BRIDGING THE GAP

A mixed methods study exploring the impact of the involvement of researchers with lived experience on a multi-site randomised control trial in the National Probation Service in England and Wales.

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Thesis declaration:

I, Elizabeth Simes confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Background: The involvement of individuals with lived experience of the subject area being studied is a requirement for grant applications in the UK. Patient and Public Involvement (PPI) can lead to the reduction of power differentials and strengthen results. However, there is a lack of conclusive evidence about the impact of PPI on clinical trials. To address this limitation in the evidence-base, this study evaluated if the inclusion of User Voice peer researchers as data collectors in a multi-site randomised control trial in the National Probation Service enhanced the validity of the data collected and the transfer of knowledge between peers and traditional researchers.

Methods: In this mixed methods study, trial participants and stakeholders were recruited. Participants were eligible, if they had consented to participate in the clinical trial and completed a research assessment with a peer or research assistant, or worked alongside the peer researchers. Eligible trial participants (n=30) and stakeholders (n=17) completed a semi-structured interview, and an additional sample of trial participants (n=76) completed a self-report scale. Transcripts were analysed using thematic analysis and an independent samples t-test was conducted for the self-report data.

Findings: Five themes were generated for the trial participants and 11 for the stakeholders. Accounts emphasized how shared lived experience can break down barriers to engagement through the creation of automatic common ground. The transfer of knowledge strengthened the trial and was an opportunity for personal development for the peer and traditional researchers. The quantitative findings from the trial participants were positive regardless of the type of researcher they met with, and no significant difference was found.

Conclusions: This study supports PPI in clinical trials and highlights how the involvement of researchers with lived experience as data collectors enhances the quality of data. However, adequate clinical supervision should be available for peer researchers in future studies. The

approach was mutually beneficial for the peer and traditional researchers and challenged

stereotypes associated with being an ex-offender and how knowledge is valued.

Impact statement

There is a lack of conclusive evidence about the impact of involving patients and members of the public in clinical trials, and although the value of adopting the approach has been suggested, there are inconsistencies in reported results. This mixed methods study has made a contribution to addressing these limitations in the evidence base by evaluating the impact of involving researchers with lived experience as data collectors in a multi-site randomised control trial in the National Probation Service (NPS). This study reported on the experiences of the trial participants who met with the peer researchers and the academic, criminal justice and third sector stakeholders who worked alongside the peers to implement the trial. The impact of the findings from this study reflects the range of backgrounds of the participants who shared their experiences, and the multiple number of agencies involved in MOAM, the clinical trial this study is based on.

To the author's knowledge, this is the first evaluation of Patient and Public Involvement (PPI) in a multi-site randomised control trial conducted in the NPS in England and Wales. For the academic community the results from this study challenge the bio-medical model by demonstrating the positive impact of involving researchers with lived experience as data collectors in a clinical trial. The findings provide evidence that through the inclusion of experiential knowledge, the validity of the data is enhanced through more honest answers, and share learning about the challenges that may arise through the adoption of this approach. This study demonstrates the mutual benefits for the peer and traditional researchers of working directly with colleagues with different lived experience, and how this transfer of knowledge can strengthen the results of the trial. Furthermore, the findings from this study support the PPI policy adopted by the National Institute for Health Research who funded the MOAM trial, and demonstrate the importance of ensuring funding for PPI in health care research continues to be prioritised.

For criminal justice professionals, this study highlights the important contribution lived experience can play in the rehabilitation process of current service users and those individuals who are no longer under supervision of the NPS. The involvement of the User Voice peer researchers in a national government funded clinical trial challenges the stereotypes associated with being an ex-offender, and demonstrates it is possible to break the cycle of reoffending. For service user organizations, findings from this study highlight the mutual benefits for the third sector of collaborating with academic institutions, in order to involve researchers with lived experience as data collectors. This study provides evidence that knowledge learnt through experience has an important role to play in clinical trials, which cannot be replicated by expertise obtained through academic study. Finally, the findings from this mixed methods study demonstrate to service users the value of their knowledge developed through their own experiences and their unique ability to be able to bridge the gap between service users and professionals to contribute to the generation of knowledge.

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INTRODUCTION

The involvement of patients and members of the public in health care research is a requirement of all grant applications to the National Institute for Health Research (NIHR) in the United Kingdom (National Institue for Health Research, 2018). The NIHR's approach is not unique, with other large research funders adopting similar policies (Boylan, Locock, Thomson, & Staniszewska, 2019). These funding requirements go beyond the involvement of patients as sources of data, as researchers are required to demonstrate how individuals with lived experience of the topic area being studied will be involved in the planning and implementation of the research. The NIHR describes this type of involvement "as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (Health Research Authority, 2021). Involvement could include contributing to study design (Lowes et al., 2011; Taylor, Whelan, Gibson, Morgan, & Fern, 2018); recruitment and data collection (Burns & Schubotz, 2009) analysis and write up (Thornton, Edwards, & Elwyn, 2003; Williamson, Brogden, Jones, & Ryan, 2010) or advisory roles through membership of oversight committees (Awenat et al., 2018). A wide variety of terms is used to refer to the patients or members of the public who contribute to the design or implementation of health care research including "Service user involvement" (Wallcraft, Schrank, & Amering, 2009), "Community researcher" (Salway, Chowbey, Such, & Ferguson, 2015) or "Co-researcher" (McLaughlin, 2006). In line with terminology adopted by the NIHR, this thesis will use the term Patient and Public Involvement (PPI) to describe the individuals who take on this role (National Institue for Health Research, 2018).

Moral and methodological arguments have been made for involving patients and members of the public in health care research. Firstly, it is argued morally we should not conduct research without involving those individuals who will be directly affected by the outcomes of the study: "nothing about me, without me" (Delbanco et al., 2001). The

inclusion of researchers with lived experience of the subject area being studied is a form of "civic partnership" which leads to the "democratisation of science" (Rose, 2014). Arnsteins' ladder of participation (Arnstein, 1969), and more recently Boote's Level of Involvement Continuum (Boote, Telford, & Cooper, 2002) illustrate this moral argument by describing how participation in research beyond the role of the participant can lead to the empowerment of individuals as they become part of the process of generating knowledge. Secondly, through the reduction of power differentials and the inclusion of knowledge gained through experience it is argued results are strengthened because participants feel more able to disclose honest answers and the data becomes meaningful (Milton et al., 2017). This change in power dynamics, could be suggested to be a shift away from the socially constructed relationship between the patient and clinician which is structured around control and power, described by Foucault as the "Modern Experience" (Foucault, 1965). Empowerment through participation and the reductions of power differentials between the researcher and the participant are especially important for those populations who are defined as hard to reach or hidden and struggle to engage in health care research.

Lambeth and colleagues describe hidden populations as "those who are disadvantaged and disenfranchised: the homeless and transient, chronically mentally ill, high school drop-outs, criminal offenders, prostitutes, juvenile delinquents, gang members, runaways and other street people" (Lambert, 1990). These hidden or hard to reach populations are under-represented in health care research which leads to a limited understanding of how to develop effective interventions for these groups. Studies have raised a number of reasons why these hidden populations may struggle to engage in research including physical risk to participation, access to limited resources to enable them to engage and mistrust of the research processes (Ellard-Gray, Jeffrey, Choubak, & Crann, 2015). It is argued that the inclusion of patients and members of the public in health care research creates

opportunities to break down these barriers to engagement. Study teams are able to access hidden populations and therefore topic areas which may not be accessible to traditional researchers (Byng et al., 2012). Through the involvement of researchers with lived experience, trust is facilitated leading to the development of rapport and the promotion of honest disclosure (Livingston et al., 2014).

The process of giving value to knowledge learnt through experience, also known as experiential knowledge, can be traced back to the rise of the Disability Studies movement in the 1960s in Canada, but became more established in health care research in the United Kingdom in the 1990s. The development of the approach was driven in part by government policy over the last two decades, which put a premium on lived experience. New Labour set out their ambitions in 1998 to place service users and carers at the heart of social care (Department of Health, 1998b). Successive Conservative governments have highlighted the importance of involving patients and members of the public in research and in 2012 the government went a step further by stipulating NHS England had a legal duty to involve patients and members of the public in their work in a meaningful way (Department of Health, 2012). Alongside the growth in policy development, the research environment has started to evolve with the creation of specific PPI academic and third sector spaces to share learning and examples of best practice.

In the United Kingdom, a central PPI research group known as INVOLVE, funded by the NIHR was established in 1996 to support active public involvement in the NHS, public health and social care research (National Institue for Health Research, 2021). More recently, there has been the development of research groups at higher education institutions, for example The Service User Research Enterprise at King's College London, established in 2001. Across the third sector service user organisations have become more prominent representing the "voice" of patients (Jongsma, Rimon-Zarfaty, Raz, & Schicktanz, 2018).

Some third sector organisation focus specifically on giving a voice to mental health patients, for example Pink Sky Thinking or Shaping Our Lives that aims to ensure disabled people are involved in decisions about their communities, health and social care services. Others user led organisations have developed which focus on the rehabilitation and recovery of service user in the criminal justice system, for example User Voice which was established by ex-offender and former drug user Mark Johnson (Johnson, 2009). The creation of Research Involvement and Engagement, an interdisciplinary, co- produced journal launched in 2015, has created a specific academic space for the publication of PPI literature. The adoption of the approach is also increasing (Boote, Wong, & Booth, 2015) with approximately half of research studies conducted within primary care in the United Kingdom involving patients and members of the public in the design and implementation of health care research (Blackburn et al., 2018). Alongside the growing number of study teams adopting the approach, an evidence base is starting to emerge to support understanding of the impact of PPI.

Current evidence predominately favours the inclusion of experiential knowledge in health care research suggesting there is a range of impacts of the approach. It is argued, due to the involvement of individuals who have lived experience of the subject area being studied, PPI can increase the relevance of research findings (Ross et al., 2005); recruitment rates (Staley, 2009b) and the validity of the data collected (Livingston, Nijdam-Jones, & Team, 2013). For the patients and members of the public who participate, the approach can lead to individuals feeling empowered and valued (Brett, Staniszewska, Mockford, Herron-Marx, et al., 2014) and the experience can provide the opportunity to develop news skills, and a greater understanding of research (Williamson et al., 2010). However, researchers have also highlighted the limitations of involving patients and members of the public in their work. One of the main criticisms of PPI is the risk of patients and members of the public feeling over burden by the experience, if they are not given appropriate levels of support (Clark, Glasby,

& Lester, 2004). Without a well thought out study design, the involvement of researchers with experiential knowledge can feel tokenistic (Brett, Staniszewska, Mockford, Herron-Marx, et al., 2014), especially when patients are not acknowledged or appropriately paid for their contributions (Ashcroft, Wykes, Taylor, Crowther, & Szmukler, 2016). There is also limited evidence of any economic analysis of the costs involved of including patients and members of the public in designing and implementing research (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). Despite these limitations, researchers and policy makers have suggested that PPI in clinical trials may be particularly valuable (INVOLVE, 2013).

INVOLVE highlighted in their case study review, the involvement of patients and members of the public in clinical trials has the potential to address many of the methodological issues that arise within this particular study design, because the inclusion of experiential knowledge brings a different perspective to the table (INVOLVE, 2012b). PPI in clinical trials may also improve the design of the study and ensure the outcome measures collected are relevant to the study population (Staley, 2009b). Patients and members of the public have started to contribute to the design and implementation of clinical trials, but despite the suggested benefits, the prevalence of the adoption of the approach is relatively low (Boote, Baird, & Sutton, 2011). There are also inconsistences in the literature about the reported impact of PPI on this particular type of research design.

