and resources available) and organisational readiness (meso-level support for staff to work on improvement). These conditions further highlight the important of psychological safety.

Amidst challenges of using service user experience data, the findings from Montgomery et al's (2020 p.14) study is particularly pertinent. The authors suggest expanding the traditional service user experience lens (perspectives and survey-based data) to incorporate wild data, "the informal, embodied and sometimes intuitive knowledge about patients' experiences that staff acquired through daily interactions". This type of data is often filtered out in conventional quantitative and survey-based formats. This, then, may also represent another area to consider development. Although some caution must be taken to ensure that the same professional voices do not dominate if this type of data is solely relied upon to relay the service user experience.

ii) Service Users

QI represents new forms of working for both professionals and service users. When involved in QI, service users are asked to take a broader and collective outlook as opposed to making decisions around individual care and treatment. Therefore, just as professionals receive training and education, I suggest similar support may also be extended to service users. I subscribe to the view that provision of learning and support for service users is a strength, despite competing arguments of potential professionalization and service users losing the 'laity' of their experiential knowledge. As discussed in previous chapters, vulnerable service user groups may be susceptible to already lower levels of confidence and self-esteem, yet paradoxically service users are selected on being confident and good communicators; service users find themselves in a catch-22 situation (Learmonth et al., 2009). Therefore, learning and support may help level the credibility deficit that currently dominates practice and increase the confidence of service users which may allow them to communicate their experiences in more effective ways. Where achievable, opportunities to be introduced to QI and further support extended to improving literacy skills (where needed), how to work in teams and communicating with peers, is needed.

There is an additional challenge to involving vulnerable service user groups and which confers the need for more care and effort during facilitation. Seeking innovative ways in which to involve these groups is imperative if service user involvement in QI is to be successful. Targeted and selected approaches to support and promote the inclusion of persons from vulnerable groups are required. The development of technology and the various online platforms now being used for communication purposes may represent an opportunity to challenge issues of access, whereby service users may be able to participate from spaces of their own choosing. Naturally, a potential technological divide needs to be considered in order to make sure participation opportunities are fair and equitable. Over time, with the type of support discussed, hopefully service users are offered further opportunities that transcend early phases of the process to enable greater collaborative efforts.

iii) Healthcare Organisations

The above set of implications has predominantly focused upon strengthening understanding, dialogue and interaction between professionals and service users. It primarily targets the individual-interactional level which may help limit instances of individual testimonial injustice and particular hermeneutical injustices (de Boer, 2021). Undoubtedly, there is need to challenge the ‘business as usual’ approach, and part of this requires attitudinal shifts; epistemic humility and reflexivity fits in here. Nonetheless, there are broader issues concerning supporting structures and the organisation of healthcare, which if not addressed, can lead to hermeneutical gaps and therefore generation of injustice (Massé et al., 2021).

This research is by no means first, and neither will it be the last, to reiterate the need for investment in time, resources and finances which are instrumental to ambitions of co-produced QI. Involving vulnerable service user groups requires more time, resources and emotional work, which can be difficult to achieve without the appropriate support. Delivering training sessions for staff and service users will require more time and finance, whilst if more service users are involved – as is the ambition - then greater finances will be also needed to compensate their efforts. The creation of psychologically safe and discursive spaces must also be created to allow service users to develop their agency whilst enabling professionals to feel comfortable and actively seek out exchanges. Given that structural and organisational inadequacies are frequently highlighted to explain poorly facilitated practice, it would have to be questioned how serious organisations are when they purport ambitions to place ‘patients at the centre’ or call for the ‘co-production of healthcare and QI’.

Similar arguments may be offered in respect to stakeholder engagement with QI, and this returns back to the research findings presented in Chapter 8. If the value of QI, as is purported, is to be realised, it might be required that necessary changes to respective workload demands are made and inhibitive structures are better understood. A more tailored approach to QI, where organisations are increasing the capacity and capability to engage with this work, is likely to result in more satisfactory and psychologically safe conditions. Once secured, the impetus, then, is on frontline teams to engage with QI.

12.5 Directions for Future Research

The results of this study suggest the importance of further organisational research in regard to the negotiation and management of service user involvement in QI efforts, particularly in settings where services are delivered to vulnerable groups. The involvement of service users in QI is key, and this is underpinned by the frequency of recent research. The involvement of service users in QI is important to mobilise a move from a professionally-driven healthcare system to a service-logic, power-balanced situation. As Batalden (2018) argues, healthcare services are always, by nature, co-produced and therefore it should be the role of QI facilitators and organisations to acknowledge and facilitate steps to accrue valuable knowledge that would otherwise be lost, in the sense, of co-production taking place between professionals AND service users.

Generating evidence-based guidance that provides support to healthcare QI teams on how to involve service users will be of great value. In particular, I suggest empirical research that seeks to better understand the relational dynamics and the process of integrating service user involvement in QI work revolving around service and organisational processes. Within this examination of the process, future research should aim to explore what types of service user groups are involved or excluded from QI, how relationships develop and change, and how this ultimately influences knowledge production. Understanding what specific types of knowledge (and their particular contribution) drive improvement will also be helpful, with greater exploration of what value is being created from communicative exchanges taking place; this is both the creation of value for stakeholders involved in the process and the wider impact on service improvement e.g. safety and quality of services provided. This may be further aided by research which establishes the key competencies and skills required by healthcare professionals and service users for co-production activity to be performed well in the context of QI. Such research will entail greater appreciation of the technocratic and democratic outcomes. It is likely that in order to measure values such as equity, trust and respect (more democratically-orientated values), different methodological approaches will be required, and thus should be considered in the design of studies. This may further emphasise the need to involve service user groups in the design of studies themselves, as this will allow recognition of the different quality indicators before a QI project begins, with the study being able to track whether these are met at the culmination of the project. At the same time, aware of terminological confusion, the extent to which service users are involved in QI should reflect the nature of the improvement task. However, such decisions must be made transparent. Greater consideration of the rationale for co-production should be undertaken before proceeding. This would help avoid ‘cobiquity’ (Williams et al., 2020a), where practice is labelled ‘co-production’, but which lacks the fundamental underlying principles.

The role of power in service user involvement and co-production has been made explicit throughout this thesis. I have argued that my research extends existing understanding regarding the role of power in service user involvement and co-production through applying the lens of epistemic injustice. Certainly, the application of epistemic injustice in the area of service user involvement and co-production is ever growing and therefore presents an area that is rife for further research development (de Boer, 2021; Knowles et al., 2021b; Liabo et al., 2022). To this end, I suggest further research which explores the various activities and exchanges taking place under a lens of epistemic injustice may provide a deeper consideration of power issues and structural inequalities. This, I argue, would be essential to help understand how to facilitate more equitable partnerships within collaborative work and deepen our understanding of the need for service users to adopt active roles in QI. In addition, following Moes et al. (2020), there needs to be interrogation of how knowledge is developed in the first instance – "how knowing gets done" (p.8) - which may explain how epistemic justice in practice can be strengthened in practice. The area of epistemic injustice in itself is ever expanding to accommodate 'different and evolving varieties of epistemic injustice' that includes epistemic oppression, exclusion and violence (Hookway, 2010; Fricker, 2017; Mladenov and Dimitrova, 2022). My research has predominantly focused upon pathocentric epistemic injustices that focus upon testimonial and hermeneutical injustice linked to ill-health. It may be, then, that further research explores the various intricacies of service user involvement and co-production in QI through locating and mapping where other specific injustices arise and provide description over the exact nature of these injustices and how this influences the involvement of service users.

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Appendices

Appendix 1a - Key Informant Interview Schedule - Staff Members

The University Of Sheffield.

Key Informant Interview Schedule *(with staff members)*

Background

Current role/Main responsibilities

Understanding

What is your understanding of service user involvement? (What does it mean to you and how you think it has been built up in the service/trust?)

When you hear terms such as co-production and co-design, what is your understanding?

Are there preferences for any terms that you use or are used across your work to describe activities where service users are being involved?

How would you define quality and quality improvement (QI)?

What is your knowledge/experience of the CMS process in the Trust?

Expectations and Experience

What is the significance of involving service users in QI and CMS work? How possible do you think it is to achieve?

What have been your experiences of service user involvement and co-production in your role?

Are there any particular examples of good practice that stand out?

In your role, what are your expectations of service users when they become involved in QI?

What do you think service users expect from being involved in QI work like CMS?

Have you experienced any challenges of involving service users? If so what are these challenges?

Changes and Development

What do you see for the future of service user involvement in healthcare design and quality improvement?

Is there anything you would like to add?

Thank You for Your Time and Participation

Appendix 1b - Key Informant Interview Schedule - Service User Volunteers

The University Of Sheffield.	Key Informant Interview Schedule *(with service user volunteers)*

Background

Current role/Main responsibilities

Understanding

What is your understanding of service user involvement? (What does it mean to you and how you think it has been built up in the service/trust?)

When you hear terms such as co-production and co-design, what is your understanding?

Are there preferences for any terms that you use or are used across your work to describe activities where service users are being involved?

How would you define quality and quality improvement (QI)?

What is your knowledge/experience of the CMS process in the Trust?

Expectations and Experience

What is the significance of involving service users in QI and CMS work? How possible do you think it is to achieve?

What have been your experiences of being involved?

Are there any particular examples of good practice that stand out?

What are your expectations when you get involved?

Have you experienced any challenges during involvement? If so what are these challenges?

Changes and Development

What do you see for the future of service user involvement in healthcare design and quality improvement?

Is there anything you would like to add?

Thank You for Your Time and Participation

Appendix 1c - CMS Team-Based Interview Schedule - Staff Members

The
University
Of
Sheffield.

CMS Team-based Interview Schedule

Background

Current role/Main responsibilities

Understanding

What is your understanding of service user involvement? (What does it mean to you and how you think it has been built up in the service/trust?)

When you hear terms such as co-production and co-design, what is your understanding?

Are there preferences for any terms that you use or are used across your work to describe activities where service users are being involved?

How would you define quality and quality improvement (QI)?

Expectations and Experience

What are your experiences of attending CMS meetings and being involved in the process?

How does the nature of the service influence CMS work?

What has been the effect, you feel, of implementing CMS methods and processes?

What have been the positives? Equally what do you think have been the challenges?

What is the significance of involving service users in CMS work? How possible do you think it is to achieve?

In your role, what are your expectations of service users when they become involved in QI?

What do you think service users expect from being involved in QI work like CMS?

What have been your experiences so far?

Have you experienced any challenges of involving service users? If so what are these challenges?

Changes and Development

What do you see for the future of service user involvement in healthcare design and quality improvement?

Is there anything you would like to add?

Thank You for Your Time and Participation

Appendix 1d - CMS Team-Based Interview Schedule - Service User Volunteers

The
University
Of
Sheffield.

CMS Team-based Service User Volunteer Interview Schedule

Background

Current role/Main responsibilities

Understanding

What does service user involvement mean to you?

When you hear terms such as co-production and co-design, what is your understanding of this?

Are there preferences for any terms that you use or you are familiar with when involved?

What does quality and quality improvement (QI) mean to you?

Expectations and Experience

How did you first get involved within the service as a volunteer?

What are your experiences of being involved in service PPI meetings and wider service activities?

What is your understanding of the CMS process here?

Is there a particular example of where you feel you have positively affected the focus and direction of a project?

Are there times when involvement has not worked well or it has been difficult?

What is the significance, if any, of involving service users in the decision-making process around care and services?

What do you expect from being involved? What do you expect from staff?

What are the influences to make service users and staff collaborate effectively in QI?

Changes and Progress

What do you feel are the main barriers to service user involvement in QI?

In your view, what are the key practices and structures that organisations and staff can employ to help overcome these?

Is there anything you would like to add?