Some researchers have highlighted the positive impact of PPI in consultancy roles for clinical trials. Coulman's work suggests how the involvement of patients and members of the public in oversight committees provide the opportunity for the patient's voice to be heard and understood. However, there was also a risk of tokenism as patients were was not always actively involved at committee meetings (Coulman et al., 2020). In contrast, Dudley's qualitative study of 28 clinical trials found the impact of involving patients and members of the public in oversight committees and trial management groups ranged from no

unfavourable impact to some impact and for some trials no impact at all. This study team triangulated the accounts of multiple informants to strengthen their results. However, the team reported the informants struggled to recall examples of PPI, and it was difficult to establish if the suggested effects of the approach were exclusively a result of the contributions of the patients and members of the public (Dudley et al., 2015). Other researchers have explored the impact of involving patients and members of the public in the development of the study design. Koops and Lindley argued in their paper, the inclusion of experiential knowledge can be a very important part of the development of randomised controlled trials and the approach has the ability to strengthen the ethical acceptability of trial design. However, questions have been raised about the validity of the results in this particular study as the participants who were approached to share their views were selected from one city in Scotland, and the suggested lack of independence of the lead researcher could have introduced bias (Koops & Lindley, 2002). Researchers have also attempted to explore the impact of PPI beyond a consultation role, focusing on impact on enrolment and retention rates (Crocker et al., 2018).

Crocker's systematic literature review involved 26 studies and concluded the involvement of patients and members of the public in clinical trials does increase rates of enrolment, but found there was no significant improvement in retention rates of participants over time. These findings are of particular importance for clinical trials, as recruitment and retention are often one of the more challenging aspects of implementing these types of studies. However, similar to Dudley's study about the impact of PPI in oversight committees, the study team suggested the positive reported impact on engagement rates might have been due to the non-PPI components of the studies, which the study team were unable to separate from the involvement of patients and members of the public in their review (Crocker et al.,

2018). Other studies have explored the impact of PPI more broadly, and in some cases across

multiple case studies (Mann, Chilcott, Plumb, Brooks, & Man, 2018; South et al., 2016).

Mann's qualitative study suggested that PPI in clinical trials has a positive impact

across a range of aspects of a study, including for the patient and members of the public who

were involved. Through their involvement patients and members of the public felt valued and

the experience of being involved in a clinical trial was an opportunity to develop new skills

(Mann et al., 2018). The format of PPI in this trial was broad, including advisory groups,

oversight committee membership and contributing to the analysis phase of the study.

However, the evaluation only focused on the specific structure of PPI in one study, therefore,

it is unclear how generalizable these results are. Others study teams have explored the impact

of experiential knowledge across multiple aspects of the research design and multiple studies.

South's study concluded the use of a range of PPI at different stages of the research process

might maximise the impact of the approach in clinical trials. The scope of this study provided

an opportunity to understand the impact of PPI in trials outside of the NHS and included 11

case studies based in Africa, South America, Asia, Europe and North America (South et al.,

2016). However, the range of cultural differences of how patients and members of the public

were defined and involved may have meant it was difficult to compare the impact of PPI

across multiple case studies.

A number of different factors should be considered when attempting to understand the

inconsistencies in reporting the impact of the PPI in clinical trials. Due to the range of

methods of PPI adopted it can be difficult for researchers to evaluate impact across multiple

case studies (Mann et al., 2018). Researchers have suggested low levels of reporting of PPI

activities in research, often due to the limited requirements by journals, may have also led to

a lack of understanding about the breath of the impact of the approach on clinical trials (Price

et al., 2018). Bower describes how the outcome of this underreporting means our current

understanding is like a "black box"; when PPI input is described, research reports are rarely

specific about the type of involvement and how patients and members of the public have

shaped or changed the course of the research (Bowers, Lovick, Pollock, & Barclay, 2020).

Other contributing factors could also include the complexities of evaluating a process which

is subjective and socially constructed (Barber et al., 2012) and an absence of robust methods

of measurement of impact (Mockford et al., 2012).

To summarise, despite the growth of policy and research there is a lack of conclusive

evidence about the impact of PPI on clinical trials, and the results that have been reported are

inconsistent. Therefore, there is a need for further research to explore the potential impact of

PPI in health care research, and particularly the impact of the approach on clinical trials

(Crocker et al., 2018; Kearney et al., 2017). This argument is supported by the NIHR Going

the Extra Mile recommendations published as part of the Breaking Boundaries review in

2015 (National Institue for Health Research, 2014a) and the more recent NIHR Taking Stock

report (National Institue for Health Research, 2019) which suggested although progress has

been made, there is limited understanding of the overarching impact of PPI in health care

research in the United Kingdom. However, researchers have also highlighted that, in order to

explore the impact of PPI in clinical trials in more depth, future research must explore context

(Staley, 2015) and consider the possibility of shared learning, power relations and the

possible harms as well as benefits of the approach (Russell, Fudge, & Greenhalgh, 2020). The

intention of this thesis is to build on the work of Croker, Kearney and others by evaluating

the impact of involving researchers with lived experience, known as peer researchers, in a

randomised control trial (RCT) conducted in the national probation services (NPS) in

England and Wales. This multi-site clinical trial, known as Mentalization for Offending Adult

Males (MOAM) (Fonagy et al., 2020) involved peer researchers with lived experience of the

criminal justice system as data collectors. The peer researchers were employed by User

Voice, a service user led organization, and worked alongside a team of traditional researchers at UCL to collect data from male participants who met threshold for anti-social personality disorder under the supervision of the NPS. The thesis aims to answer the following research question:

Does the involvement of researchers with lived experience as data collectors in a RCT in the

criminal justice system exploring the effectiveness of community-based interventions enhance

   1) The validity of the data collection through more honest responses

   2) The transfer of knowledge between peers and traditional researchers

CHAPTER 1 Experiential knowledge

This chapter explores the development and theories associated with involving patients and members of the public with lived experience in health care research, also known as the implementation of experiential knowledge. Theories of power and participation are examined alongside three models of the approach Mad Studies, Survivor Research and Patient and Public Involvement. The chapter concludes with a brief introduction of the Mentalization for Offending Adult Males trial (MOAM), which is the case study and focus of the thesis.

Theoretical background

Our understanding of the most effective methods of treating mental health patients and conducting health care research is changing. Researchers have started to ask questions about what constitutes valid evidence, and who decides? (Glasby & Beresford, 2006). These questions have led to the development of actively involving patients and members of the public in designing and conducting research, challenging the traditional ideas of the production of knowledge. In the first section of this chapter, the role of power and participation is explored in relation to the development of valuing knowledge gained through experience.

1.1   Power

In order to understand the role of power in the development of experiential knowledge, we must first review the history of the treatment of mental health patients and the development of the patient and clinician relationship. Our understanding of mental health has changed over time, from madness being considered a part of everyday life to a stigmatized condition that society needs protection from. Foucault describes in his work three phases of our understanding of madness. He argues we started at the Renaissance Phase when the mad were portrayed as wise and knowledgeable. During the mid-seventeenth century, madness

became understood as a moral error and the individual needed to be encouraged to change their behaviour through programmes of punishment and reward. This was known as the Classical Age. Finally, at the end of the eightieth century we entered the Modern Experience where patients are placed under the supervision, and therefore control, of medical doctors (Foucault, 1965). Through the development of society's understanding of how mental health patients should be treated, power differentials have emerged. Foucault argues the shift from madness being portrayed as a form of wisdom to a focus on supervision, is linked to the development of power and control more broadly within our society to ensure those who are considered undesirable are separated and confined (Foucault, 1965). It could be argued these socially constructed power differentials between the patient and clinician are mirrored in the development of the relationship between the participant and the researcher in health care research.

Critical theorists describe how the adoption of the traditional bio-medical model in research, dictates who gets to study whom (Sweeney & Beresford, 2020). It is argued researchers who have developed their knowledge and expertise through academic training have traditionally designed and conducted health care research similar to the approach adopted for treatment. This traditional positivist approach is based on the view that rigorous, independent and scientifically based research is best placed to discover the objective truth (Crotty & Crotty, 1998). The approach places a higher level of value on professional knowledge than experiential, and sees people as "sources of data, rather than shapers and interpreters of their own experience" (Campbell, 2009). Those who have power, socially construct what is valid knowledge and how this knowledge is disseminated (Sweeney, 2016). Critical theorists argue the service user is stigmatized and exploited through this intrusive process, which disempowers them as the research only aims to benefit the researcher's interests (Barnes & Mercer, 2010). However, it is suggested by increasing the value and

therefore recognition of experiential knowledge this balance of power starts to shift, leading to suggested positive outcomes for service users and the quality of the research produced.

It is argued the involvement of patients and members of the public in health care research can lead to the empowerment of individuals (Brett, Staniszewska, Mockford, Herron-Marx, et al., 2014). Studies have shown service users have the opportunity to increase their skills and confidence (Sweeney, 2016) and the quality of the data improves as power differentials are reduced between the participant and the researcher through their shared lived experience (Faulkner, 2017). Through the involvement of patients and members of the public in health care research, those with lived experience become involved in the production of knowledge and therefore are part of the process of shaping society's understanding of mental health. The process of readdressing these imbalances of power can also be understood in the way citizens participate in society, and these ideas are explored in the sub section below.

1.1.1   Participation

The traditional measurement of participation was defined by Sherry Arnstein and has been widely adopted to explore the concept of participation in society (Macdonald & Taylor-Gooby, 2014). Arnstein described how through their Ladder of Citizen Participation "power is redistributed enabling the have nots, who are often excluded from political and economic decision making processes, to become actively involved in decisions about their own communities" (Arnstein, 1969). Arnstein's measurement of participation was developed as a critique of the urban development policy in America in the 1960s. At the time, local governments were required to engage their community in the development of local policy and provide the opportunity for local residents to review and share their feedback about redevelopment plans. However, members of the community felt the consultation process was designed to ensure residents had little influence over the decision making progress, leading to

the targeting of primarily poor African American neighbourhoods for removal (Coghlan & Brydon-Miller, 2014). Arnstein's Ladder challenged this process arguing without genuine participation a "tokenistic" or "none participation" approach creates powerless citizens, who are excluded from the decision making process about their communities. At the same time, Arnstein suggested the approach of tokenism "allows the power holders to claim that all sides were considered, but makes it possible for only some of those sides to benefit" (Arnstein, 1969). More recently, authors have argued that the redistribution of power through the meaningful participation of citizens in decision making processes can have a positive impact beyond the individual or group directly involved identified by Arnstein (Verba & Nie, 1987), and meaningful participation is vital to enable social action and change (Larsen et al., 2004). Boote builds on Arnstein's Ladder by developing a Level of Involvement Continuum to explore how different levels of participation can affect how health care research is conducted, and the quality of the findings produced (Boote et al., 2002).