Thank You for Your Time and Participation

Appendix 2a - Initial Codes and Emergent Ideas

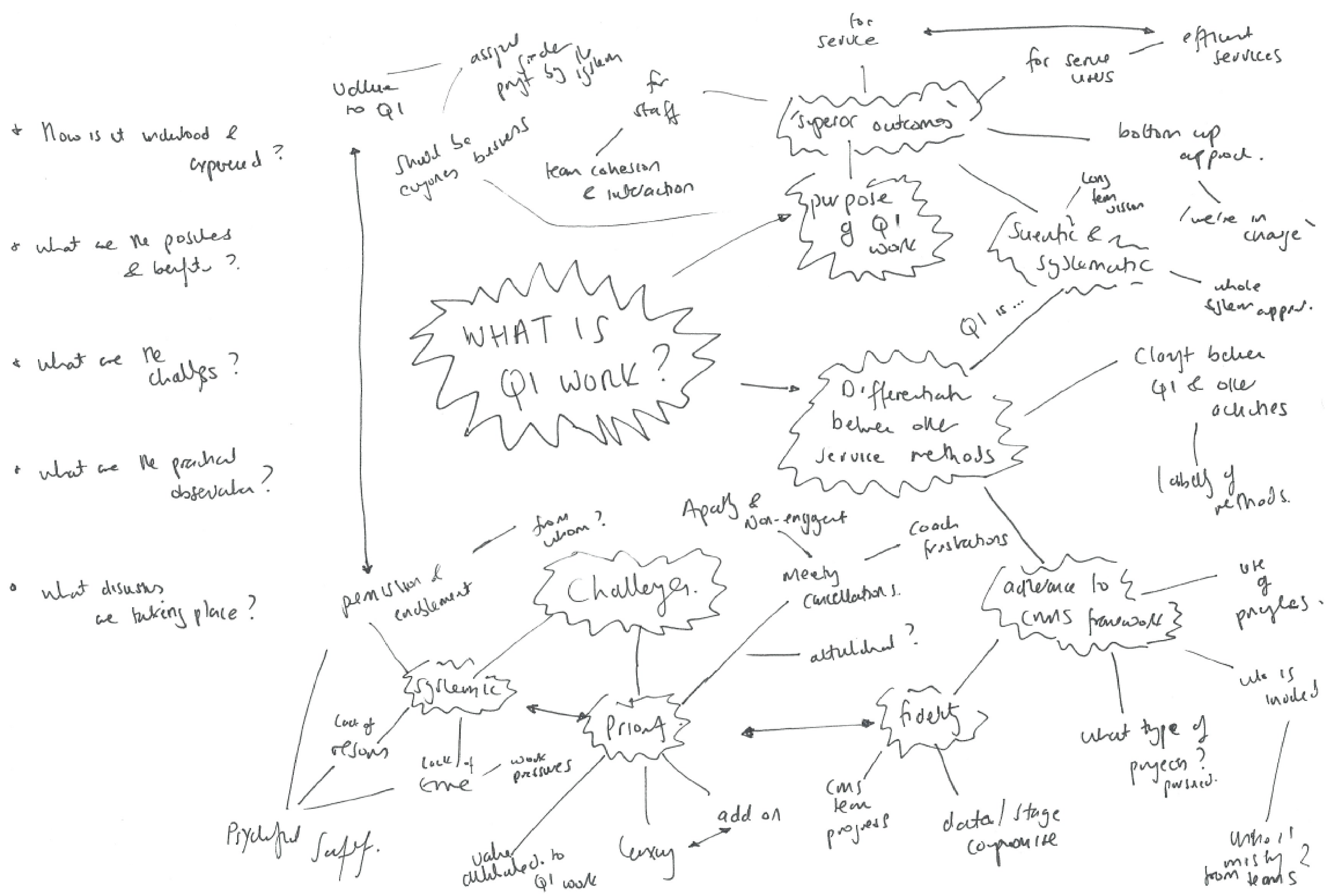
Area of exploration	Nodes – emergent ideas	
What is QI?	1. Understanding, Expectations and Purpose	**QI is a specialist, structured process** > *1) uses specialist methods and tools, 2) scientific and evidence-based medicine, 3) technical methodology* **CMS is a structured and novel approach to service improvement** > *1) Coaching model, 2) Deliberative process style keeps teams focused on service improvement activities* **QI aligns with org. ambition** > *1) broader QI management* **QI is similar to audit** > *1) QI represents no difference to previous improvement activity* **QI is a bottom-up collaborative approach** >*1) Individual teams dictate improvement, 2) Professionally-led process, 3) collaborative approach amongst different groups, 4) democratic decision-making that allows teams to change service* **Better 'quality' services** > *1) 'superior' outcomes for all, 2) More efficient use of resources* **QI as a professional activity and responsibility** > *1) 'should be everyone's business' 2) affects all parts of a service/professional groups*
	2. Experiences 2i) Positives of QI work	**QI is a bottom-up collaborative approach** > *1) Individual teams dictate improvement, 2) collaborative approach amongst different groups, 3) democratic decision-making that allows teams to change service* **CMS is a structured and novel approach to service improvement** > *1) Coaching model, 2) Deliberative process style keeps teams focused on service improvement activities* **Improved teamwork and communication**
	2. Experiences	**Lack of priority for QI work** > 1) cancellation of meetings, 2) delayed progress, 3) Stakeholder

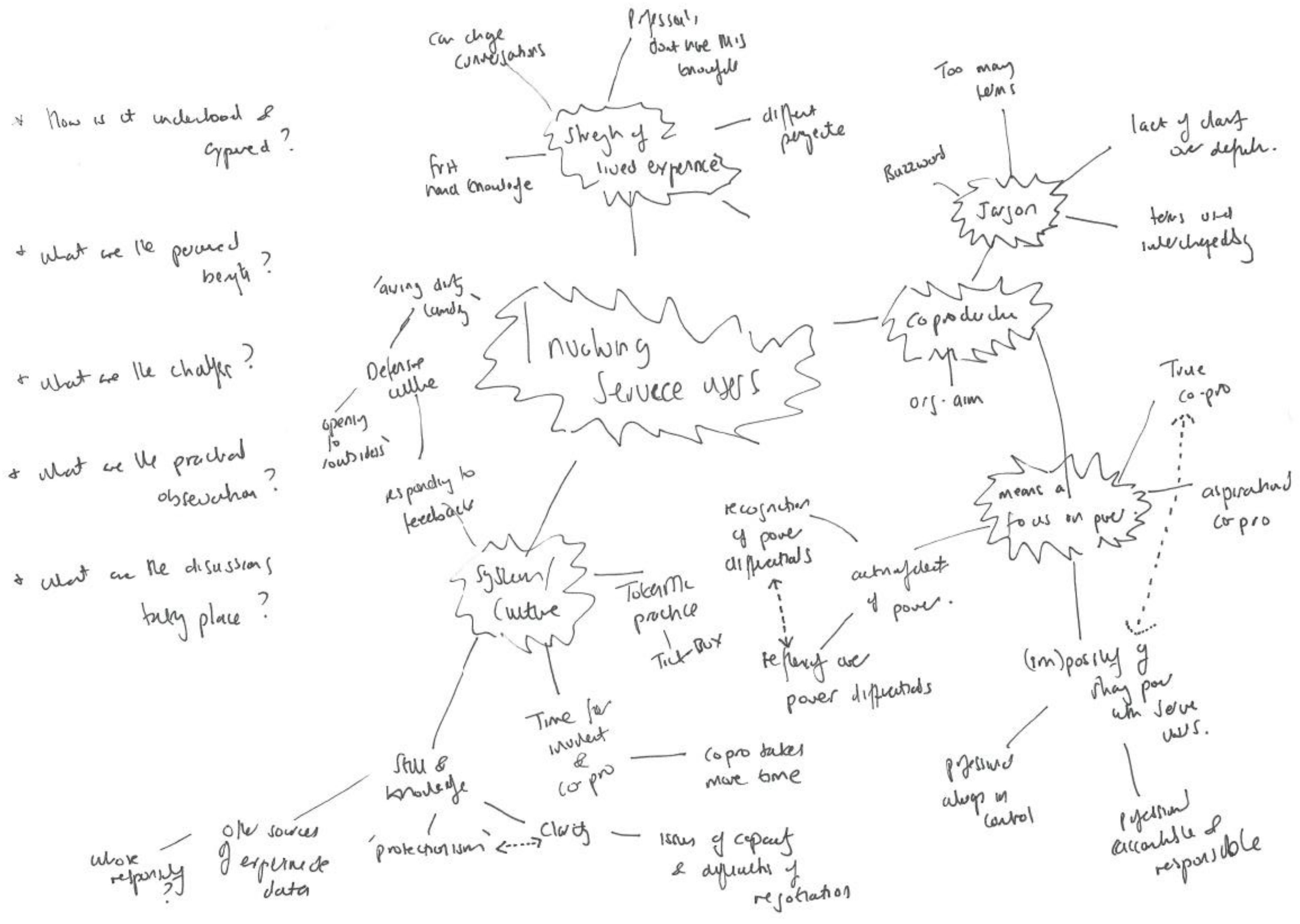
	2ii) Tensions related to QI work	ownership > 4) Not everyone takes responsibility - reliance on particular professionals, 5) Varied attitudinal issues towards engagement **Systemic tensions** > *1) Time and space for QI work, 2) Lack of resources to support QI work* **Permission and Enablement to engage with QI >** *1) Perceived lack of org. support (conflicting views between frontline and senior mgmt.), 2) Time and Space for QI work, 3) Priority to QI and fearful of rebuttal* **Poor fidelity to QI** > *1) Compromising elements of the CMS process, 2) Incorrect use of time, 3) Project not QI-specific, 4) Lack of measurement of progress* **Different indicators of quality** > *1) Individual view of quality (professional and service users), 2) Org. view of quality, 3) Objective and subjective nature of quality*
	Nodes – emergent ideas	
What is service user involvement and co-Production?	1. Understanding, Expectations and Purpose	**More meaningful role for service users >** *1) Patient at the centre 2) Stronger service relationships, 3) Involvement involves power /exchanges sharing, 4) Philosophical commitment, 5) Rights-based - 'their service'/'our service', 6) Transformative way of thinking,* **Honesty and transparency in service delivery** > *1) Equity and equality, 2) Trust and respect between service and service user* ***Co-production is jargon*** > *1) Buzzword, 2) NHS affinity for 'new' phrases, 3) possibility of power-sharing questioned* **Conflation between PPI and co-production** > *1) lack of differentiation, 2) failure to recognise power exchange, 3) 'True' co-production – possibility to share power with service user, 4) Co-option of language*
	2. Experiences	**Strength of lived experience knowledge >** *1) Lay knowledge unique to ill-health, 2) Service users change conversation, 3) Collaboration is an asset*

	2i) Positives of engaging service users in QI	**Altruistic benefits >** *1) Better informed service users, 2) Better informed services* **Honesty and transparency in service delivery** > *1) Equity and equality, 2) Trust and respect between service and service user*
	2. Experiences 2ii) Tensions related to engaging service users and co-production in QI	**Systemic tensions** > *1) Lack of time and space, 2) Lack of resources, 3) Defensive culture, 4) Organisational support* **Professional Skill Gap >** *1) Lack of understanding ('how' to engage groups), 2) Utilising service user feedback* **Challenges due to ill-health** > *1) Negotiating capacity issues', 2) 'Too ill' to participate* **Lack of diversity and representation >** *1) Usual suspects, 2) 'Over-representative' and professionalisation* **Failure to share power with service users** > *1) Tokenistic practice, 2) Professional expertise assigned greater knowledge, 3) Professional status, 4) Spaces controlled by professionals/professionally-orientated*
	Nodes – emergent ideas	
Service user involvement in CMS teams	Role and influence of service user	**Strength of lived experience knowledge >** *1) Lay knowledge unique to ill-health, 2) Service users change conversation, 3) Collaboration is an asset* **5Ps phase of CMS process** >1) Considers service user population
	Barriers to engagement	**Professional Skill Gap >** *1) Lack of understanding ('how' to engage groups), 2) Utilising service user feedback, 3) Making sense of feedback data* ***Systemic tensions*** > *1) Lack of time and space, 2) Lack of resources, 3) Defensive culture, 4) Organisational support* **Nature of Ill-health** > 1) 'Too ill' to participate, 2) Negotiating capacity issues, 3) Protecting service users **Ability to facilitate 'physical' presence of SU in meetings**

		Perceived skill and knowledge gap amongst SU > 1) Service users' lack of knowledge, 2) Appropriateness of service user knowledge, 3) Technicalities of process **Professional Assumptions** > 1) Not valuing service user knowledge, 2) Appropriateness of service user knowledge
	Conditions of involvement	**Careful selection process >** 1) Service needs confidence about who participates, 2) Service user with particular characteristics **Representativeness of service user involvement and representation** **Control over involvement process** >1) Involvement considered at appropriate times/when relevant **Ability to facilitate physical presence of SU in meetings**