Boote outlined three levels of consumer involvement. Firstly "consultation" which increases empowerment of consumers within the research process (Boote et al., 2002). This type of involvement could include a service user providing feedback about the wording of a participation information sheet that has already been developed by a traditional researcher. In this scenario, the service user becomes a passive member of the research team. Boote described the next level as "collaboration" which involves the ongoing partnership between traditional researchers and consumers throughout the research process (Boote et al., 2002). This level of participation involves the service user guiding the direction of the research, for example as a member of the trial steering committee. Through the collaboration level, the service user begins to have more ownership of the research as they work with traditional researchers to implement the study. Finally, Boote describes the highest level of involvement as "consumer control" when the individual with the lived experience takes full control of the

research process (Boote et al., 2002). As the name suggests, at this level of participation the researchers with lived experience leads on all aspects of the study, with very little or no input from traditional researchers. This approach gives full control to the service user. Similar to Arnstein's Ladder, Boote's Continuum suggests the higher the level of involvement, the higher the level of empowerment for the patient or member of the public involved in the research process. Boote's and Arnstein's different levels or rungs of participation can help us to understand the degree to which power is redistributed through the implementation of experiential knowledge and the potential impact on service users, participants and the quality of the research produced. These ideas are explored in the second section of this chapter below.

1.2   Models of experiential knowledge

Experiential knowledge is defined as knowledge gained through experience as opposed to knowledge that is learnt through professional training, accreditation or research (Beresford, 2020). One example of the implementation of experiential knowledge is the involvement of researchers with lived experience of the subject being studied. Through involvement, the individual plays an active role in contributing to the research process as an adviser or co-researcher, and in some cases in the delivery of the study. The researcher's experiential knowledge gained through their own experiences is prioritized and valued, because it is believed the adoption of the approach reduces the power differentials between the participant and researcher leading to a more authentic connection (Faulkner, 2017). Although the involvement of individuals with lived experience in research is clearly defined as the involvement of patients and members of the public, different models have developed over the last 30 years which can be broadly be described as Mad Studies, Survivor Research and Patient and Public Involvement (PPI). These models of study define involvement through

different lenses, and are explored in the sub sections below in relation to theories of power and participation.

1.2.1   Mad Studies

"Mad Studies is described as an emerging model that is not owned by one person or one discipline" (LeFrançois, Menzies, & Reaume, 2013). Mad identified scholars include a wide range of individuals, who consider themselves patients, survivors or consumers who work at higher education institutions or within the third sector. The model of study challenges the traditional idea that "the mad cannot do science because that space of ultimate rationality is by definition closed to irrational beings" (Rose, 2017). The approach can be understood as a collective aim to create a space to make and preserve mad people's knowledge (Mad Studies Network, 2014). The first use of the term "Mad Studies" is primarily associated with Ingram at Ryerson University in Canada. However, Ingram himself suggests although he has been credited with coining the term in 2008, the ideas of Mad Studies have been developing since the 1960s, and are rooted in the Disability Studies movement in Canada (Ingram, 2016). The disabled people's movement highlighted the importance of challenging the social norms of the production of knowledge, and campaigned for those with lived experience to become actively involved in research about their conditions and treatment beyond a source of data. Alongside the growing disability movement in Canada, a parallel movement developed in Europe that has recently been revived by the user control organisation Shaping Our Lives (Rose, 2017).

Mad identified scholars suggest two key strengths of the model. Firstly, through the approach those with the lived experience are central to the production of knowledge about madness, giving power to groups who have previously been disempowered. The Mad movement argue the approach enables those who have direct lived experience of accessing

mental health services to become empowered by reclaiming their stories from organisations who have used them to further their own interests (Costa et al., 2012). Due to the level of service user control, Mad Studies could be described as "Citizen control" or "consumer control", the highest rung on Arnstein's Ladder or level on Boote's Continuum, as those with direct lived experience are in control of all aspects of the research. Secondly, authors have suggested Mad Studies has the potential to create vibrant new ideas about the discourse of madness and its treatment because those with lived experience can bring a different perspective (Rose, 2017). However, despite the strengths of the approach critics have suggested some limitations of the model.

Firstly, the term "Mad" and the use of the expression "Mad Studies" has been criticised because of the associations with fear and danger, and the use of this language reinforces the idea that those who are considered undesirable need to be confined for the safety of others (Beresford, Nettle, & Perring, 2010). This creation of fear could be suggested to be part of the narrative of the "Modern Experience" described by Foucault, which leads to the disempowerment of service users as they are seen as a threat to others and should therefore be controlled. Secondly, concerns have been raised about the inclusiveness of the model. To date, a Eurocentric and Northern hemisphere focus has led to the exclusion of some scholars from black and minority groups and lack of consideration of indigenous cultures (King, 2016). The lack of diversity within the movement could be linked to the relatively recent development of the model. However, due to the aims of the movement to create a space for Mad people's knowledge to be preserved there is a need for a more inclusive approach to be adopted. In addition to these identified limitations the Mad Studies movement is also navigating an overarching challenge as to where to place themselves.

Mad Studies aims to create real equality for experiential knowledge, whilst at the same time preserving the approach as a challenge to the traditional bio-medical model.

Ingram described this challenge as, "showing that there is method in our madness, and on the other side, preserving madness in our method" (Ingram, 2016). This challenge raises questions about how to increase levels of participation and therefore reduce power differentials, without creating tokenistic scenarios where a select few Mad scholars merely join the group that holds the power. Differing opinions on this subject have led to some survivor activists attacking Mad Studies scholars who work in an academic settings as they believe the practice is a betrayal of the movement (Carr, 2019). However, others have suggested the importance of the role of those survivors who choose to work at an academic institution alongside traditional researchers as it gives authority to service users' experiences whose voices have previously been devalued (Russo, 2012). Rose supports this argument, highlighting the ability to work together and build bridges between survivors and traditional researchers will strengthen findings, and our understanding of what is valid knowledge (Rose, 2017). One of the strongest expressions of Mad Studies is described as Survivor Research. The development and the strengths of this model are explored in the sub section below.

1.2.2   Survivor Research

Survivor Research is described as the "systematic investigation of issues of importance to survivors, from their perspective and based on their experiences, leading to the generation of new, transferable knowledge" (Sweeney, 2016). Alternative terms for the approach also found in the literature include "survivor-controlled research", "survivor-led research", "service user-controlled research" and "service user-led research". In Survivor Research, individuals with lived experience lead the whole research process with very little or no input from traditional researchers. Therefore, the aims and the design of the research are shaped by the perspective of the survivor, which often means those with lived experience not only control the direction of the research, but also funding and dissemination of the findings. Survivor Research focuses on the importance of developing ownership of the research so the

subjects become participants and partners (Sweeney, 2016). By giving the control of the

research to the survivor, the approach aims to "restore credibility and authority to those who

have been historically deprived of it through psychiatric labeling" (Russo, 2012). Through the

process of giving control and ownership to the survivor, levels of participation increase and

therefore power is redistributed to those who have traditionally been excluded from the

production of knowledge.

Survivor Researchers argue the field of study has two main strengths. Firstly, the

approach challenges the traditional powerful research norms of the biomedical model of who

gets to study whom. Through Survivor Research, service users take back control and are no

longer excluded from the generation of knowledge about their own experiences (Sweeney &

Beresford, 2020). Similar to the strengths of the Mad Studies approach, Survivor Research

could be described as the highest rung on Arnstein's Ladder or Boote's Continuum as those

citizens with lived experience of the subject area control all aspects of the research. Secondly,

authors have described how Survivor Research increases the validity of the findings, as the

research is conducted from an explicit standpoint and therefore there are no hidden agendas

(Faulkner & Thomas, 2002). It could be suggested that all research is conducted from a

particular standpoint. For example, in qualitative research, the author's standpoint is

traditionally declared in the methods section of the publication. However, authors argue the

standing of the researcher in Survivor Research is especially important because the

knowledge of those who are traditionally excluded is now validated, as they are able to

contribute thoughts and ideas not accessible to others (Kokushkin, 2014). Harding explains

this process through their concept of Objectivity. It is argued "Strong Objectivity" is

knowledge that is grounded socially and is therefore more objective when compared to the

bio-medical model that is suggested to be "Weak Objectivity" as the researcher hides their

position. Harding argues, "Weak Objectivity" normalises and reinforces the position of

marginalised groups and therefore the status quo about mental health conditions (Harding, 1992). The process of normalisation described by Harding through their concept of Objectivity could be suggested as another example of how Foucault's "Modern Experience" of mental health continues to be reinforced, and the importance of thinking beyond the bio-medical model to broaden our understanding.

In addition to the Mad Studies movement and Survivor Research, a third model of experiential knowledge known as Patient and Public Involvement (PPI) has developed over the last 30 years and increased awareness of the potential benefits of involving researchers with lived experience in health care research. However, the origins and structure of the PPI model differ considerably from the grass roots developed Mad Studies movement and Survivor Research discussed up until this point. These differences and similarities, and the role of power and participation for the PPI model are discussed in more detail in the sub section below.

1.2.3   Patient and Public Involvement

Patient and Public Involvement, or PPI, is the dominant model in health care research adopted by the National Institute for Health Research (NIHR) in the United Kingdom (INVOLVE, 2012a). PPI entails "research being carried out with or by members of the public, rather than to, about or for them" (Health Research Authority, 2021). The term public can refer to a patient or potential patients, but also people who use social care services as well as general members of the public. PPI could include the involvement of individuals with lived experience at any stage of the research process from design and data collection, through to analysis and dissemination of findings working alongside traditional researchers. Historically, the approach grew out of a decision by the Department of Health in 1996 to fund a new unit named Consumers in NHS research, later renamed INVOLVE, followed by the

formation of the NIHR in 2006 and the Mental Health Research network who put a premium on user involvement in research (Rose, 2017). The increase of PPI in research has in part been driven by government policy in England and Wales and the successive flow of national policies aimed at increasing PPI in health care research. For example, the first research and development guidance published by the NIHR in 1991 did not reference the involvement of patients or members of the public in research. However, the importance of PPI is now deeply embedded in research policy and guidance (Evans, 2014). There has also been change of focus within the research environment with major research funders now expecting to see evidence of PPI in grant applications (Department of Health, 1998a), and academic institutions developing their own public engagement units to support and encourage researchers to involve patients and members of the public in their work. The increase of the adoption of the PPI model has led to the development of a growing evidence base about the potential strengths of the approach.

Firstly, due to their lived experience of the topic area being studied, it has been argued that patients and members of the public have the ability to contribute ideas about the development and implementation of the research that may be overlooked by traditional researchers. Through the involvement of patients, the aims of the research become more relevant to those who are affected by the results of the study (Rose, 2017). Secondly, researchers have suggested the involvement of those with lived experience can enable study teams to engage participants who traditional researchers without lived experience of the topic area may struggle to reach (Byng et al., 2012). This approach not only enables research teams to potentially recruit a more representative sample, but may also enables them to reduce rates of drop out. Thirdly, it has been suggested the PPI model may have a positive influence on the patients and members of the public themselves, as they feel empowered by the experience and are participating in the production of knowledge (Brett, Staniszewska, Mockford,

Herron-Marx, et al., 2014). These arguments suggest, through participation, power is redistributed to patients who may have previously been excluded from the production of knowledge demonstrating Arnstein's Ladder of Citizen Participation (Arnstein, 1969). However, despite the growing evidence base for PPI, some authors have highlighted the limitations of the approach by raising questions about the level of participation and therefore to what degree power is redistributed to those who have traditionally been excluded.