Appendix 2b – Analytical Maps

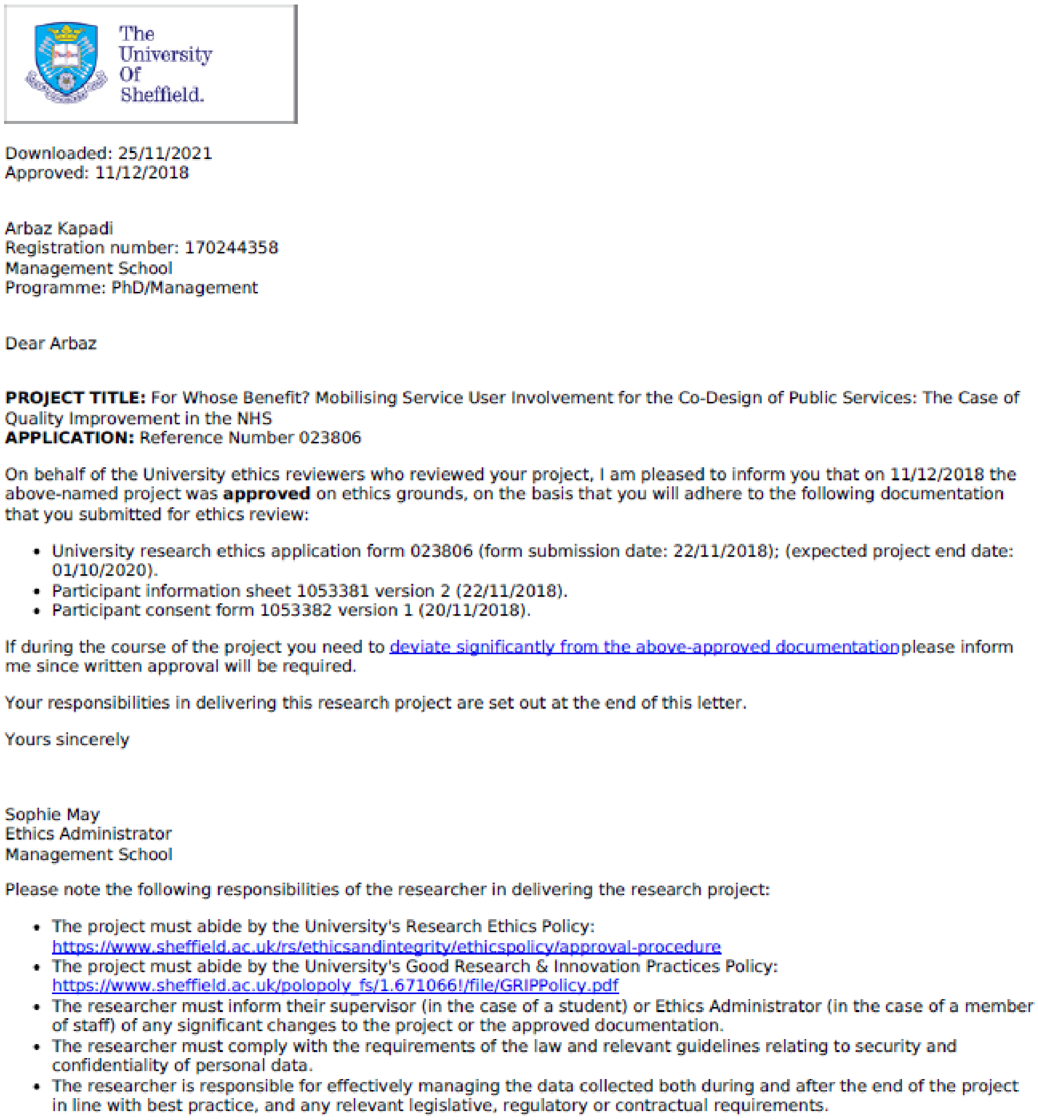




- How is it understood & captured?
- What are the perceived benefits?
- What are the challenges?
- What are the practical observations?
- What are the discussions taking place?


Absence of service users in CMS team.
'appropriateness' of involvement
relevance of involvement
role of service users in professional project.
'what can they contribute?'
professional holds expert knowledge.
QI work is somewhat specialised.
avoid being tokenistic
the 'right' service user
Team needs confidence
SU has to be confident
'ex-service user' preferred
Potential 'presence' of service user?
Paradox of representation.
Aware of the usual suspects
need diverse representation.
SU present SW can not be representable.
Professionals.
lack of visible representation 'in the room'
other methods of engagement
email
'phone'
difficulty of monitoring relationship & contact
preferred method of engagement
speedy group of communication.
Challenge of impairment
lack of SW & budget to facilitate involvement
'vulnerability'
can they be involved?
do they want to be involved?
Claims to knowledge.

Appendix 3 - University of Sheffield Research Ethics Study Approval



The University Of Sheffield.

Approved: 11/12/2018

Arbaz Kapadi
Registration number: 170244358
Management School
Programme: PhD/Management

Dear Arbaz

PROJECT TITLE: For Whose Benefit? Mobilising Service User Involvement for the Co-Design of Public Services: The Case of Quality Improvement in the NHS
APPLICATION: Reference Number 023806

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 11/12/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 023806 (form submission date: 22/11/2018); (expected project end date: 01/10/2020).
- Participant information sheet 1053381 version 2 (22/11/2018).
- Participant consent form 1053382 version 1 (20/11/2018).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

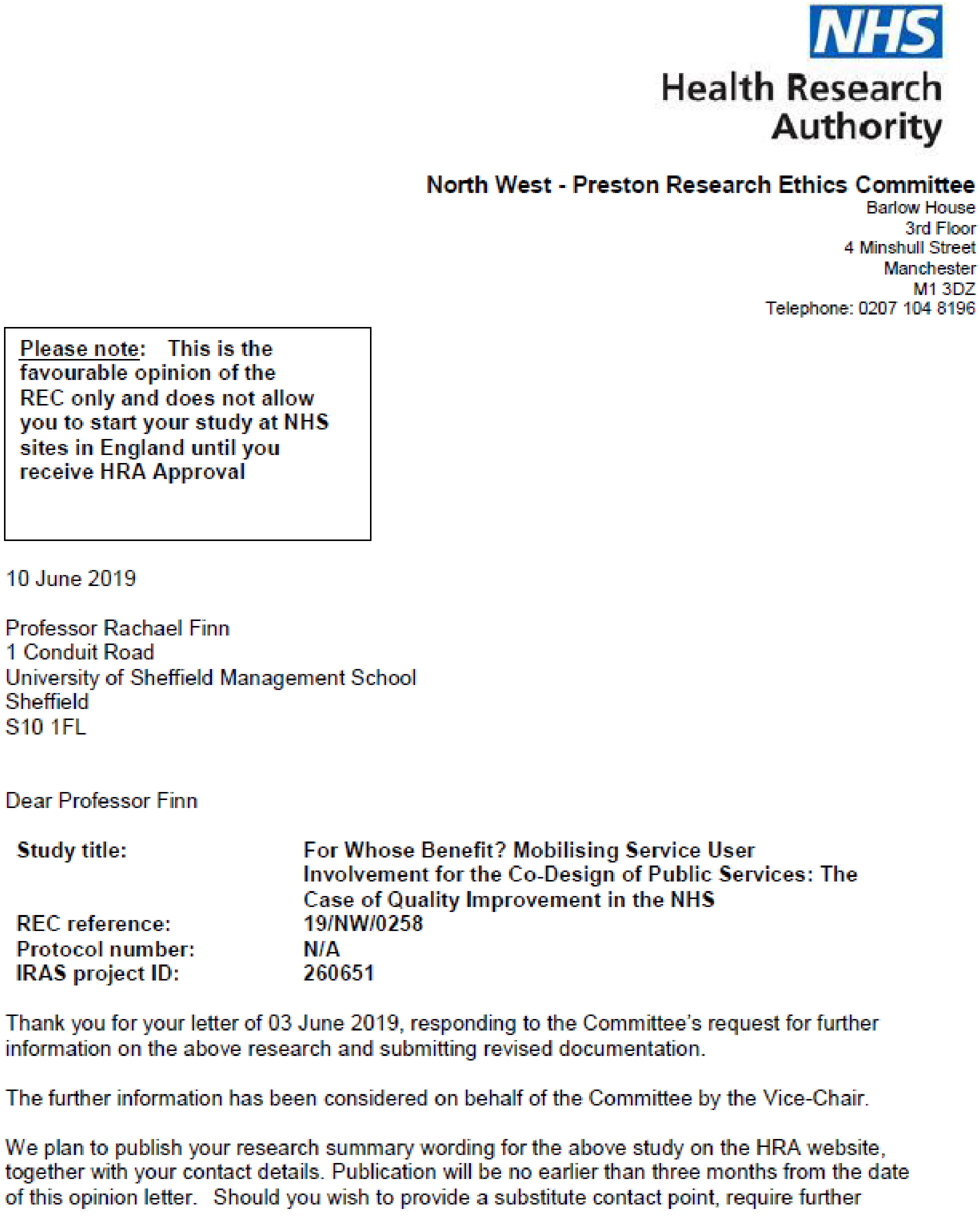
Yours sincerely

Sophie May
Ethics Administrator
Management School

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix 4a - NHS REC Study Approval



NHS
Health Research
Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ
Telephone: 0207 104 8196

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

10 June 2019

Professor Rachael Finn
1 Conduit Road
University of Sheffield Management School
Sheffield
S10 1FL

Dear Professor Finn

Study title:	**For Whose Benefit? Mobilising Service User Involvement for the Co-Design of Public Services: The Case of Quality Improvement in the NHS**
REC reference:	**19/NW/0258**
Protocol number:	**N/A**
IRAS project ID:	**260651**

Thank you for your letter of 03 June 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Evidence of Sponsor Insurance]	1.0	11 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 1 Key Informant Interviews]	1.0	28 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 2 Staff Member Interviews]	1.0	28 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 2 Service User Interviews]	2.0	03 June 2019
IRAS Application Form [IRAS_Form_01032019]		01 March 2019
Letter from funder [University of Sheffield Letter from Funder]	1.0	10 May 2016
Letter from sponsor [University of Sheffield Letter from Sponsor]	1.0	22 February 2019
Letters of invitation to participant [Invitational email - Phase 1 Key Informant Interviews]	1.0	03 June 2019
Letters of invitation to participant [Invitational email - Phase 2 Staff and Service User Interviews]	1.0	03 June 2019
Other [Evidence of Sponsor Indemnity]	1.0	11 February 2019
Participant consent form [Participant Consent Form - Phase 1 Key Informants]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Staff Interviews]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Service User Interviews]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Team Observations]	3.0	07 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Service User Interviews]	2.0	03 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Case Study Team Observations]	2.0	03 June 2019

Participant information sheet (PIS) [PIS - Phase 1 Key Informant Interviews]	3.0	07 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Staff Member Interviews]	3.0	07 June 2019
Referee's report or other scientific critique report [University of Sheffield Referee's Report]	1.0	23 November 2018
Research protocol or project proposal [Research Protocol]	2.0	03 June 2019
Response to Request for Further Information [Response to provisional opinion]		03 June 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV - Professor Rachael Finn]	1.0	20 January 2019
Summary CV for student [Student CV - Arbaz Kapadi]	1.0	20 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 1 CV - Professor Rachael Finn]	1.0	20 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 2 CV - Dr Diane Burns]	1.0	20 January 2019
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flowchart of Research Protocol]	1.0	28 February 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/NW/0258	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of;
Professor Karen Wright
Chair

Email:nrescommittee.northwest-preston@nhs.net

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	Mrs Deborah McClean

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Rachael Finn
1 Conduit Road
University of Sheffield Management School
Sheffield
S10 1FL

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

10 June 2019

Dear Professor Finn

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**For Whose Benefit? Mobilising Service User Involvement for the Co-Design of Public Services: The Case of Quality Improvement in the NHS**
IRAS project ID:	**260651**
Protocol number:	**N/A**
REC reference:	**19/NW/0258**
Sponsor	**University of Sheffield**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