Although PPI is the dominant approach adopted by researchers working in the NHS, some authors have suggested there is a risk of tokenism as traditional researchers still tend to adopt the bio-medical research model with patients and members of the public only involved at certain stages of the research process. Russo highlights this distinction in their work explaining how "in PPI service user involvement could be described as an optional add on component with the aim of extending the perspective of academic researchers" (Russo, 2012). Hodge demonstrates this limitation through their case study of patient involvement suggesting how the patient's expressions of their personal experiences are only considered relevant if they are part of the pre-determined discourse identified by the traditional researcher (Hodge, 2005). The limitations of adopting a pre-determined discourse can also be understood through Arnstein's Ladder. PPI cannot be truly described as "citizen control" (rung 8), as control of the research is not given to the patient or member of the public. There may be some degree of "delegation of power" (rung 7) or "partnership" (rung 6), but unless a patient is appointed as a principal investigator in an academic setting they would not have any degree of power or control over the research. This leads to the increased chance of PPI falling into the "degrees of tokenism" category on the participation ladder where the involvement of patients and members of the public may "break down barriers" (rung 5), "consult" (rung 4) or "inform the design of the research" (rung 3). This process not only causes frustration for the patient (Hodge, 2005) but some may find the experience

disempowering and in some cases traumatic. Due to this risk of tokenism, others branches of experiential knowledge could be considered to enable the redistribution of power more effectively and therefore the active participation of patients and members of the public in health care research.

1.3   Summary

This chapter has summarised three models of experiential knowledge, and the role of theories of power and participation in evaluating the impact of involving researchers with lived experience in health care research. The origins of the three identified models are distinct, with Mad Studies and Survivor Research developing from grass root organizations compared to the development of PPI that has been driven by government policy in the United Kingdom. Despite these differences, the identified benefits of the approaches appear very similar. All three models argue by involving patients and members of the public with lived experience in health care research the quality of the data improves and the patient, participant or citizen benefits, as they feel empowered by the process. It is suggested through this process of participation power is redistributed from those individuals who traditionally conducted research through the bio-medical model, to those who have be labelled mad and confined for the safety of others. However, although the overarching suggested strengths of the models are very similar, the degree to which power is redistribution varies considerably between the different approaches.

The Mad Studies and Survivor Research models suggest in some sense a greater redistribution of power, as the research is led and implemented by those with the lived experience. These models could be described as the highest rung on Arnstein Ladder, and therefore "citizen control". However, there have been questions raised about the movement's inclusiveness and the impact of the terminology adopted. There are also still questions to be addressed about how to keep Mad Studies, Mad whereas, PPI adopts a more co-production

approach with the blending of experiential knowledge and the bio-medical model as those with lived experience work alongside those without. However, several authors have highlighted how the PPI model risks becoming "tokenistic" as patients and members of the public become an "optional add on" (Russo, 2012) allowing the traditional researchers to claim patients were consulted but no power was actually redistributed. Despite the growing evidence base which has been explored in this chapter, the impact of experiential knowledge remains a relatively unexplored area. This thesis aims to make a contribution to our understanding of the impact of experiential knowledge in health care research by evaluating the PPI model, which is the dominant field of experiential knowledge adopted for research conducted in the NHS, through the examination of a case study known as the MOAM trial.

The MOAM trial was a multi-site randomised control within the national probation service in England and Wales. The trial aimed to evaluate Mentalization Based Therapy for male offenders with antisocial personality disorder compared to standard treatment. The study team believed the involvement of PPI would improve the quality of the data collected and enable the study team to engage participants who were not accessible to traditional researchers (Fonagy et al., 2020). Working in collaboration with a service user led organisation User Voice, the trial methodology involved researchers with lived experience as data collectors. To explore the prevalence of this approach the thesis begins with a systematic literature review of the studies that, similar to MOAM, involved researchers with lived experience as data collectors.

CHAPTER 2 Systematic literature review

This chapter describes a systematic literature review, which was conducted to explore the characteristics of mental health intervention studies that involved researchers with lived experience as data collectors, also known as peer researchers. The review identified 25 records, which included primary and secondary publications of 20 research studies that adopted the peer researcher approach, and reported their methodology in either a peer reviewed or none-peer reviewed journal published in English. The background to the review, study selection, analysis and results are described in the subsections of this chapter below.

2.1   Background

There is a growing consensus amongst policy makers and researchers about the potential positive impact of involving patients and members of the public in health care research. The involvement of those individuals with lived experience of the area of study, known as Patient and Public Involvement (PPI), is considered to produce better quality research because it is grounded in user experience which produces a more reflective view point (Brett, Staniszewska, Mockford, Herron-Marx, et al., 2014). PPI is defined as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or for 'them'" (Health Research Authority, 2021). Examples of PPI could include the involvement of patients or members of the public at any stage of the research process, including data collection.

User participation in the delivery and evaluation of mental health services has become an important policy element in the development of services especially with the satisfaction of care (Stevenson et al., 2016). The establishment of INVOLVE in 1996, funded by the National Institute for Health Research (NIHR), has supported and raised awareness of the development of PPI in the NHS, public health and social care research in the United

Kingdom. Following the Department of Health Research and Development for a first-class service guidance document (Department of Health, 1998a), researchers applying for funding are required to state in grant applications how users will be involved in a study, and report on their involvement throughout the research process. A series of guidelines has been published to support and encourage researchers to involve patients and members of the public in research. The National Institute for Health and Care Excellence (NICE) published a Patient and Public Involvement policy in 2013 providing national guidance about involving patients, service users, cares and members of the public in the development of best practice for health and social care (The National Institute for Health and Care Excellence, 2021). In 2014, the NIHR published the PPI in health and social care research handbook providing guidance on all stages of the research process from recruitment through to evaluation (National Institue for Health Research, 2014b). In addition, we have seen the development of research groups including the Service User Research Enterprise at King's College London, and the creation of the Research Involvement and Engagement journal specializing in patient involvement and engagement research.

Despite the growth in policy, guidance and research, there is a lack of conclusive evidence about good practice and the potential impact of involving patients and members of the public in health care research highlighted by the Going the Extra Mile recommendations published as part of the Breaking Boundaries review in 2014 (National Institue for Health Research, 2014a). The report concluded whilst significant progress has been made there is a need to consolidate learning and accelerate the spread of effective practice, drawing on evidence (Staniszewska, Denegri, Matthews, & Minogue, 2018). More recently, the NIHR Taking Stock report in 2019 (National Institue for Health Research, 2019) suggested although progress is being made, there is limited activity in aggregating current knowledge to assess the overarching position of PPI in health care research in the United Kingdom.

Previous systematic literature reviews have explored the involvement of patients and members of the public across both health and social care research to support the development of an evidence base. Brett et al. 2014 explored the conceptualization, measurement, impact and outcomes of PPI in health and social care research between 1995 and 2009. This was the first international review of the potential impact of PPI. The review highlighted the positive impact of PPI at all stages of the research process and the approach enabled research to be more relevant and appropriate, improving the quality and developing better relationships between researchers and the community. One of the key strengths of this view was the breath of the inclusion criteria, including studies of all designs and published and unpublished reports, providing the opportunity to broaden our understanding of the potential impact of the approach. However, the review did highlight there is a clear need to develop a more consistent and robust evidence base by enhancing the quality of reporting of PPI in health care research to enable the impact to be fully identified and evaluated (Brett, Staniszewska, Mockford, Herron-Marx, et al., 2014). Other authors have focused their reviews on the potential impact of PPI on specific elements of the research process.

A review completed by Domecq explored how to approach patient engagement in research, the benefits, harms and barriers to the model. This study concluded PPI is feasible in many settings, however it can often be tokenistic and research which aims to achieve engagement is lacking and clearly needed. The study team highlight the findings of their review might have been limited by the lack of uniformed reporting of PPI (Domecq et al., 2014). However, the conclusions reached mirror the concerns raised by others about the risk of tokenism when involving patients and members of the public in research (Hahn et al., 2017; Ocloo & Matthews, 2016a; Sangill, Buus, Hybholt, & Berring, 2019). Mockford explored the effect of the peer researcher approach, and identifying economic cost in their review of NHS health care between 1997 and 2009. The review indicated that PPI had a

range of impacts, but there was little evidence of any economic analysis of the costs involved. The study team completed an in-depth review by searching seventeen key online database as part of their study selection process. However, the findings of the review might have been limited by only including research conducted within the NHS in the United Kingdom, and therefore the results may not reflect the impact of PPI in other settings (Mockford et al., 2012). Reviews of rates of enrolment and retention in clinical trials (Crocker et al., 2018) and trial design and research materials (Oliver et al., 2004; Staley, 2009a) have suggested PPI has some positive impact. However, non-PPI activity may have contributed to this impact as the reviewers reported they were not able to separate out the effects of the different approaches. Therefore, the possible impact of non-PPI activities should be considered in future evaluations. Other authors have focused their reviews on specific populations in physical or mental health settings (Baldwin, Napier, Neville, & Wright-St Clair, 2018; Cukor et al., 2016; Di Lorito et al., 2017).

Cukor reviewed patient and other stakeholder engagement in studies of patients with kidney diseases and highlighted the importance of defining roles and engaging stakeholders, so they appreciate the value of their own participation (Cukor et al., 2016). Baldwin explored the impact of involving older people in health and social care research reporting the impact was mixed although benefits appeared to outweigh the challenges, and further consideration of how the approach was implemented was needed. However, as the review excluded articles that only reported reflections from academic researchers, the strength of the knowledge generated may have been limited by the inclusion criteria adopted by the study team (Baldwin et al., 2018). Di Lortito explored peer research for vulnerable adults with dementia and found seven records that involved patients undertaking research activities such as data collection or analysis alongside academics (Di Lorito et al., 2017). Of the seven identified studies, only two involved mental health services users (Miller et al., 2006; Rose, 2003)

whilst five involved dementia patients, older people or those with learning disabilities (Clough, Green, Hawkes, Raymond, & Bright, 2006; Littlechild, Tanner, & Hall, 2015; Scottish Dementia Working Group Research Sub-Group, 2014; Tanner, 2012; Walmsley, 2004). The study team attempted to strengthen the findings of their review by including studies with similar recruited populations to dementia patients, for example, learning disabilities and mental health service users. However, this approach may have weakened the conclusions reached by the review, as the experiences of these populations may have been similar, but not the same as patients with dementia. Sangill looked more broadly at the involvement of service users in mental health research completing a scoping review in 2019 to identify and evaluate empirical research as to how mental health service users partake in the research process. The review included 32 studies, and of the identified studies four involved researchers with lived experience in data collection either conducting survey tools (Croft, Ostrow, Italia, Camp-Bernard, & Jacobs, 2016; Kim, 2005; O'Donoghue et al., 2013) or contributing to the collection of self-report measures (Hancock, Bundy, Tamsett, & McMahon, 2012). Sangill's review concluded collaborative research in mental health required changes to traditional research practices to create and support genuine collaborative partnerships and therapy to avoid tokenism and power inequalities. However, despite the study team's efforts to strengthen the findings of their review by using the Critical Appraisal Skills Programme checklist (Singh, 2013) in their analysis, some highly collaborative studies were difficult to evaluate using this approach due to their complex study design, which may have limited the strengths of the findings of this review (Sangill et al., 2019).

To date no systematic reviews have been completed specifically about the involvement of data collectors with lived experience as the primary aim. This systematic review aims to build on the work of Sangill and others, to explore the inclusion of researchers

with lived experience as data collectors in mental health intervention research and the suggested impact of this approach.

2.2   Methods

The subsections below describe the screening and study selection process of the review, and the data extraction as well as the analysis that were conducted to explore the characteristics of the identified studies and the reported impact of the peer researcher approach.