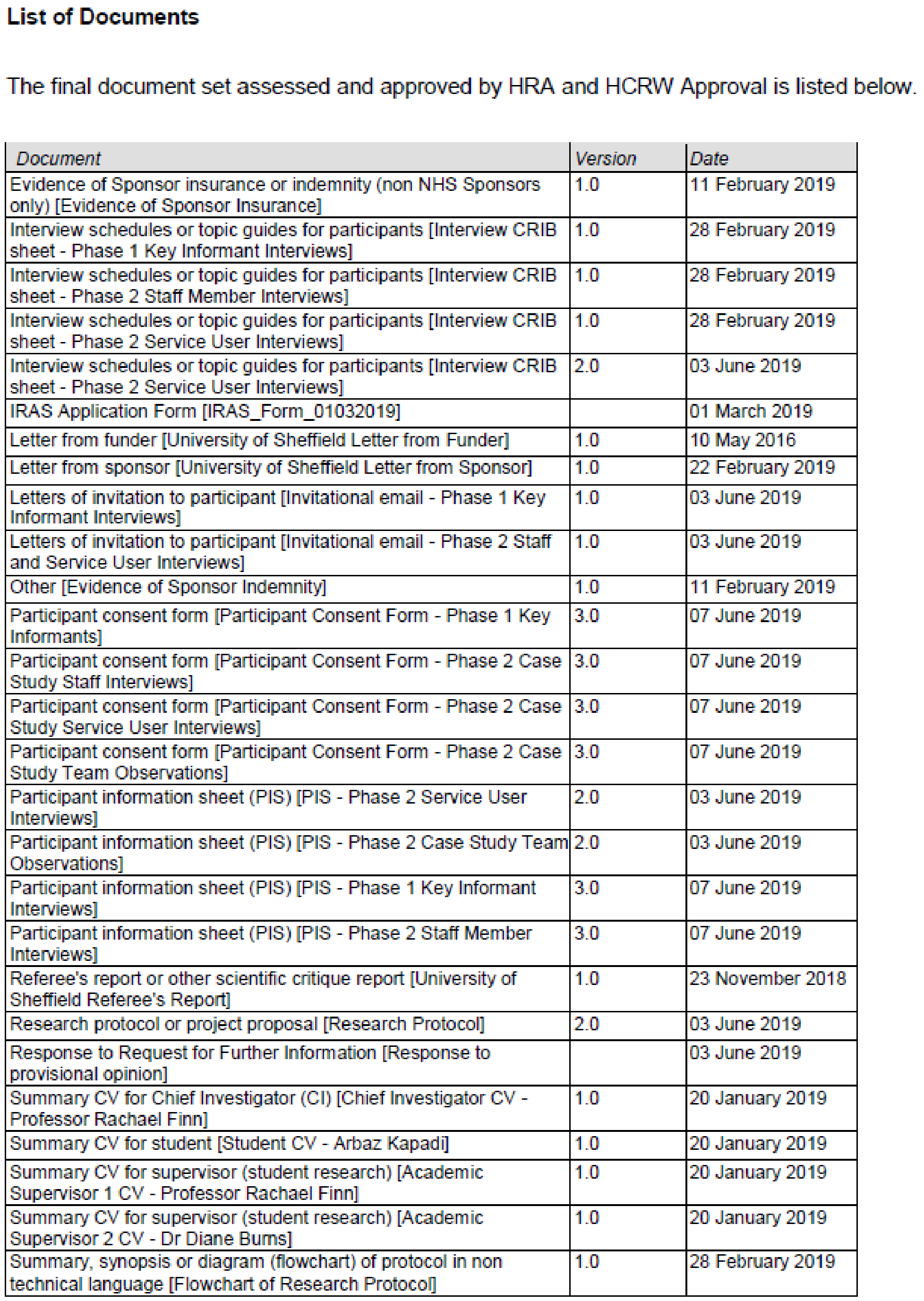
Your IRAS project ID is **260651**. Please quote this on all correspondence.

Yours sincerely,
Michael Pate

Approvals specialist

Email: hra.approval@nhs.net

Copy to: *Mrs Deborah McClean – University of Sheffield – Sponsor contact.*

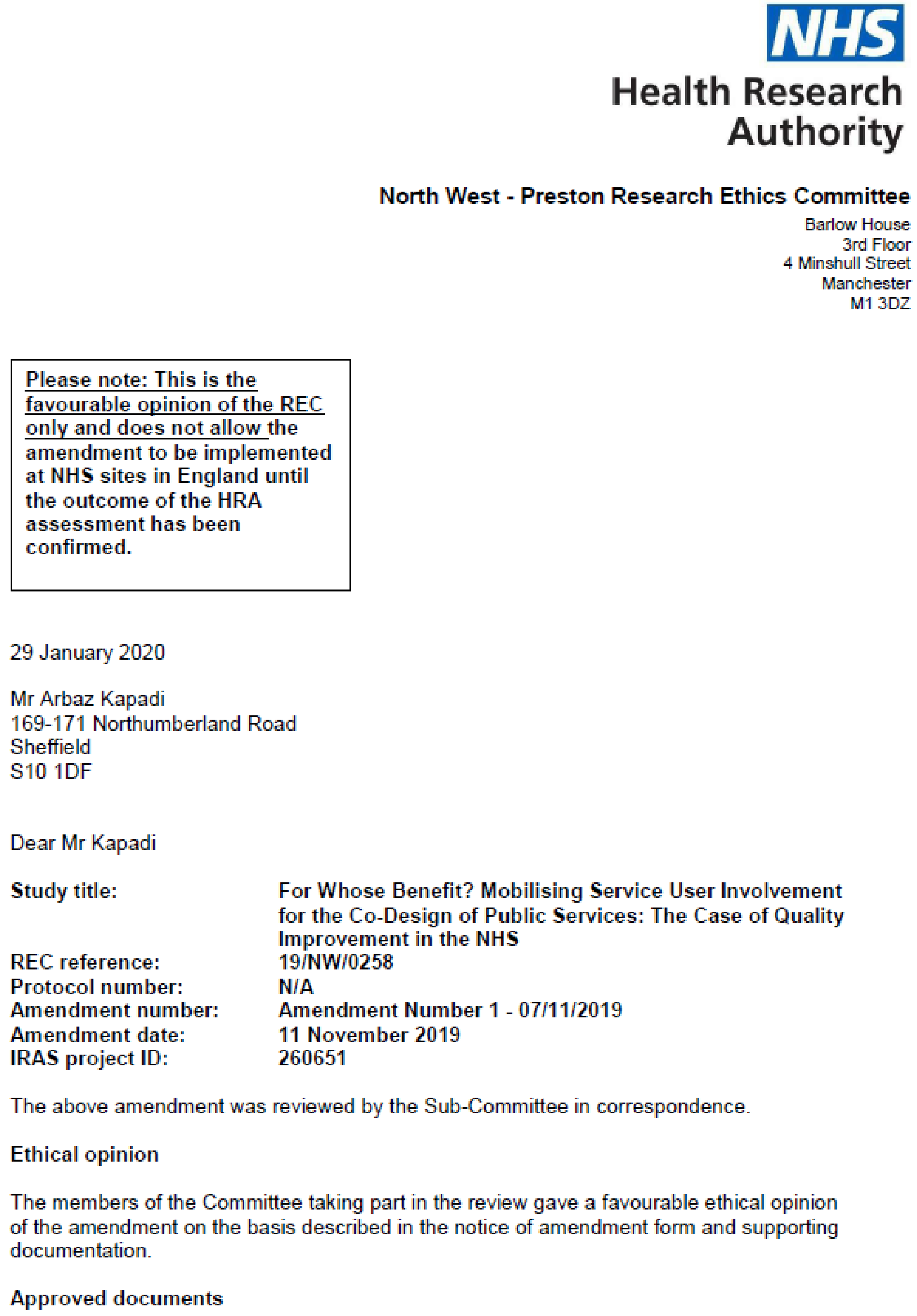


List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1.0	11 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 1 Key Informant Interviews]	1.0	28 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 2 Staff Member Interviews]	1.0	28 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 2 Service User Interviews]	1.0	28 February 2019
Interview schedules or topic guides for participants [Interview CRIB sheet - Phase 2 Service User Interviews]	2.0	03 June 2019
IRAS Application Form [IRAS_Form_01032019]		01 March 2019
Letter from funder [University of Sheffield Letter from Funder]	1.0	10 May 2016
Letter from sponsor [University of Sheffield Letter from Sponsor]	1.0	22 February 2019
Letters of invitation to participant [Invitational email - Phase 1 Key Informant Interviews]	1.0	03 June 2019
Letters of invitation to participant [Invitational email - Phase 2 Staff and Service User Interviews]	1.0	03 June 2019
Other [Evidence of Sponsor Indemnity]	1.0	11 February 2019
Participant consent form [Participant Consent Form - Phase 1 Key Informants]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Staff Interviews]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Service User Interviews]	3.0	07 June 2019
Participant consent form [Participant Consent Form - Phase 2 Case Study Team Observations]	3.0	07 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Service User Interviews]	2.0	03 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Case Study Team Observations]	2.0	03 June 2019
Participant information sheet (PIS) [PIS - Phase 1 Key Informant Interviews]	3.0	07 June 2019
Participant information sheet (PIS) [PIS - Phase 2 Staff Member Interviews]	3.0	07 June 2019
Referee's report or other scientific critique report [University of Sheffield Referee's Report]	1.0	23 November 2018
Research protocol or project proposal [Research Protocol]	2.0	03 June 2019
Response to Request for Further Information [Response to provisional opinion]		03 June 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV - Professor Rachael Finn]	1.0	20 January 2019
Summary CV for student [Student CV - Arbaz Kapadi]	1.0	20 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 1 CV - Professor Rachael Finn]	1.0	20 January 2019
Summary CV for supervisor (student research) [Academic Supervisor 2 CV - Dr Diane Burns]	1.0	20 January 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart of Research Protocol]	1.0	28 February 2019

Appendix 4b - NHS REC Study Amendment Approval



NHS
Health Research
Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

29 January 2020

Mr Arbaz Kapadi
169-171 Northumberland Road
Sheffield
S10 1DF

Dear Mr Kapadi

Study title:	**For Whose Benefit? Mobilising Service User Involvement for the Co-Design of Public Services: The Case of Quality Improvement in the NHS**
REC reference:	**19/NW/0258**
Protocol number:	**N/A**
Amendment number:	**Amendment Number 1 - 07/11/2019**
Amendment date:	**11 November 2019**
IRAS project ID:	**260651**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview CRIB Sheet - Phase 2 Service User Interviews]	1.0	07 November 2019
Interview schedules or topic guides for participants [Interview CRIB Sheet - Phase 2 Staff Member Interviews]	1.0	07 November 2019
Letters of invitation to participant [Invitational Email - Phase 2 Interviewing Participants - Staff and Service Users]	2.0	08 January 2020
Notice of Substantial Amendment (non-CTIMP) [Amendment form]	Amendment Number 1 - 07/11/2019	11 November 2019
Other [Amendment details]	1.0	07 November 2019
Other [Participant Consent Sign-In Sheet - Team Meeting Observations]	1.0	07 November 2019
Other [Flowchart Summary of Research Activities]	2.0	07 November 2019
Other [Revisions to provisional amendment outcome]		08 January 2020
Participant consent form [Participant Consent Form for Phase 2 Case Study - Service User Interviews]	1.0	07 November 2019
Participant consent form [Participant Consent Form for Phase 2 Case Study - Staff Member Interviews]	1.0	07 November 2019
Participant consent form [Participant Consent Form for Phase 2 Case Study - Team PPI Meeting Observations]	1.0	07 November 2019
Participant information sheet (PIS) [Participant Information Sheet for Phase 2 Case Study - PPI Meeting Observations]	1.0	07 November 2019
Participant information sheet (PIS) [Participant Information Sheet for Phase 2 Case Study - Staff Members Interviews from PPI meetings]	2.0	08 January 2020
Participant information sheet (PIS) [Participant Information Sheet for Phase 2 Case Study - Service Users Interviews from PPI meetings]	3.0	21 January 2020
Research protocol or project proposal [Research Protocol]	3.0	07 November 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/NW/0258: Please quote this number on all correspondence