2.2.1   Inclusion criteria

The eligibility criteria were broad to capture all types of mental health intervention studies that involved researchers with lived experience as data collectors. All study types, from both peer reviewed and none-peer reviewed literature were included, but discussion papers, editorials and dissertations were not. The focus of this review was to explore studies that included researchers with lived experience as data collectors in mental health intervention research. Therefore, studies that did not explicitly state this type of PPI involvement in the method section of the paper were excluded.

2.2.2   Information sources

This review followed the PRISMA statement (Liberati et al., 2009). A systematic literature search was completed in the following electronic databases: Medline, Embase, PsycEXTRA, PsycINFO, Criminal Justice Database and the Cohrane Library. In addition, the NIHR INVOLVE evidence library was searched for any papers pertaining to the impact of public involvement on health or public health research. The electronic databases and libraries were searched for the period from inception to May 2019 and limited to studies written in the English language. The search strategy was constructed by combining PPI terms identified through an initial scoping review and a range of mental health diagnosis.

The following combination of search terms were used in searching the databases:

("Peer researcher*" or "peer support*" or "peer interviewer*" or "patient and public involvement" or "PPI" or "PPIE" or "public participation" or "service#user researcher*" or "service#user involvement" or "community researcher*" or "community#based particpat*" or "co#research* co#production" or "consumer involvement" or "consumer#led" or "user#controlled" or "user involvement" or "user#led research" or "user tester" or "lay stakeholder" or "lay#researcher" or "stakeholder engagement" or "survivor#led" or "survivor#research*" or "participant-led" or "volunteer-researcher")

AND

(depress* or "anxiety disorder*" or "GAD" or "OCD" or "bipolar disor*" or "eating disorder*" or anorexi* or bulimi* or "substance abuse" or "substance use" or PTSD or post?trauma* or somatoform or "somatic symptom" or "schizo*" or "psychosis" or "psychotic" or "personality disorder" or ASPD or BPD or NPD or AVPD or "mental health" or psychopathology)

In addition, the journal of Research Involvement and Engagement was hand searched from its first issue in 2015 to May 2019 to identify studies which included researchers with lived experience as data collectors. Authors of included studies were contacted for further information about secondary papers.

2.2.3   Screening and study selection

After duplicates were removed, a total of 5794 references were identified and collated in citation files using Endnote software. Records were screened for published peer reviewed and non peer reviewed studies and 1,438 records were removed. Titles and abstracts of potentially eligible studies were screened, and 3,151 references were removed. 1,205 full

texts were then reviewed against the inclusion criteria. The reviewer was not blinded to the name(s) of the study author(s), their institution(s) or publication sources at any stage of the review.

2.2.4   Data extraction

Extracted data was entered into a database for comparison. The review concentrated on the characteristics of the studies which included researchers with lived experience as data collectors. The following was extracted for each study: aim, date, study type, data collection method, name of intervention, study population, sample size, setting, location, PPI term, demographic of PPI data collectors and description of additional PPI activities.

2.2.5   Analysis and synthesis of results

Two analyses were completed. Firstly, the characteristics of the studies were explored through comparison of the identified records and then the extracted data was reviewed to identifying common characteristics amongst the sample. Secondly, a thematic analysis was completed of each paper to identify themes across the studies to explore the potential impact of the approach. Braun and Clarke's six phase approach of thematic analysis was adopted. Firstly, all 25 papers were read and re read; initial ideas were noted down. See section 2.3 below. Secondly, initial inductive coding was completed by hand across the entire data set. Thirdly, codes were then collected into potential themes. Fourthly, all themes were checked against the codes extracted and the entire data set. Fifthly, specific themes were then refined to develop an overall story of the analysis and a clear definition of each theme and name were created. Finally, extracted examples of each theme were identified relating to the research question and were included in the final write up (Braun & Clarke, 2006).

2.3   Results

The search strategy identified 5,794 references. However, only 25 met the full inclusion criteria for the review. The 25 records included primary and secondary publications of 20 research studies that adopted the peer researcher approach, involving researchers with lived experience as data collectors, and reported their methodology in either a peer reviewed or nonpeer reviewed journal. A PRISMA flow diagram of records included at each stage of the screening process is included in appendix A. The characteristics of the identified studies and the reported impact of the adoption of the peer researcher approach are described below.

2.3.1   Study characteristics

There were broad similarities across the 20 research studies reported in the 25 identified records. All of the studies aimed to explore the effectiveness of a mental health intervention and the majority of the studies were based in a health setting in the United Kingdom. A qualitative methodology was adopted for most of the identified records and the peer researchers were involved in conducting interviews, focus groups or telephone interview surveys with the participants. Almost all of the studies involved adult populations, with only one record exploring the effectiveness of a mental health intervention for teenagers. Despite the similarities, there were differences across the identified records.

The most notably difference was the range of the recruited sample size which varied from 3,909 participants, for a national study, to one participant in a case study report. Although the majority of the studies involved the collection of qualitative data, the design of the studies varied, with five studies adopting a mixed methods approach and only two of these studies using randomised control trials. The description of the researchers was consistent across the studies with the authors describing all data collectors as having lived experience. However, the range of terms used was vast. The majority of studies adopted a

term that highlighted the researchers' shared lived experience for example "peer researcher" or "peer interviewer". Whilst others linked their title to the researchers' involvement with services adopting terms such as "user researcher" or "lived experience co – facilitators". In contrast, one study used a traditional term of "research associate" and did not refer to the researcher's lived experience in their job title.

Finally, the records described a range of different areas of the research process that the peer researchers contributed to. For the majority of the studies, in addition to data collection, which was the focus of this review, the researchers also supported the analysis of the data. However, for other studies the researchers with lived experience were involved in the initial planning stages and writing up of the findings. In four studies, the peer researchers were not involved in any other stages of the research process beyond data collection. Appendix B outlines the characteristics of all the twenty-five identified records. The study aims, setting, methodology and type of patient and public involvement are explored in more detail in the subsections below.

2.3.1.1 Study aims and setting

This review aimed to identify mental health intervention studies and therefore most of the research was conducted in a health setting; twenty-two in mental health and two in a forensic mental health hospital. Only one study was implemented outside of a health setting exploring the effectiveness of a psychosocial mental health promotion workshop in a secondary school in the North West of England (Campbell, Shryane, Byrne, & Morrison, 2011). Without exception, all studies aimed to explore the experience of the patients who accessed support.

Although the inclusion criteria specified a mental health intervention, the results of this review included a wide range of studies. Two studies included researchers with lived

experience to explore the effectiveness of medication (Pinfold et al., 2019; Stevenson et al., 2016), two on self-referral (Olsø et al., 2016; Rise et al., 2014) and two on compulsory interventions under a mental health act (Barnes, Davis, & Tew, 2000; Ridley & Hunter, 2013). Of the identified records one study explored the effectiveness of a workshop (Campbell et al., 2011) and another on programme interventions and treatment planning (Livingston, Nijdam-Jones, Lapsley, Calderwood, & Brink, 2013). Three studies investigated mental health interventions which involved technology including a smart phone application (Korsbek & Tønder, 2016); barcode medication administration (Strudwick, Clark, McBride, Sakal, & Kalia, 2017) and a mental health patient portal (Leung, Clark, Sakal, Friesen, & Strudwick, 2019). In addition to the involvement of patients and members of the public in the data collection process, five of the studies also included peer support as part of the mental health intervention (Barber, Rosenheck, Armstrong, & Resnick, 2008; Bocking et al., 2018; Crain et al., 2009; Livingston, Nijdam-Jones, & Team, 2013; Siantz, Henwood, McGovern, Greene, & Gilmer, 2019).

The oldest study included in this review was published in 2000 in the United Kingdom exploring how the use of compulsion affects relationships with the patient's mental health worker (Barnes et al., 2000). There was an increase in the number of published papers from 2014, with over half of the studies published from this date onwards. As only papers written in English were included in the review it is unsurprising that just under half of the studies were implemented in the United Kingdom: (Barnes et al., 2000; Campbell et al., 2011; Gillard, Simons, Turner, Lucock, & Edwards, 2012; Gillard, White, Miller, & Turner, 2015; Hart, Saunders, & Thomas, 2005; Milton et al., 2017; Pinfold et al., 2019; Ridley & Hunter, 2013; Sampogna et al., 2017; Stevenson et al., 2016; Tew, 2008); five in Canada (Crain et al., 2009; Leung et al., 2019; Livingston, Nijdam-Jones, Lapsley, et al., 2013; Livingston, Nijdam-Jones, & Team, 2013; Strudwick et al., 2017); two in Australia (Bocking

et al., 2018; Fletcher et al., 2019) and two in the United States (Barber et al., 2008; Siantz et al., 2019). One fifth of the studies were carried out in Scandinavia, but also published in English and therefore met the criteria for the review (Biringer, Davidson, Sundfør, Ruud, & Borg, 2017; Korsbek & Tønder, 2016; Olsø et al., 2016; Rise et al., 2014; Stevenson et al., 2016).

2.3.1.2 Study methodology

Most of the studies were qualitative, involving interviews, focus groups or telephone interview surveys. Five studies adopted a mixed methods approach with a combination of interview and questionnaire data collected by the peers (Gillard et al., 2012; Leung et al., 2019; Livingston, Nijdam-Jones, Lapsley, et al., 2013; Milton et al., 2017; Stevenson et al., 2016) and two studies collected only quantitative data (Barber et al., 2008; Campbell et al., 2011). Of the twenty-five studies included in the review, there were two randomised control trials, one quantitative (Campbell et al., 2011) and one qualitative (Rise et al., 2014). All except one of the studies included adult participants (Campbell et al., 2011). In line with the criteria for the review all participants were accessing mental health support at the time of recruitment or had previously accessed support. Two studies recruited their population from a forensic hospital (Livingston, Nijdam-Jones, Lapsley, et al., 2013; Livingston, Nijdam-Jones, & Team, 2013) and one specifically from an inpatient ward (Fletcher et al., 2019). The remaining studies were based in the community.

Sample size varied significantly amongst the identified studies. The largest recruitment sample was 3,909 for a study that explored the impact of an anti-stigma programme on coping strategies over four years between 2011 and 2014. In this study, peer interviewers conducted telephone interview surveys with adults with a diagnosis of a mental health disorder (Sampogna et al., 2017). Another large-scale study recruited 1,847

participants over a 2-year period who were war veterans with chronic psychiatric disorders. Peer facilitators collected questionnaire data to explore the dissemination of peer support for this study (Barber et al., 2008). Amongst the identified studies, the smallest recruited sample was for a case study of a 42-year-old man with schizophrenia and the effectiveness of Individual Placement Support for serious mental illness (Crain et al., 2009). The population sample for the remaining studies ranged from 11 to 227.