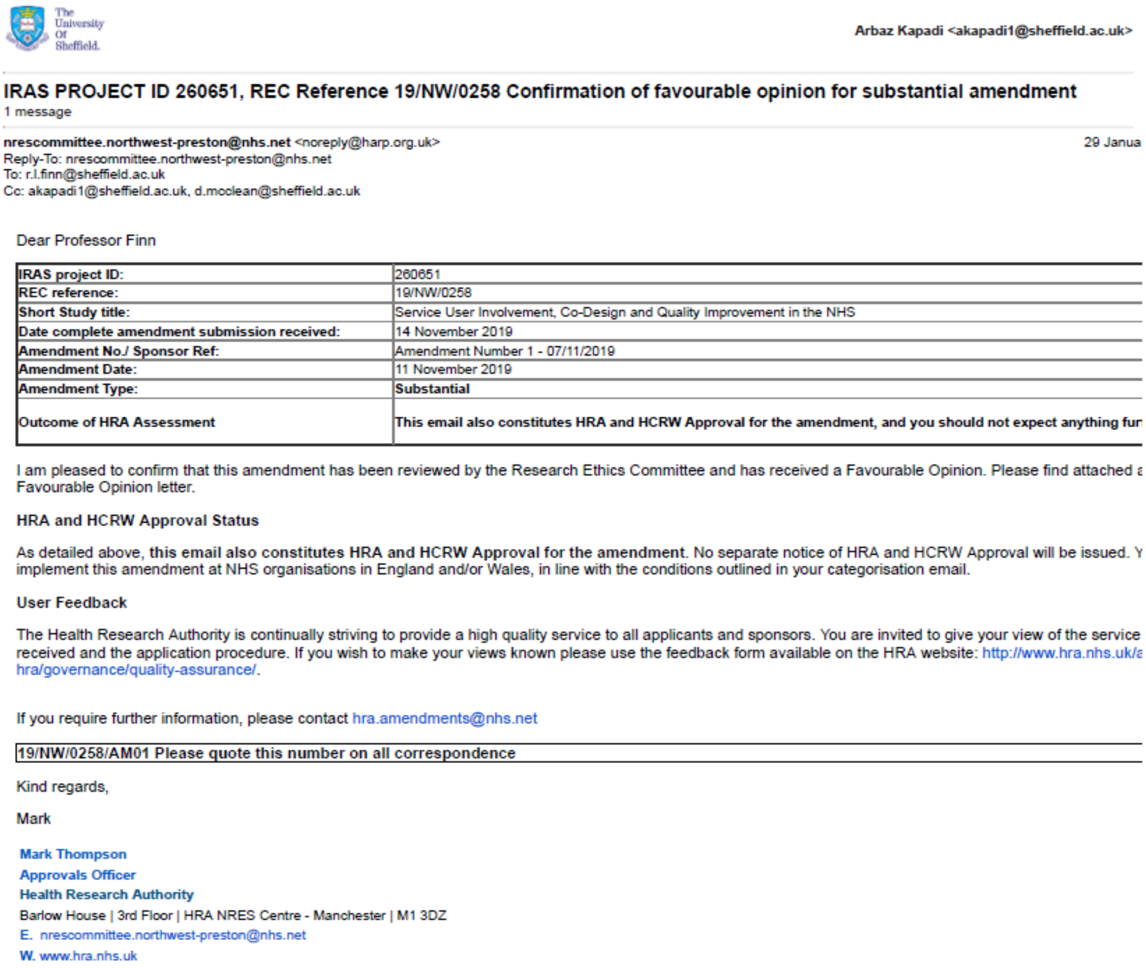
Yours sincerely

Mark Thompson

On behalf of Dr Karen Rouse
Vice-Chair

E-mail: nrescommittee.northwest-preston@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Mr Arbaz Kapadi*



The University Of Sheffield.

Arbaz Kapadi <akapadi1@sheffield.ac.uk>

IRAS PROJECT ID 260651, REC Reference 19/NW/0258 Confirmation of favourable opinion for substantial amendment

1 message

nrescommittee.northwest-preston@nhs.net <noreply@harp.org.uk>
Reply-To: nrescommittee.northwest-preston@nhs.net
To: r.l.finn@sheffield.ac.uk
Cc: akapadi1@sheffield.ac.uk, d.mcclean@sheffield.ac.uk

29 Janua

Dear Professor Finn

IRAS project ID:	260651
REC reference:	19/NW/0258
Short Study title:	Service User Involvement, Co-Design and Quality Improvement in the NHS
Date complete amendment submission received:	14 November 2019
Amendment No./ Sponsor Ref:	Amendment Number 1 - 07/11/2019
Amendment Date:	11 November 2019
Amendment Type:	**Substantial**
Outcome of HRA Assessment	**This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything fur**

I am pleased to confirm that this amendment has been reviewed by the Research Ethics Committee and has received a Favourable Opinion. Please find attached a Favourable Opinion letter.

HRA and HCRW Approval Status

As detailed above, **this email also constitutes HRA and HCRW Approval for the amendment**. No separate notice of HRA and HCRW Approval will be issued. Y implement this amendment at NHS organisations in England and/or Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/a hra/governance/quality-assurance/.

If you require further information, please contact hra.amendments@nhs.net

19/NW/0258/AM01 Please quote this number on all correspondence

Kind regards,

Mark

Mark Thompson
Approvals Officer
Health Research Authority
Barlow House | 3rd Floor | HRA NRES Centre - Manchester | M1 3DZ
E. nrescommittee.northwest-preston@nhs.net
W. www.hra.nhs.uk

Appendix 5a - Key Informant Participant Information Sheet

The University Of Sheffield.

Participant Information Sheet – Key Informant

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn **Date:**

Service User Involvement, Co-Production and Quality Improvement

Introduction

You are invited to participate in an academic study being conducted by myself, Arbaz Kapadi, a 2nd year PhD Student at Sheffield University Management School. This research is a University of Sheffield PhD Doctoral project and is funded by the Economic and Social Research Council (ESRC). [redacted]. Before deciding to take part, it is important for you to understand why the research is being undertaken and what it will involve.

What is the purpose of the study?

The aim of this project is to explore and understand the process of co-production and how it can help improve the quality of healthcare services, particularly given the drive at national and local levels to involve service users in the planning, management and delivery of services. Studies call for ongoing research into service user involvement and quality improvement to further knowledge and share learning. The main objective of this project is to understand how people interpret co-production and its value, and the various conditions that may act as facilitators and/or barriers to service user involvement in quality improvement.

Why have I been invited?

I am contacting you as someone who has expert knowledge and experience of leading, organising and/or managing service user involvement. As such, I would like to invite you for a 1:1 interview, in person, where I would be interested to hear your views on what co-production and quality improvement means to you, your experiences in work and how you feel co-production is developing as a means of collaborative working in quality improvement.

Do I have to take part?

It is up to you to decide whether to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You uphold the right to data withdrawal without having to provide a reason. However, as your information will need to be managed in specific ways in order for the research to remain reliable and accurate, your rights to access, change or move your information are limited, particularly once the study data has been processed and during which personally identifiable data will have been removed. You will have 21 days from the date of interview to withdraw data. Beyond this point, data collected in the interview will begin being processed and analysed. If you wish to withdraw, please let me know before, during or after the interview using the contact details provided (see overleaf).

What will happen to me if I decide to take part?

Interviews will take place, in-person, at an agreed date, time and location. The interview will last for around 60 minutes. I would like to audio-record the interview with your permission. If you do not wish the interview to be audio-recorded, I will take written notes. If you wish to terminate the session at any point, let me know and the session will stop immediately; subsequent data will be removed from the study. There is no payment for taking part in the research and any expenses incurred (e.g. travel costs) will not be reimbursed by the research team.

What are the possible benefits and risks of taking part?

There are no direct benefits to being involved in this study. The purpose of this study is to gather important insight into how service users and professionals can collaborate effectively, which will be helped by your views and experiences, and as such, your participation would be appreciated.

The research is not intended to be about blame or recrimination and nor is it an evaluation of service performance. The research respects that co-production and quality improvement are relatively new approaches introduced into practice, and as such, questions will seek to explore ambitions, arrangements and experiences of involving service users. Where information is offered with a request for strict confidentiality, this will be respected and not included. With any research, there is a potential concern for details to be identified from places of work, practices and roles. Measures to preserve anonymity and confidentiality will be in place as early as possible in the process (see below).

Will my taking part in the study be kept confidential? What anonymity measures are in place?

All information collected during the course of the research that relates to you will be kept strictly confidential. Personal information will be restricted to your name, role and email/telephone for contact purposes. In the event that something is disclosed during the interview that is perceived to require further action, for example, evidence of any wrongdoing or there is a risk to your safety or others, then confidentiality will be broken. However, this will be discussed with you and you will be told what will be done to this information and whom this information will be shared with. In such cases, relevant statutory agencies within [redacted] will be notified.

Contact details will be kept to relay findings and summary versions of the research back to you; this is expected to be up to six months after the study finishes. Recordings and transcripts of interviews will be retained in encrypted format on a password-protected University of Sheffield system that I can only access. If information is offered with a request for strict confidentiality, this will be respected and not included. Consent forms and any additional notes taken during the interviews will be securely stored within a locked filing cabinet. Within transcripts, your identity will be removed and replaced by a pseudonym. Your role and place of work will also be given a pseudonym.

What will happen to the information you give? What happens at the end of the study?

Information that you provide during the interview will be transcribed and thematically analysed. I will be responsible for this. Analysis of this information will involve looking for relevant themes that correspond with how service user involvement is considered, arranged and the various facilitators and barriers. [redacted]

A summary of the study will be produced and this will be made available to you if you wish. Extracts from our interview may also be included in additional project outputs during and after the study has ended e.g. journals, reports, other research outputs. Confidentiality and anonymity will continue to be preserved at all times. Data from the study will be kept for a minimum of ten years after the PhD has been completed; data will be deposited in a safe and secure data repository, the UK Data Archive.

Who is the data controller for this study?

As a University-based PhD study, The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, there must be a basis in law to do so. This research is seen as being 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

How can I find out more?

If you have any questions about the study, you can call, write or email me using the details below. Please feel free to contact me and I will be happy to give you further information.

Principal Investigator - Arbaz Kapadi

[redacted]

If you wish to discuss the study with the Chief Investigator/Academic Supervisor on this project, please feel free to email, call or write to her using the following details:

Chief Investigator - Professor Rachael Finn,

[redacted]

What if there is a problem?

If you wish to raise a concern about the conduct of the study, please contact the following [redacted]

[redacted]

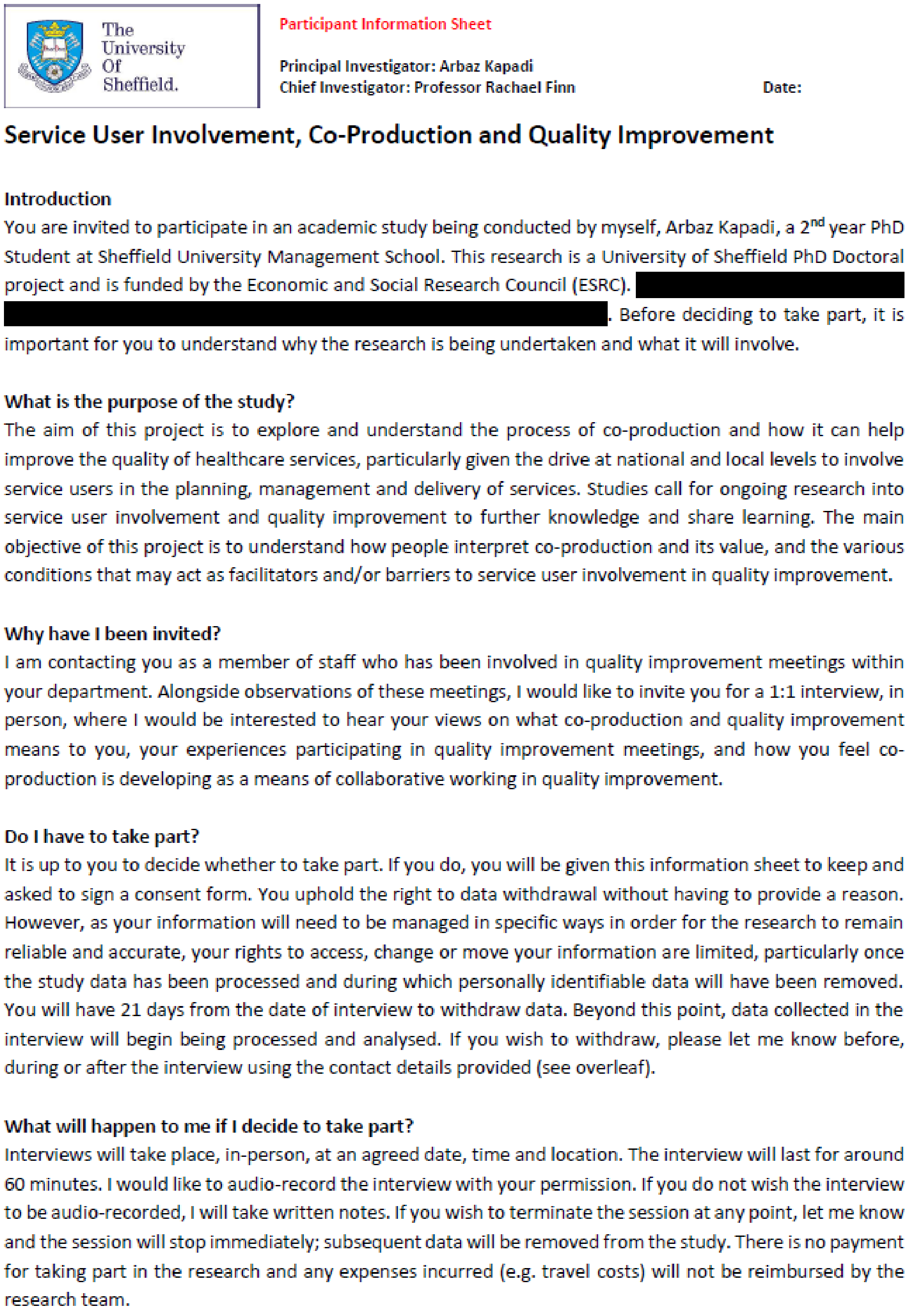
What arrangements are place for insurance and/or indemnity for harm arising from this research?

The University of Sheffield has, in force, public liability insurance and non-clinical trials insurance. This policy provides indemnity to staff and students acting on behalf of the University for their legal liability for claims of 'negligent harm' and the activities here are included within that coverage. [redacted]

Who has reviewed the study?

This study has been academically reviewed by the University of Sheffield Management School and has been given **HRA and Health and Care Research Wales (HCRW) Approval – 19/NW/0258.** This research has been planned and designed with the knowledge of [redacted], whilst ethical guidance has been sought from the [redacted] in the management and conduct of this research.

Appendix 5b - CMS Team-Based Interview Participant Information Sheet



The University
Of
Sheffield.

Participant Information Sheet

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn **Date:**

Service User Involvement, Co-Production and Quality Improvement

Introduction

You are invited to participate in an academic study being conducted by myself, Arbaz Kapadi, a 2nd year PhD Student at Sheffield University Management School. This research is a University of Sheffield PhD Doctoral project and is funded by the Economic and Social Research Council (ESRC). [redacted]. Before deciding to take part, it is important for you to understand why the research is being undertaken and what it will involve.

What is the purpose of the study?

The aim of this project is to explore and understand the process of co-production and how it can help improve the quality of healthcare services, particularly given the drive at national and local levels to involve service users in the planning, management and delivery of services. Studies call for ongoing research into service user involvement and quality improvement to further knowledge and share learning. The main objective of this project is to understand how people interpret co-production and its value, and the various conditions that may act as facilitators and/or barriers to service user involvement in quality improvement.

Why have I been invited?

I am contacting you as a member of staff who has been involved in quality improvement meetings within your department. Alongside observations of these meetings, I would like to invite you for a 1:1 interview, in person, where I would be interested to hear your views on what co-production and quality improvement means to you, your experiences participating in quality improvement meetings, and how you feel co-production is developing as a means of collaborative working in quality improvement.

Do I have to take part?

It is up to you to decide whether to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You uphold the right to data withdrawal without having to provide a reason. However, as your information will need to be managed in specific ways in order for the research to remain reliable and accurate, your rights to access, change or move your information are limited, particularly once the study data has been processed and during which personally identifiable data will have been removed. You will have 21 days from the date of interview to withdraw data. Beyond this point, data collected in the interview will begin being processed and analysed. If you wish to withdraw, please let me know before, during or after the interview using the contact details provided (see overleaf).

What will happen to me if I decide to take part?

Interviews will take place, in-person, at an agreed date, time and location. The interview will last for around 60 minutes. I would like to audio-record the interview with your permission. If you do not wish the interview to be audio-recorded, I will take written notes. If you wish to terminate the session at any point, let me know and the session will stop immediately; subsequent data will be removed from the study. There is no payment for taking part in the research and any expenses incurred (e.g. travel costs) will not be reimbursed by the research team.

What are the possible benefits and risks of taking part?

There are no direct benefits to being involved in this study. The purpose of this study is to gather important insight into how service users and professionals can collaborate effectively, which will be helped by your views and experiences, and as such, your participation would be appreciated.

The research is not intended to be about blame or recrimination and nor is it an evaluation of service performance. The research respects that co-production and quality improvement are relatively new approaches introduced into practice, and as such, questions will seek to explore ambitions, arrangements and experiences of involving service users. Where information is offered with a request for strict confidentiality, this will be respected and not included. With any research, there is a potential concern for details to be identified from places of work, practices and roles. Measures to preserve anonymity and confidentiality will be in place as early as possible in the process (see below).

Will my taking part in the study be kept confidential? What anonymity measures are in place?

All information collected during the course of the research that relates to you will be kept strictly confidential. Personal information will be restricted to your name, role and email/telephone for contact purposes. In the event that something is disclosed during the interview that is perceived to require further action, for example, evidence of any wrongdoing or there is a risk to your safety or others, then confidentiality will be broken. However, this will be discussed with you and you will be told what will be done to this information and whom this information will be shared with. In such cases, relevant statutory agencies within [redacted] will be notified.

Contact details will be kept to relay findings and summary versions of the research back to you; this is expected to be up to six months after the study finishes. Recordings and transcripts of interviews will be retained in encrypted format on a password-protected University of Sheffield system that I can only access. If information is offered with a request for strict confidentiality, this will be respected and not included. Consent forms and any additional notes taken during the interviews will be securely stored within a locked filing cabinet. Within transcripts, your identity will be removed and replaced by a pseudonym. Your role and place of work will also be given a pseudonym. These measures will attempt to protect identity, however, full anonymity can not be guaranteed owing to the small size of the service team.

What will happen to the information you give? What happens at the end of the study?

Information that you provide during the interview will be transcribed and thematically analysed. I will be responsible for this. Analysis of this information will involve looking for relevant themes that correspond with how service user involvement is considered, arranged and the various facilitators and barriers. [redacted]

A summary of the study will be produced and this will be made available to you if you wish. Extracts from the interview may also be included in additional project outputs during and after the study has ended e.g. journals, reports, other research outputs. Confidentiality and anonymity will continue to be preserved at all times. Data from the study will be kept for a minimum of ten years after the PhD has been completed; data will be deposited in a safe and secure data repository, the UK Data Archive.

The University Of Sheffield.

Participant Information Sheet

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn **Date:**

Who is the data controller for this study?

As a University-based PhD study, The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, there must be a basis in law to do so. This research is seen as being 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

How can I find out more?

If you have any questions about the study, you can call, write or email me using the details below. Please feel free to contact me and I will be happy to give you further information.

Principal Investigator - Arbaz Kapadi

[redacted]

If you wish to discuss the study with the Chief Investigator/Academic Supervisor on this project, please feel free to email, call or write to her using the following details:

Chief Investigator - Professor Rachael Finn,

[redacted]

What if there is a problem?

If you want to raise a concern about the conduct of the study, you may wish to notify your departmental service lead, whom has agreed to act as a point of contact. Equally, you can direct any problems or concerns to the following [redacted] department:

[redacted]

What arrangements are place for insurance and/or indemnity for harm arising from this research?

The University of Sheffield has, in force, public liability insurance and non-clinical trials insurance. This policy provides indemnity to staff and students acting on behalf of the University for their legal liability for claims of 'negligent harm' and the activities here are included within that coverage. [redacted]

Who has reviewed the study?

This study has been academically reviewed by the University of Sheffield Management School and has been given HRA and Health and Care Research Wales (HCRW) Approval – 19/NW/0258 (10/06/19). This research has been planned and designed with the knowledge of [redacted] whilst ethical guidance has been sought from the [redacted] in the management and conduct of this research.

Appendix 5c – Service User Volunteer Participant Information Sheet

The
University
Of
Sheffield.

Participant Information Sheet

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn **Date:**

Service User Involvement, Co-Production and Quality Improvement in the NHS

Introduction

You are invited to participate in an academic study being conducted by myself, Arbaz Kapadi, a 3rd year PhD Student at Sheffield University Management School. This research is a University of Sheffield PhD Doctoral project and is funded by the Economic and Social Research Council (ESRC). [redacted]. Before deciding to take part, it is important for you to understand why the research is being undertaken and what it will involve.

What is the purpose of the study?

The aim of this project is to explore and understand the process of co-production and how it can help improve the quality of healthcare services, particularly given the drive at national and local levels to involve service users in the planning, management and delivery of services. Studies call for ongoing research into service user involvement and quality improvement to further knowledge and share learning. The main objective of this project is to understand how people interpret co-production and its value, and the various conditions that may act as facilitators and/or barriers to service user involvement in quality improvement.

Why have I been invited?

I am contacting you as a service user/service user representative, who has been involved in patient and public improvement (PPI) meetings within your service. Alongside observations of these meetings, I would like to invite you for a 1:1 interview, in person, where I would be interested to hear your views on what co-production and quality improvement means to you, your experiences participating in PPI meetings, and how you feel co-production is developing as a means of collaborative working within quality improvement.

Do I have to take part?

It is up to you to decide whether to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You uphold the right to data withdrawal without having to provide a reason. However, as your information will need to be managed in specific ways in order for the research to remain reliable and accurate, your rights to access, change or move your information are limited, particularly once the study data has been processed and during which personally identifiable data will have been removed. You will have 21 days from the date of interview to withdraw data. Beyond this point, data collected in the interview will begin being processed and analysed. If you wish to withdraw, please let me know before, during or after the interview using the contact details provided (see overleaf).

What will happen to me if I decide to take part?

Interviews will take place, in-person, at an agreed date, time and location. The interview may last between 30 to 60 minutes. I would like to audio-record the interview with your permission. If you do not want the interview to be audio-recorded, I will take written notes. If you wish to terminate the session at any point, let me know and the session will stop immediately; subsequent data will be removed from the study and you will not have to give a reason. Audio recordings will be uploaded onto a computer and deleted from the recorder on the day after the interview. Uploaded audio recordings will be deleted after the interview has been transcribed. This is likely to be between three to six months after the date of the interview. There is no payment for taking part in the research and any expenses incurred (e.g. travel costs) will not be reimbursed by the research team.

What are the possible benefits and risks of taking part?

There are no direct benefits to being involved in this study. The purpose of this study is to gather important insight into how service users and professionals can collaborate effectively, which will be helped by your views and experiences, and as such, your participation would be appreciated.

The research is not intended to be about blame and nor is it an evaluation of service performance. The research respects that co-production and quality improvement are relatively new approaches introduced into practice, and as such, questions will seek to explore ambitions, arrangements and experiences of involving service users; I am interested to hear your personal experiences of being involved in meetings rather than experiences of care and treatment. Where information is offered with a request for strict confidentiality, this will be respected and not included. If for any reason you should feel uncomfortable or distressed in the interview, the interview will be stopped immediately and immediate support will be offered. With your consent, the departmental service lead will be notified. Interview questions are not expected to touch on sensitive topics, but we will have the opportunity to discuss them between us shortly before the interview starts if you would like. You will not have to answer every question and you will not have to give a reason if you opt not to. A dedicated quite space will also available during the interview if required. With any research, there is a potential concern for details to be identified from places of work, practices and roles. Measures to preserve anonymity and confidentiality will be in place as early as possible in the process (see below).

Will my taking part in the study be kept confidential? What anonymity measures are in place?

All information collected during the course of the research that relates to you will be aimed to be kept strictly confidential. In the event that something is disclosed during the interview that is perceived to require further action, for example, something that poses a risk to your safety or others, then confidentiality will be broken. However, this will be discussed with you and you will be told what will be done to this information and whom this information will be shared with. This information will be shared with the departmental service lead in the first instance.

Contact details may be kept to relay findings of the research back to you; this is expected to be up to six months after the study finishes. Recordings and transcripts of interviews will be retained in encrypted format on a password-protected University of Sheffield system that I can only access. Consent forms and any additional notes taken during the interviews will be securely stored within a locked filing cabinet. Within transcripts, your identity as a service user/service user representative and the service in which you attend these meetings will be given pseudonyms. These measures will attempt to protect identity, however, full anonymity can not be guaranteed owing to the small size of the service team.

What will happen to the information you give? What happens at the end of the study?

Information that you provide during the interview will be transcribed and thematically analysed. I will be responsible for this. Analysis of information you provide will involve looking for relevant themes that corresponds with how service user involvement is considered, arranged and the various facilitators and barriers. [redacted] A summary of the study will be produced and this will be made available to you if you wish. Extracts from the interview may also be included in additional project outputs during and after the study has ended e.g. journals, reports, other research outputs. Confidentiality and anonymity will continue to be preserved at all times. Data from the study will be kept for a minimum of ten years after the PhD has been completed; data will be deposited in a safe and secure data repository, the UK Data Archive.