2.3.1.3   Patient and public involvement

The studies used a variety of terms to refer to the patients and members of the public who were involved in the collection of data. The majority adopted the term "peer researcher", "peer facilitator" or "peer interviewer" specifically highlighting the shared lived experience between the participant and the data collector (Barber et al., 2008; Crain et al., 2009; Leung et al., 2019; Livingston, Nijdam-Jones, Lapsley, et al., 2013; Livingston, Nijdam-Jones, & Team, 2013; Milton et al., 2017; Pinfold et al., 2019; Ridley & Hunter, 2013; Sampogna et al., 2017; Siantz et al., 2019; Stevenson et al., 2016; Strudwick et al., 2017). A smaller number of studies used "service user researcher", "user member" or "consumer researcher" linking an individual's involvement with services to their job title (Barnes et al., 2000; Bocking et al., 2018; Campbell et al., 2011; Gillard et al., 2012; Gillard et al., 2015; Hart et al., 2005; Stevenson et al., 2016; Tew, 2008). Only two studies chose to include "lived experience" (Fletcher et al., 2019; Korsbek & Tønder, 2016) despite the phrase commonly being used in the literature to describe the methodology (Given, 2008). Interestingly one study did not adopt a specific PPI term, but used a traditional job title of "research associate" in both papers to describe the researcher with lived experience (Olsø et al., 2016; Rise et al., 2014). The descriptions included in each of the papers to define the demographics of the data collectors were consistent. Most studies described a group of researchers with lived experience of mental health services, although some specified in addition the researcher had

participated in the intervention which was being evaluated (Barber et al., 2008; Crain et al., 2009; Livingston, Nijdam-Jones, Lapsley, et al., 2013; Stevenson et al., 2016) and in two studies had previous research or PPI experience (Bocking et al., 2018; Siantz et al., 2019).

This review found for most studies, members of the research team with lived experience participated in additional elements of the research process beyond data collection. Contributing to data analysis was the most common role with ten research teams involving the peers in this aspect of the research process. However, only four studies involved these researchers in the writing stage and reporting of the findings (Biringer et al., 2017; Crain et al., 2009; Rise et al., 2014; Stevenson et al., 2016). PPI involvement has typically been part of the planning stages as traditional researchers consult patients about study design and research materials (Boote, Baird, & Beecroft, 2010) and this was also the case for a quarter of the selected studies. However, although peers were consulted on their opinions only one study described a PPI leadership role (Hart et al., 2005).

2.3.2   Impact

A thematic analysis of each of the identified papers was also completed to explore the impact of the involvement of researchers with lived experience as data collectors on a research study and the individuals involved in the process. The analysis produced two themes; adopting the peer researcher approach and patient and public involvement in action.

For most studies, the authors' expectations of adopting the peer researcher model were met, and the approach had a positive impact on the quality of the data collected. The identified records described how participants felt more able to share honest answers, and the peer researchers themselves benefited from the interaction. The authors explained how the involvement of researchers with lived experience bought real value and potential for mental health research. However, some authors highlighted the potential complexity of adopting the

approach due to navigating different standpoints about how to implement the research study. Moreover, some records reported due to the lack of the peer researchers' experience, the adoption of the approach might have led to a reduction in the quality of the research because of poor data collection techniques.

The study team explained how the involvement of researchers with lived experience provided an opportunity for co-production, with shared learning leading to examples of shared decision-making at all stages of the research process. The identified records highlighted examples of how the traditional researchers and peer researchers worked together to develop the study protocol and training manuals for the data collectors. In addition, one study suggested how the experience provided the peer researchers with the opportunity to learn about the delivery of mental health services from the perspective of the clinical service instead of the patient. Trust between both groups of researchers was described as important to support this translation of knowledge. However, despite the examples of shared decision-making, there were limited reports of how disagreements were managed and when these scenarios were described the study teams highlighted the complexities of navigating these situations. The identified themes and sub themes are set out by domain in appendix C, and described in more detail below.

2.3.2.1   Theme: Adopting the peer researcher approach

The first theme explored the research teams' expectations and the reported impact of adopting the peer researcher approach. Authors described how they expected the involvement of researchers with lived experience would improve the quality of the data and the interpretation of the findings because the research participants would feel more comfortable and therefore more able to give honest answers. The discussion sections of the records reported the involvement of researchers with lived experience as data collectors did improve

the quality of the study. However, the authors raised concerns about the peer researchers'
lack of experience, and for one study the involvement of the peer researchers created a
sampling bias highlighting the potential complexity of adopting this approach. The two sub
themes are described below and include: Expectations and Impact.

2.3.2.1.1 Sub theme: Expectations

Each of the twenty-five records included in this review involved patients and
members of the public as data collectors. Several studies suggested the expected impact of
the involvement of peers as data collectors would improve the quality of the data collected
and interpretation of findings.

"Our approach was based on a belief that the quality of evidence would be enhanced if the
research was conducted with service users" (Bocking et al., 2018).

"The research was carried out in partnership with mental health service users in line with the
now well-established argument that better quality mental health research is produced when
people are involved in the process" (Ridley & Hunter, 2013).

Some of the research teams described their expectations in more depth explaining
how they predicted the involvement of researchers with lived experience as data collectors
would improve the quality of the research study as the involvement of patients and members
of the public could create an ethos of relative equality and breaking down power imbalances.

"It seemed clear to all of us that service users would be better placed to take on this position of
interviewer and listener. Capitalizing on the possibility that they might be able to create an
ethos of relative equality in terms of power relations, free from any baggage of expert or
professional roles, under pinned by some degree of shared understanding of what it is like to
have been through the system" (Tew, 2008).

Leung and Pinfold highlighted how the experience of meeting with a peer may enable a research participant to feel more comfortable and therefore more able to give honest answers.

"Previous research has indicated that patients may feel more comfortable answering questions when asked by a peer, and provide more honest response to questions" (Leung et al., 2019).

"For data collection, a methodology that has been described as peer research was employed, designed to enable peer researchers to illicit accounts through qualitative interviews with participants by drawing on their own experience and reflecting upon them again within the data analysis phase" (Pinfold et al., 2019).

In addition, other authors suggested the approach may have a positive impact on recruitment and engagement rates.

"The inclusion of lived experience co-facilitators was designed to improve recruitment and engagement with participants and enhance the quality of the discussion" (Fletcher et al., 2019).

2.3.2.1.2   Sub theme: Impact

In the discussion sections of the papers, the research teams reflected on the impact of adopting the approach in their work. In line with original expectations, some authors felt the inclusion of researchers with lived experience as data collectors did improve the quality of the study.

"The major strengths include our use of participatory action research approach and qualitative techniques to ensure methodological quality" (Livingston, Nijdam-Jones, & Team, 2013).

"User participation during the research process strengthen the authenticity of the results and helps ensure the users voices are heard" (Rise et al., 2014).

The academic staff and the peers themselves explained the participants felt able to be more honest and relaxed with the researchers because of their shared experience.

"The interviewers reported that their degree of shared experience helped the development of a rapport with interviewees and that their own nervousness about interviewing meant that interviewees did not themselves feel intimated (Barnes et al., 2000).

"The use of peer interviewers for service users and carer interviews may have helped participants to feel comfortable and speak frankly" (Milton et al., 2017).

Strudwick and Siantz expanded on this idea, highlighting how the approach had the potential to normalize stigmatized experiences, which supported engagement.

"The role focuses on seeing an individual as an expert in their life experiences and the worker often helps normalize stigmatized experiences" (Strudwick et al., 2017).

"For many participants, being in an environment with other persons who have mental illness and peer-staff normalized the experience of having an illness" (Siantz et al., 2019).

Barnes reported that for some participants the involvement of a researcher with lived experience was essential to their involvement in the project.

"Some interviewees said they would not have taken part if the interviewer had not been a service user" (Barnes et al., 2000).

The peers also positively described their personal experiences of meeting with participants to collect data. The peer researchers explained how rewarding and inspiring the process was.

"A majority of the interviewers found their commission rewarding and positive. The interviews had been inspiring and fun to do, and it was contributing and interesting to talk to the users" (Stevenson et al., 2016).

Despite the positive examples, some study teams highlighted the challenges of adopting the methodology. It was suggested the peers' lack of experience of conducting interviews might have had an impact on the quality of data collected.

"There were also challenges to using this approach. Conducting semi-structured interviews was a new experience for the peer interviewers and despite having received training, the lack of previous experience in conducting qualitative interviews may have impacted the data quality" (Siantz et al., 2019).

Livingston's study suggested the involvement of peer researchers as data collectors might have created a sampling bias as some participants were reluctant to be interviewed by a researcher with lived experience.

"The PAR approach may have created a sampling and response bias. We are aware that some service providers were reluctant to participate in the interviews because of their discomfort disclosing certain information to the patient interviewers" (Livingston, Nijdam-Jones, & Team, 2013).

The complexity of PPI and navigating different standpoints about preconceived ideas of conducting and being involved in research was highlighted as another potential barrier.

"Bringing their experience and expertise together was not necessarily a straight forward process as the situation in which we had gained experience was located in very different standpoints" (Tew, 2008).

Gillard expanded on this concept in more detail describing how under some circumstances the involvement of peers in the research process had directly challenged some of the academic conventions of conducting mental health research, changing the design of the study.

"The reflective process undertaken by the team suggested the service user involvement not only added 'expertise by experience' to the research process but also to some extent had changed the process. Some of the academic conventions of doing research about mental health had been challenged, and there was something different about the way the research had been done as a result" (Gillard et al., 2012).

Despite the challenges, the findings from the identified studies concluded the involvement of researchers with lived experience as data collectors still had real value and potential for mental health research.

"The participatory action research approach used in this study demonstrated the value and real potential of involving forensic mental health patients in research" (Livingston, Nijdam-Jones, & Team, 2013).

"These findings, along with the growing evidence base in this area, suggest that service users should be involved in mental health promotion" (Campbell, 2009).

2.3.2.2   Theme: PPI in action

The second theme explored PPI in action. The first sub theme explored the opportunity of learning together from the perspective of both the peer researchers and traditional researchers was highlighted. The authors of 19 of the identified records reflected on the translation of knowledge through shared learning. The exchange of ideas through a common agenda was described as mutually beneficial for the researchers with lived experience and the traditional researcher during the study. The authors explained how the peers shared their knowledge to develop the trial protocol, and traditional researchers

supported the peers to develop their research skills. The second sub theme explored how decisions about the research study were made together with the peer researchers through a process of shared decision making. Eight out of the 25 records reported examples of when patients or members of the public were part of the decision-making process at each stage, from design to analysis and the interpretation of the data. Although there were several examples of shared decision making described in the identified records, there were limited descriptions of how disagreements were resolved. Despite this limitation, the research teams highlighted the importance of building trust between the peer researchers and traditional researchers to enable the shared decision making process. The involvement of the peers in decisions about the qualitative studies was described as integral. The two quantitative studies did not report examples of co-production and therefore were not included in this part of the analysis. The two sub themes are described below and include: Learning together and Shared decision making.

2.3.2.2.1 Sub theme: Learning together

The authors of the identified studies described how the involvement of researchers with lived experience was mutually beneficial for both groups of researchers. The adoption of the approach was an opportunity for the peer researchers and research assistants to grow and share ideas to develop the research study.

"The role is unique from other clinical roles since there is an acknowledgment that the peer support process is of mutual benefit, with both the peer and the worker learning and growing together" (Strudwick et al., 2017).

"Through reflexive collaboration and exchange of ideas with service users driving the entire research process we aim to expand our understanding of the lived experience of the

participants to provide a context for the readers' understanding of the findings" (Biringer et al., 2017).

This translation of knowledge between the peer and traditional researchers developed the study protocol in all areas. Training of the peers who would be meeting with participants to collect data was a significant part of the step-up process from patient to data collector for the identified studies, as in most cases the peers had not completed interviews or collected outcome data before. Two studies provided examples of how the traditional researchers shared their interviewing skills with the peer researchers who in turn shared their knowledge with other peers as part of the training process.

"Each interviewer participated in at least 3 mock interviews and received feedback from both the evaluation team and the peer providers to strengthen their skills" (Siantz et al., 2019).