Who is the data controller for this study?

As a University-based PhD study, The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, there must be a basis in law to do so. This research is seen as being 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

How can I find out more?

If you have any questions about the study, you can call, write or email me using the details below. Please feel free to contact me and I will be happy to give you further information.

Principal Investigator - Arbaz Kapadi

[redacted]

If you wish to discuss the study with the Chief Investigator/Academic Supervisor on this project, please feel free to email, call or write to her using the following details:

Chief Investigator - Professor Rachael Finn,

[redacted]

What if there is a problem?

If you want to raise a concern about the conduct of the study, you may wish to notify your departmental service lead, whom has agreed to act as a point of contact. Equally, you can direct any problems or concerns to the following [redacted] department:

Complaints and Legislation Department,
[redacted]

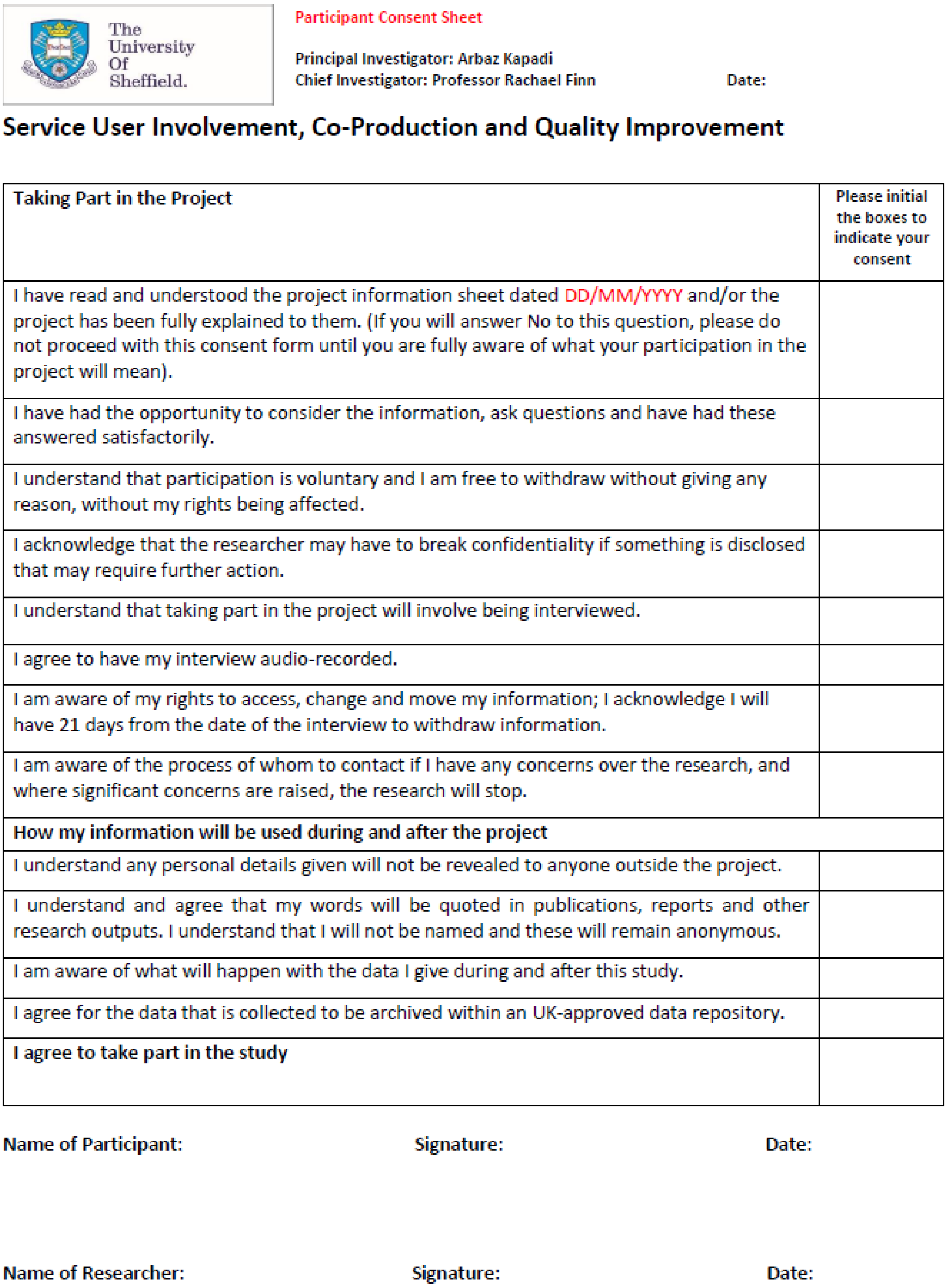
What arrangements are place for insurance and/or indemnity for harm arising from this research?

The University of Sheffield has in force a public liability insurance and non-clinical trials insurance. This policy provides indemnity to staff and students acting on behalf of the University for their legal liability for claims of 'negligent harm' and the activities here are included within that coverage. [redacted]

Who has reviewed the study?

This study has been academically reviewed by the University of Sheffield Management School and given favourable opinion by HRA and Health and Care Research Wales (HCRW) Approval – 19NW/0258. This research has been planned and designed with the knowledge of [redacted] and your department, whilst ethical guidance has been sought from the [redacted] in the management and conduct of this research.

Appendix 5d - Interview Participant Consent Form



The University Of Sheffield.

Participant Consent Sheet

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn
Date:

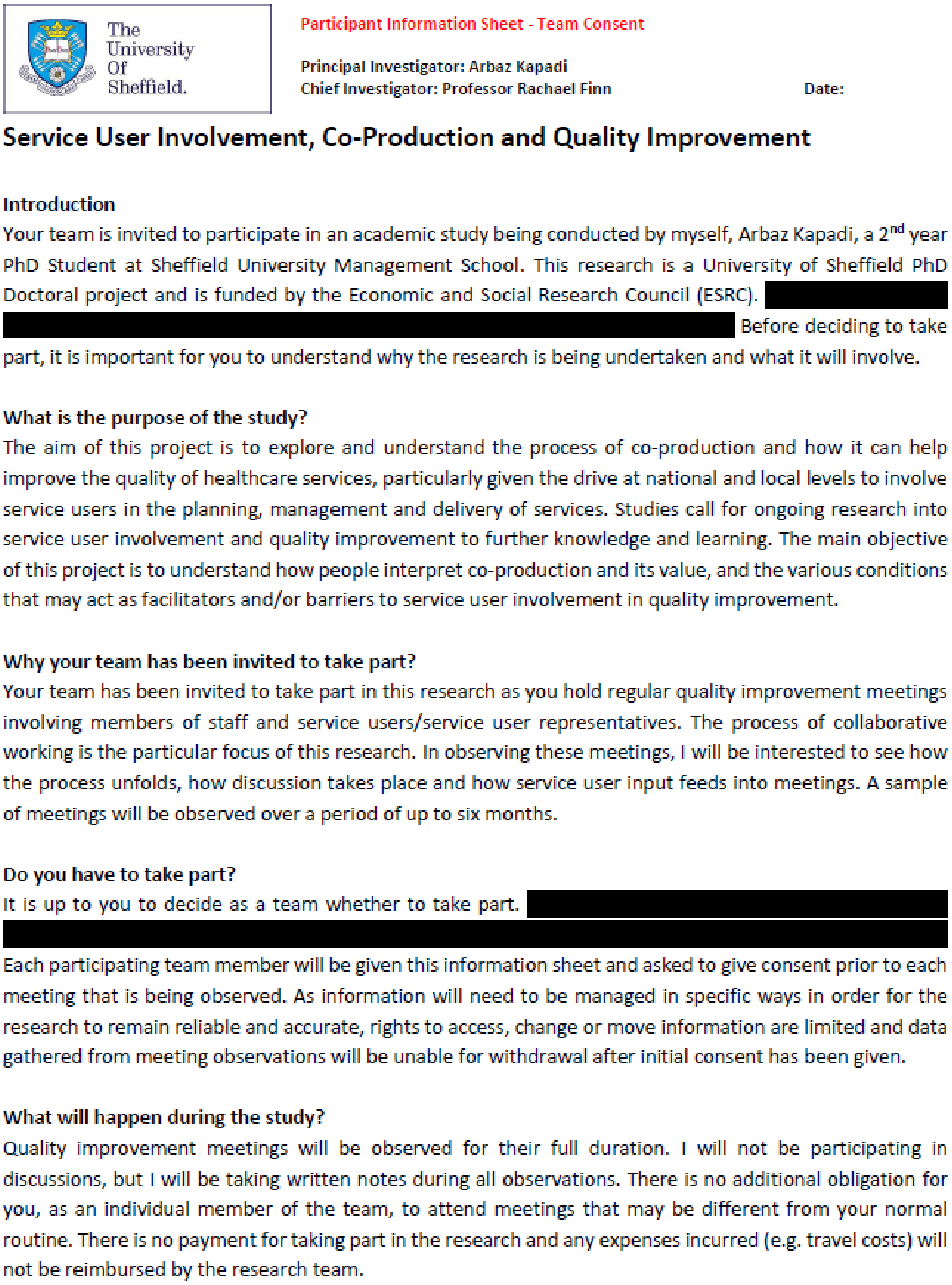
Service User Involvement, Co-Production and Quality Improvement

Taking Part in the Project	**Please initial the boxes to indicate your consent**
I have read and understood the project information sheet dated DD/MM/YYYY and/or the project has been fully explained to them. (If you will answer No to this question, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean).	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that participation is voluntary and I am free to withdraw without giving any reason, without my rights being affected.	
I acknowledge that the researcher may have to break confidentiality if something is disclosed that may require further action.	
I understand that taking part in the project will involve being interviewed.	
I agree to have my interview audio-recorded.	
I am aware of my rights to access, change and move my information; I acknowledge I will have 21 days from the date of the interview to withdraw information.	
I am aware of the process of whom to contact if I have any concerns over the research, and where significant concerns are raised, the research will stop.	
How my information will be used during and after the project	
I understand any personal details given will not be revealed to anyone outside the project.	
I understand and agree that my words will be quoted in publications, reports and other research outputs. I understand that I will not be named and these will remain anonymous.	
I am aware of what will happen with the data I give during and after this study.	
I agree for the data that is collected to be archived within an UK-approved data repository.	
I agree to take part in the study	

Name of Participant: **Signature:** **Date:**

Name of Researcher: **Signature:** **Date:**

Appendix 6a - CMS Team Observation Participant Information Sheet



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Participant Information Sheet - Team Consent

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn **Date:**

Service User Involvement, Co-Production and Quality Improvement

Introduction

Your team is invited to participate in an academic study being conducted by myself, Arbaz Kapadi, a 2nd year PhD Student at Sheffield University Management School. This research is a University of Sheffield PhD Doctoral project and is funded by the Economic and Social Research Council (ESRC). [redacted] Before deciding to take part, it is important for you to understand why the research is being undertaken and what it will involve.

What is the purpose of the study?

The aim of this project is to explore and understand the process of co-production and how it can help improve the quality of healthcare services, particularly given the drive at national and local levels to involve service users in the planning, management and delivery of services. Studies call for ongoing research into service user involvement and quality improvement to further knowledge and learning. The main objective of this project is to understand how people interpret co-production and its value, and the various conditions that may act as facilitators and/or barriers to service user involvement in quality improvement.

Why your team has been invited to take part?

Your team has been invited to take part in this research as you hold regular quality improvement meetings involving members of staff and service users/service user representatives. The process of collaborative working is the particular focus of this research. In observing these meetings, I will be interested to see how the process unfolds, how discussion takes place and how service user input feeds into meetings. A sample of meetings will be observed over a period of up to six months.

Do you have to take part?

It is up to you to decide as a team whether to take part. [redacted]

Each participating team member will be given this information sheet and asked to give consent prior to each meeting that is being observed. As information will need to be managed in specific ways in order for the research to remain reliable and accurate, rights to access, change or move information are limited and data gathered from meeting observations will be unable for withdrawal after initial consent has been given.

What will happen during the study?

Quality improvement meetings will be observed for their full duration. I will not be participating in discussions, but I will be taking written notes during all observations. There is no additional obligation for you, as an individual member of the team, to attend meetings that may be different from your normal routine. There is no payment for taking part in the research and any expenses incurred (e.g. travel costs) will not be reimbursed by the research team.

What are the possible benefits and risks of taking part?

There are no direct individual benefits to being involved in this study. However, through observations of meetings and exploring how service users and professionals collaborate within these settings, findings may provide important insight that your team may also be able to reflect upon in their practice.

The research is not intended to be about blame or recrimination and nor is it an evaluation of service performance. The research respects that co-production and quality improvement are relatively new approaches introduced into practice, and as such, observations will seek to understand the process of quality improvement, what discussions are taking place and how. Where information is offered with a request for strict confidentiality in meetings, this will be respected and not included. With any research, there is a potential concern for details to be identified. Measures to preserve anonymity and confidentiality will be in place as early as possible in the process (see below).

What will happen with the information you give? What anonymity measures are in place?

All information collected during the course of the research that relates to the team will be kept strictly confidential. Within transcripts and notes, the team's identity (individual roles, department) will be removed and replaced by a pseudonym [redacted] Transcripts, minutes and written notes will be retained in encrypted format on a password-protected University of Sheffield system that I can only access. Where information is offered with a request for strict confidentiality in meetings, this will be respected and not included. Consent forms and any additional notes taken will be securely stored within a locked filing cabinet. These measures will attempt to protect identity, however, full anonymity can not be guaranteed owing to the small size of the service team.

What will happen after the research has been collected?

Information that is collected will be transcribed and thematically analysed. I will be responsible for this. Analysis of information will involve looking for relevant themes that corresponds with the research questions and information provided from other sources. [redacted] A summary of the study and/or internal report will be produced and this will be made available to the team. Extracts from meeting observations may also be included in additional project outputs during and after the study has ended e.g. journals, reports, other research outputs. Confidentiality and anonymity will continue to be preserved at all times. Data from the study will be kept for a minimum of ten years after the PhD has been completed; data will be deposited in a safe and secure data repository, the UK Data Archive.

Who is the data controller for this study?

As a University-based PhD study, The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, there must be a basis in law to do so. This research is seen as being 'a task in the public interest'. Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

How can I find out more?

If you have any questions about the study, you can call, write or email me using the following details. Please feel free to contact me and I will be happy to give you further information.

Principal Investigator - Arbaz Kapadi
[redacted]

If you wish to discuss the study with the Chief Investigator/Academic Supervisor, please feel free to email, call or write to her using the following details:

Chief Investigator - Professor Rachael Finn,
[redacted]

What if there is a problem?

If you want to raise a concern about the conduct of the study, you may wish to notify your departmental service lead, whom has agreed to act as a point of contact. Equally, you can direct any problems or concerns to the following [redacted] department:

[redacted]

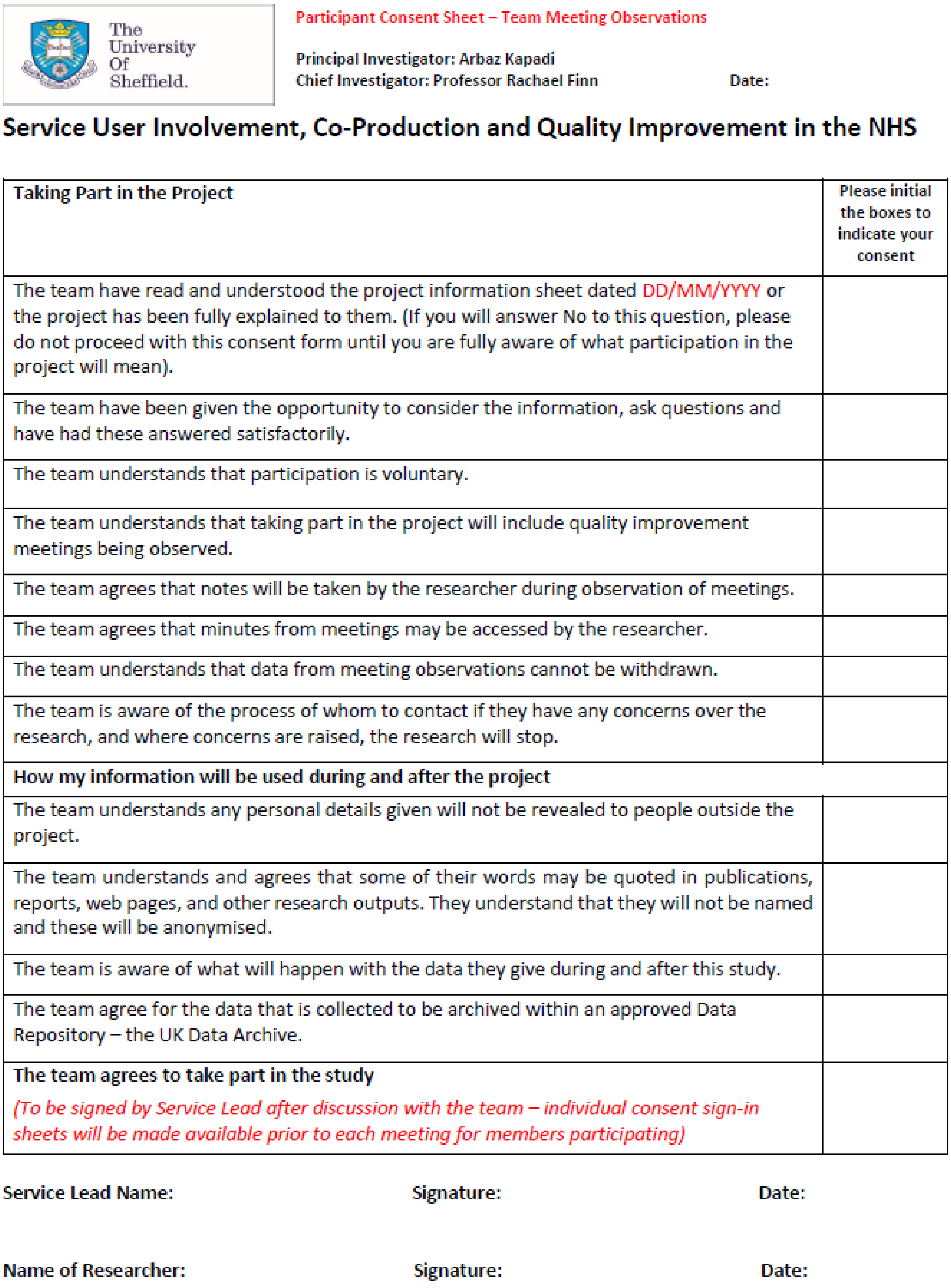
What arrangements are place for insurance and/or indemnity for harm arising from this research?

The University of Sheffield has in force a public liability insurance and non-clinical trials insurance. This policy provides indemnity to staff and students acting on behalf of the University for their legal liability for claims of 'negligent harm' and the activities here are included within that coverage. [redacted]

Who has reviewed the study?

This study has been academically reviewed by the University of Sheffield Management School and given favourable opinion by HRA and Health and Care Research Wales (GCRW) Approval – 19/NW/0258. This research has been planned and designed with the knowledge of [redacted] and your departmental service lead, whilst ethical guidance has been sought from the [redacted] in the management and conduct of this research.

Appendix 6b - CMS Team Observation Consent Form



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Participant Consent Sheet – Team Meeting Observations

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn
Date:

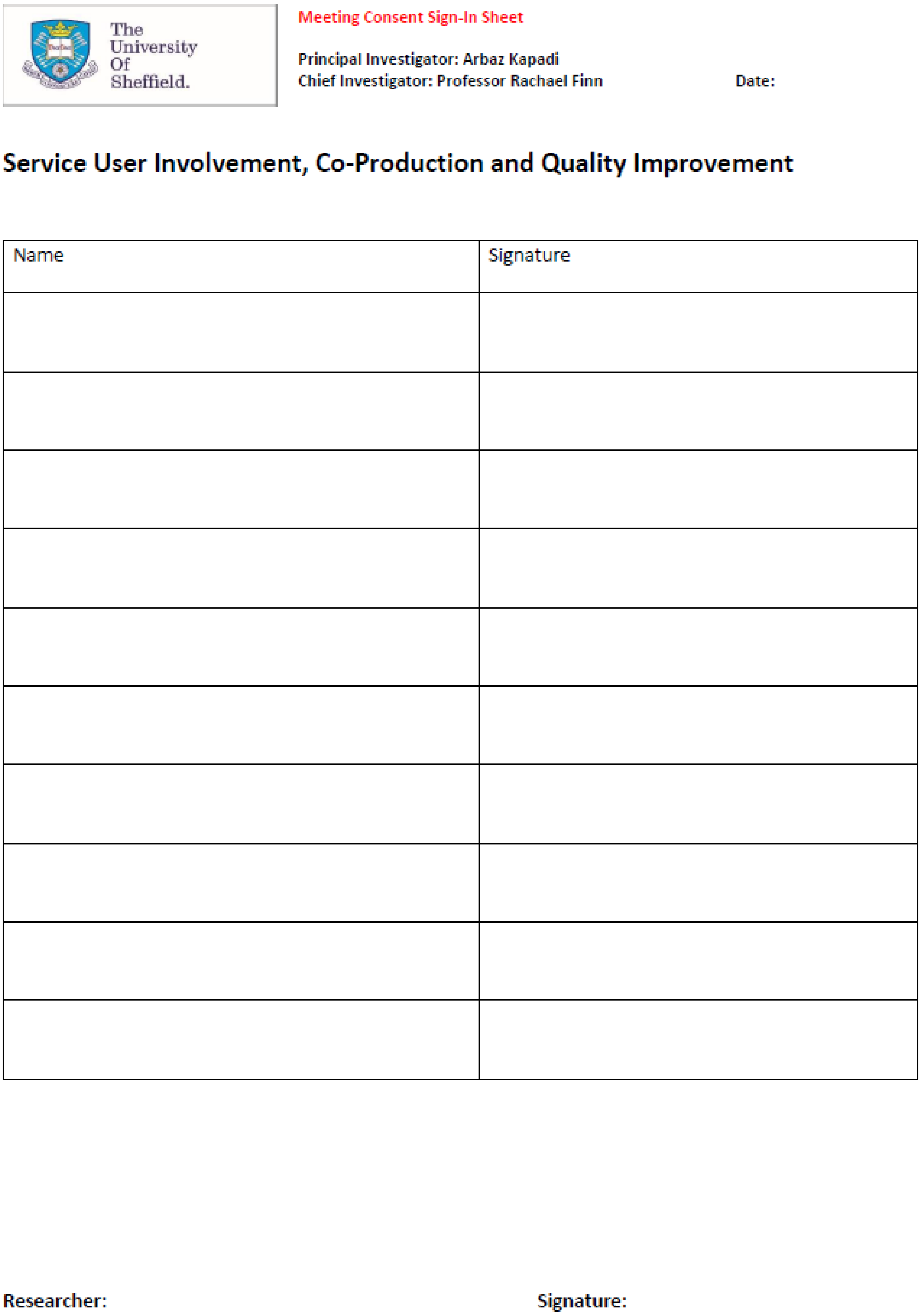
Service User Involvement, Co-Production and Quality Improvement in the NHS

Taking Part in the Project	Please initial the boxes to indicate your consent
The team have read and understood the project information sheet dated DD/MM/YYYY or the project has been fully explained to them. (If you will answer No to this question, please do not proceed with this consent form until you are fully aware of what participation in the project will mean).	
The team have been given the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
The team understands that participation is voluntary.	
The team understands that taking part in the project will include quality improvement meetings being observed.	
The team agrees that notes will be taken by the researcher during observation of meetings.	
The team agrees that minutes from meetings may be accessed by the researcher.	
The team understands that data from meeting observations cannot be withdrawn.	
The team is aware of the process of whom to contact if they have any concerns over the research, and where concerns are raised, the research will stop.	
How my information will be used during and after the project	
The team understands any personal details given will not be revealed to people outside the project.	
The team understands and agrees that some of their words may be quoted in publications, reports, web pages, and other research outputs. They understand that they will not be named and these will be anonymised.	
The team is aware of what will happen with the data they give during and after this study.	
The team agree for the data that is collected to be archived within an approved Data Repository – the UK Data Archive.	
The team agrees to take part in the study *(To be signed by Service Lead after discussion with the team – individual consent sign-in sheets will be made available prior to each meeting for members participating)*	

Service Lead Name: **Signature:** **Date:**

Name of Researcher: **Signature:** **Date:**

Appendix 6c - CMS Meeting Observation Sign-In Sheet



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Meeting Consent Sign-In Sheet

Principal Investigator: Arbaz Kapadi
Chief Investigator: Professor Rachael Finn Date:

Service User Involvement, Co-Production and Quality Improvement

Name	Signature

Researcher: **Signature:**

(Close)