"The interview was demonstrated by the course lead in a role play where one of the participants of the course was interviewed. Finally, the participants trained the interview in practice by interviewing each other. This experience of training was then discussed" (Svensson & Hansson, 2006).

In addition to the training, other studies described how following feedback from the peers to the academic researchers the protocol was amended to ensure the data collectors were able to access support if they needed to.

"Some of the interviewers felt burdened by the case histories they took in as part of listening to the users. A suggestion that came up was that if the investigation should be repeated, an easily accessible support person should be available if some needed to talk things over" (Svensson & Hansson, 2006).

"Working with people who had themselves had experience of hospital admission in designing and carrying out the research helped to ensure that interviews reflected issues of concern to service users" (Barnes et al., 2000).

During the planning stages, the peers also had the opportunity to learn from the academic researchers about the delivery of mental health interventions, reflecting on their own experiences and learning from others.

"The entire process took almost 2 years, during which the peer researchers gained rich insight into treatment planning at the forensic hospital reflecting on their experience and learning about the experiences of others" (Livingston, Nijdam-Jones, & Team, 2013).

Sharing learning and practice between academic researchers and researchers with lived experience was suggested as an opportunity to develop practice. Several of the papers concluded with the importance of continuing to work together to develop good practice for future research.

"The study serves to raise and question for both service delivery and future research; we plan to pursue the latter in the context of developing relationships between user and academic researcher" (Barnes et al., 2000).

"To optimize the impact of service users can have on such campaigns it is advised that contract involves group work to allow more direct interpersonal interactions to take place" (Campbell et al., 2011).

2.3.2.2.2 Sub theme: Shared decision making

The second sub theme explored Shared Decision Making. Peers were involved in the planning stages for some of the research studies, working with the traditional researchers to

make joint decisions about the design of the study as well as being involved in the data collection phase.

"The research team agreed the design; content and conduct of interviews and all interviews were undertaken by user members of the team" (Barnes et al., 2000).

"Together with academic researchers, the peer researchers spent almost two years planning, designing, and carrying out this study on treatment planning" (Livingston, Nijdam-Jones, & Team, 2013).

As described in appendix B, the researchers with lived experience contributed to the development of research materials for eight studies. The adoption of a Shared Decision Making approach to develop interview guides and questionnaires provided the opportunity for the instruments to reflect the issues of real concern for the service users.

"The topics covered were developed by the peer researchers, with guidance from the professional researchers. Interviewees raised the issue of decisions about infant feeing in early interviews and this was subsequently incorporated into the topic guide" (Stevenson et al., 2016).

In addition to the peers being involved in the initial planning stages, there were several examples of when study teams included patients and members of the public in decisions about the analysis of the qualitative data they had collected.

"Each of the professional researchers examined three transcripts in detail and developed their own coding framework. These were examined in a half day data clinic in which all the team members (professional and peer) presented their individual analyses. A joint coding framework was then agreed and then applied" (Stevenson et al., 2016).

In some studies the peers were also involved in identifying the overarching themes, thematic maps and theme titles in preparation for write up.

"During three workshops MB, BS (PPI) and EB together reviewed these preliminary codes and refined them into a thematic map, which all members of the group found appropriate. The text material within the theme 'expectations' and 'aims' were read and then analysed and discussed in the group" (Biringer et al., 2017).

"During the third coding cycle, the peer researchers confirmed the overarching themes and assigned a title to each category" (Livingston, Nijdam-Jones, & Team, 2013).

In the final stages of the research process, the peers were involved in decisions to confirm the qualitative data had been appropriately interpreted. Several examples of researchers with lived experience being given the opportunity to comment on qualitative preliminary results were included in the identified studies.

"Peer interviewers were presented the findings to help clarify and confirm that the study team appropriately interpreted the data. As part of the meeting, interviews participated in a discussion with the evaluation team to gleam their impression of the interview process and to note the themes and findings that stood out for them" (Siantz et al., 2019).

"The process of drafting a report was undertaken in chunks by each of the academic researchers. As drafts of the work started to be written up, these were checked out in further meetings with the service user researchers to ensure that they still rang true to their sense of what was significant" (Barnes et al., 2000).

Fletcher elaborated further by highlighting the importance of the involvement of the peers in the analysis of the data in their study into acute mental health wards in Australia.

"Co-facilitators also assisted in data analysis, this enabling an ongoing lived experience perspective during the analysis and identification of findings" (Fletcher et al., 2019).

Although there were extensive examples of the peers being given the opportunity to contribute to the decisions about the design of the study and how the data they had collected was interpreted, there was limited reference to how disagreements were managed. Two authors did touch on the subject and suggested how these scenarios could become challenging.

"During these discussions the group members' preconceptions and interpretations about semantic and latent constructs underlying the material sometimes were challenges by the other members of the group" (Biringer et al., 2017).

"Researchers were at times concerned about the impact their personal interpretation might be having on the analytical decision-making process" (Gillard et al., 2012).

To overcome some of these challenges, Pinfold highlighted the importance of developing trust between the peer researchers and the rest of the study team to support the decision making process.

"Peer researchers identified the importance of trust and developing a therapeutic relationship to support decision making" (Pinfold et al., 2019).

It is important to note, that it was not possible to fully conclude the degree to which the peers were involved in shared decision making from only analysing the information which was available in the published papers themselves as the review is reliant on the study teams' accounts of the process. However, from the evidence which was available in this review, the degree to which patients and members of the public were involved in the decision making process varied across studies but was considered to be an integral part of the process.

"Service user and carer researchers were integral to the decision-making process and about coding interview data alongside other members of the team" (Gillard et al., 2012).

"Further studies should also include peer interviewers to build rapport with study participants and to ensure that the right questions are being asked" (Siantz et al., 2019).

2.4   Discussion

The review aimed to explore the characteristics of studies which involved researchers with lived experience as data collectors, and the reported impact of adopting the approach to make a contribution to current knowledge about the overarching position of PPI in health care research. The results of the systematic literature review included 25 records, which reported the evaluation of a range of mental health interventions involving peer researchers with lived experience as data collectors across 20 research studies. The review only identified 20 studies in the last nineteen years, with the earliest paper published in 2000 in the United Kingdom (Barnes et al., 2000) suggesting the approach is relatively innovative. Despite the limited amount of studies identified, the timeline for publication of the studies which have adopted the approach does fit with the policy direction of the Department of Health (Department of Health, 1998a, 2010) and the development of the growing evidence base (National Institue for Health Research, 2019). Sample sizes varied significantly, and so did the job titles given to the data collectors with lived experience. However, despite these differences, the design of the majority of studies involved the collection of qualitative data from adult populations in a health setting in the United Kingdom. For most of the studies identified, the peers were involved in a range of research tasks in addition to collecting data, with contributing to the interpretation of the findings as the most common additional form of involvement. Some concerns were raised about the peers' lack of experience of conducting interviews. This may have had an impact on the quality of data collected, and for one study created a sampling

bias. However, overall the research teams reported the involvement of peer researchers as data collectors had a positive impact on the evaluation of mental health interventions, and strengthened the quality of the data collected.

The results of this review produced 13 different job titles across 20 research studies for patients and members of the public who collected participant data, and the study teams did not report a justification for the type of term they adopted. The majority of research studies adopted a PPI term that highlighted the researcher's shared lived experience with the participant. Other authors linked an individual's involvement with services and their job title, and only two adopted a term that included "lived experience" despite this phrase being frequently used in the literature (Given, 2008). One study did not adopt a specific PPI term, but used a traditional job title of "research associate" to describe the researcher with lived experience. The use of inconsistent terms is significantly different from the established academic titles and ranks that are widely adopted by traditional researchers in the United Kingdom. The lack of consistent terminology use in the literature (Charles & DeMaio, 1993) means it is difficult to meet the recommendation to consolidate learning highlighted in the NIHR Taking Stock report from 2019 (National Institue for Health Research, 2019). This systematic review attempted to overcome some of these challenges by including 26 PPI terms in the search strategy that were identified through an initial scoping review. However, despite the author's efforts, this review may still not have captured the full breath of the PPI terms used by research teams when involving researchers with lived experience as data collectors.

The majority of the studies included in the review adopted a qualitative methodology either completing interviews over the phone or in person. Five studies adopted a mixed methods approach and only two studies involved the collection of quantitative data. It is un surprising that the majority of studies involved the collection of qualitative data as this

approach lends itself more to the involvement of researchers with lived experience, as the relationship which is developed through shared understanding provides the opportunity to build trust during the interview process and improve the quality of the data collected (INVOLVE, 2013). However, despite this view, to explore the full potential impact of PPI to improve the quality of health research it is also necessary for peer researchers to be involved in the collection of quantitative data and to share learning from these experiences. This is particularly important when exploring the impact of PPI on mental health intervention studies as large-scale randomised control trials are considered the gold standard for effectiveness research (Hulley, 2007).

The majority of the identified studies recruited adult populations in health settings. There was only one study, which included peer researchers under the age of eighteen exploring a mental health promotion approach to reducing discrimination about psychosis in teenagers (Campbell et al., 2011). Due to the ethical and potential practical implications of employing young people or children to interview their peers this finding is not surprising. However, there is a promising emerging literature about peer delivery of health interventions for young people (Harden, Oakley, & Oliver, 2001). Furthermore, researchers are starting to explore this approach in more depth (Bradbury-Jones & Taylor, 2015) and therefore involving young people with lived experience in future studies as data collectors could potentially be a beneficial approach for study teams to consider. Moreover, only one of the identified studies involved a forensic population, recruiting participants who had received treatment for at least one month at a forensic hospital, recruiting a sample of 25 participants. To meet criteria for the role, the peer researchers had to have lived experience of forensic hospital as a patient enabling them to have that shared lived experience with the research participant (Livingston, Nijdam-Jones, & Team, 2013). However, none of the identified studies involved the recruitment of participants or peer researcher who had served a custodial

or community sentence, despite there being a higher prevalence of mental health issues amongst offenders and fewer services available compared to the general population (The National Institute for Health and Care Excellence, 2018).

The studies which did report their motivation for involving researchers with lived experience as data collectors suggested the adoption of the approach would improve the quality of data collected and interpretation of findings (Bocking et al., 2018; Crain et al., 2009; Ridley & Hunter, 2013; Siantz et al., 2019). In line with the anticipated impact, several of the research teams reported the involvement of the researchers with lived experience meant the participants felt able to be more honest and relaxed with the researcher because of their lived experience (Barnes et al., 2000; Milton et al., 2017; Stevenson et al., 2016). The findings from this review did suggest the quality of the data collected improved due to the inclusion of researchers with lived experience (Campbell et al., 2011; Livingston, Nijdam-Jones, & Team, 2013; Rise et al., 2014). The study teams reported participants felt more relaxed and therefore were able to give honest and open answers. In addition, the identified records described opportunities to share knowledge and in some cases the peer researchers were involved in a Shared Decision Making process to develop and implement the study protocol.

The translation of knowledge described in the identified records are examples of breaking down barriers between two groups, and a step away from a culture of us and them bridging the gap between those who deliver and those who access services. Despite the positive examples, it was suggested the approach might have also had a negative impact on the quality of the data collected for some studies. Some of the study teams raised concerns about the peer researchers' data collection skills, as they may not have conducted interviews or collected outcome measures before (Siantz et al., 2019) and the risk of bias (Livingston,

Nijdam-Jones, & Team, 2013). Although the peer researchers were provided with training before meeting with a participant, the scope would have been considerably different from the training and guidance which most research assistants receive during a three year undergraduate psychology degree. However, it is important not to assume that a peer researcher had not completed similar training at university level, as the educational qualifications for the researchers were not reported in the published articles. In addition, the type of supervision available for the peer researchers was not reported and therefore is it is not possible to assess the quality of the support available.

Patient and public involvement in research is defined as "researcher being carried out with or by members of the public, rather to, about or for them" (Health Research Authority, 2021). Working together, is therefore a central component of the approach. However, there were limited reports of how disagreements and conflict were managed (Biringer et al., 2017; Gillard et al., 2012). Tew explore these challenges in their paper highlighting the need to generate a broader knowledge base, and concluding "while the process of collaboration was generally positive for both service user and academic researchers, power imbalances could skew relationships and impact adversely on the potential value of the research" (Tew, 2008). It could be suggested conflict between the two groups would be inevitable due to different life experiences and the coming together of two different worlds. However, the authors reported several examples of shared learning and decision making and therefore a clash of perspectives may not be an inventible outcome for the involvement of researchers with lived experience.

Finally, one concern raised by Sangill and others regarding the involvement of researchers with lived experience relates to the issue of tokenism (Hahn et al., 2017; Ocloo & Matthews, 2016a; Sangill et al., 2019) which Domecq highlighted in their systematic review

as a "false appearance of inclusiveness" (Domecq et al., 2014). The concept of tokenism is explored by Arnstein ladder of citizen participation model where they explain "there is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process" (Arnstein, 1969). There is therefore the risk that patients and members of the public are involved in the development and delivery of health care research are powerless to affect the direction of the research, and "participation remains just a window-dressing ritual" (Arnstein, 1969). However, this does not appear to have been the case for patients and members of the public who contributed to the studies included in this systematic review, as 21 of the 25 records reported additional involvement of the researchers with lived experience beyond data collection. These findings are in line with a recent review of patient and public involvement in NIHR research between 2006 and 2019 which found there is a general sense that concerns about tokenism are less prevalent than in 2006 when the NIHR was established (Russell, Greenhalgh, & Taylor, 2019). However, although these findings are encouraging, involvement does not necessarily mean participation. In addition, as only one of the records included the direct experiences of a researcher with lived experience the majority of reported rates of participation were from the perspective of the traditional researchers. It is, therefore, not possible to draw conclusions about the degree to which patients and members of the public felt they were given real power to affect the outcome of the process.

2.4.1   Strengths and limitations

To the author's knowledge, this is the first attempt to explore the characteristics and impact of PPI as data collectors on mental health intervention studies. The study adopted a comprehensive and sensitive search strategy that spanned across multiple databases. Following the initial scoping review, 26 PPI terms and 24 mental health diagnosis were

combined to search seven online databases and one journal. However, the review also has

several limitations. The search returned a high number of results which strengthened the

findings. However, as there was only one reviewer there was an increased risk of error. In

addition, the reviewer was not blind to the name(s) of the study author(s), their institution(s)

or publication sources at any stage of the review. Due to the range of terminology used to

refer to a data collector with lived experience it may be possible that some studies were

missed in the initial search which could have biased the results of the review towards specific

disciplines. Only papers published in peer and non peer reviewed publications written in

English were included which could have limited the knowledge generated by the review.

There is therefore no guarantee that every relevant document has been identified. It is also

possible that relevant information on this topic may not have been published due to the

significant involvement of third sector organizations in this field.

2.5   Conclusion

The findings from this review highlight the differences and similarities in the type of

studies which have included researchers with lived experience as data collectors, and the

steady increase of the number of research teams who have adopted this approach. To date the

approach has generally been used in qualitative research in a health care setting with adult

populations. Only two quantitative studies were identified by the review (Barber et al., 2008;

Campbell et al., 2011). This study found, involving researchers with lived experience as data

collectors had a positive impact on the quality of the research; the experience of the

participants and the peers themselves. However, there is a considerable amount of work to be

done to define the terms we use when involving patients and members of the public in

research. Findings from the review support the understanding that we are moving away from

tokenism as examples of PPI were reported for a range of research tasks in addition to data

collection. For the majority of studies researchers with lived experience were involved in data

analysis, but examples of PPI in developing research documents and writing reports were also reported. However, this encouraging finding must continue to be monitored and the voices of those researchers with lived experience to be actively included, to support the development of meaningful PPI roles. Despite the positive outcomes, further research is needed to understand the full impact of the approach to support researchers from all backgrounds to navigate the challenges of involving researchers with lived experience as data collectors in mental health intervention research, and to ensure adequate training and support is offered to fully explore the potential of this approach.

CHAPTER 3 MOAM case study

This chapter describes the case study that is the focus of the thesis, Mentalization for Offending Adult Males (MOAM). The MOAM trial was funded by the National Institute for Health research (NIHR) and was led by Professor Peter Fonagy at University College London (UCL). Following NHS Research Ethics Committee (NHS REC) and Her Majesty's Prison and Probation Service National Research Committee (HMPPS NRC) approval the trial launched in January 2016 and will report to the NIHR in 2021. The study recruited male participants who met threshold for anti-social personality disorder (ASPD) under supervision of the national probation service (NPS) across 13 sites in England and Wales, and aimed to explore the effectiveness of Mentalization Based Therapy (MBT) in reducing rates of aggression for this population. A key component of the design of the trial was the involvement of data collectors with lived experience of either a custodial or a community sentence, known as peer researchers (Fonagy et al., 2020). The design of the study and the role of the peer researchers in this multi-site randomised control trial is described in the sub sections of this chapter below.

3.1   Background

The MOAM trial aimed to explore the effectiveness of MBT to reduce rates of aggressive behaviour amongst a sample of male participants who met threshold for ASPD, and at the time of recruitment were aged 21 years or older and under supervision of the NPS. DSM-IV characterises ASPD as a pervasive pattern of disregard for and violation of the rights of others that has been occurring in the person since the age of 15 years, as indicated by three or more of the seven identified behaviours. Possible behavioural examples could include a failure to conform to social norms; irresponsibility; deceitfulness; indifference to the welfare of others; recklessness; a failure to plan and irritability and aggressiveness (APA, 2000) . The prevalence of the disorder is disproportionately higher amongst the prison

population with between 2% and 3% among community samples, rising to 60% among male prisoners (Moran, 1999) and there is a disproportionately fewer number of mental health services available to individuals serving prison or community sentences (Bradley, 2009). In addition, rates of violent and aggressive crime are associated with a range of negative impacts for society as whole (Dolan & Peasgood, 2007), and recognised by the World Health Organisation (WHO, 2002) and the Department of Health (Bellis, Hughes, Perkins, & Bennett, 2012) as a major public health priority. The Offender Personality Disorder (OPD) pathway initiated in 2011 aims to address these inequalities and reduce reoffending rates by increasing access to appropriate support to improve the psychological health, wellbeing and relational skills of offenders likely to be diagnosed with a personality disorder (Skett & Lewis, 2019). MBT was one of the services funded by NHS England and the National Offender Management Service (NOMS) as part of the OPD pathway, and was rolled out across 13 sites in England and Wales in 2014. The MOAM trial aimed to evaluate the effectiveness of MBT across these 13 sites to reduce rates of aggression for male offenders under supervision of the NPS and to support the aims of the OPD pathway by contributing to the developing evidence base for the management of this high-risk population.

3.2   Aim

The aim of the trial was to conduct a multi-site randomised control trial in a real life NHS setting to investigate whether, in a sample of offenders under community supervision who met DSM-IV criteria for ASPD, Probation as usual (PAU) supplemented with MBT is more effective and cost effective than the standard care pathway of PAU only.

3.3   Design

The MOAM trial was a pragmatic, multi-site single blinded randomised control trial (RCT) comparing MBT with PAU, and was the first ever large-scale RCT for offenders with ASPD in the community. An RCT design was adopted to generate the highest level of evidence as it is regarded as the gold standard for clinical trials. Research participants were randomly allocated to ensure both known and unknown determinants were evenly distributed across the two study arms to minimise bias; the treatment was the only difference between the two groups (Bondemark & Ruf, 2015). Since the study aimed to evaluate a psychological treatment, it was not possible for the participants to be unaware of their treatment allocation and therefore a single blinded approach was adopted; and only data collectors were blind. The treatment in the control arm was not specified to enable MBT to be evaluated under usual conditions which treatment would be delivered. The control arm included services that were already available to the population through the NHS or probation services, collectively known as PAU. Participants were followed-up in both arms of the trial for two years at three-month intervals to determine effectiveness over time. Peer researchers with lived experience of the criminal justice system collected data alongside traditional research assistants as it was anticipated that their involvement would reduce the power differentials between the researcher and participant thus improving the accuracy of the data collected (Faulkner, 2017). The sub sections below describe the design of the study in more detail; include outcomes, eligibility criteria, interventions, ethical approval, patient and public involvement, study oversight, and a description of the research sites, clinical teams and data collectors.

3.3.1   Outcomes

The primary outcome of the trial was the frequency of aggressive acts measured by a self-report 5-item version of the Overt Aggression Scale Modified (Coccaro, 2020). Rates of

aggressive behaviour were recorded at 3 month intervals during 12 months of treatment and 12 months post treatment. Alongside the primary outcome a number of secondary self-report outcomes were collected which aimed to explore rates of violence; alcohol and drug use; mental health; treatment engagement and help seeking behaviour; personality dysfunction; mentalizing ability; health service use and offending behaviour (Fonagy et al., 2020). Despite the range of outcome measures collected there were limitations to the approach. Firstly, the research appointments were conducted in the same probation office the participant reported to their offender manager at or at the prison, they were serving their sentence. These locations were selected to ensure the safety of the participant and the researcher during the appointment. However, the participants would have associated these environments with punishment and control which may have limited the accuracy of the data collected. Secondly, the majority of the outcomes measures were self-report, which may have led to under or over reporting reducing the accuracy of the data collected. The research team attempted to reduce the impact of these limitations by including researchers with lived experience as data collectors.

The study team anticipated the involvement of the peer researchers would increase the quality of the data collected by enhancing the strengths and reducing the limitations of self-report. The use of common language in self-report outcome measures is suggested to increase the accuracy of the data collected (Paulhus & Vazire, 2001). The MOAM study team predicted this strength would be enhanced by the involvement of peer researchers as in addition to common language the peers could also breakdown barriers to engagement through their shared lived experience. Due to the participants being under the supervision of the NPS at the time of data collection, the study team anticipated the participants might under report criminal offences or rates of aggression, described in the literature as self-presentation or impression management (Paulhus & Vazire, 2001). As the peer researchers were not part of

the criminal justice, health or academic systems, the study team anticipated the peers would

be able to reduce power differentials enabling the participant to feel more comfortable and

therefore more able to disclose accurate information.

3.3.2   Eligibility Criteria

The inclusion and exclusion criteria for the trial was developed to ensure the recruited

population accurately reflected the range of antisocial service users under the management of

the NPS, and to ensure the results of the trial were generalizable to the wider population of

people diagnosed with ASPD (Ball, Cobb-Richardson, Connolly, Bujosa, & O'neall, 2005;

Davidson et al., 2009; Huband, McMurran, Evans, & Duggan, 2007). The full inclusion and

exclusion criteria for the trial is outlined in table 1 below.

Table 1: MOAM eligibility criteria

Inclusion criteria	Exclusion criteria
Male	Convictions for child sexual offences (including child pornography)
Aged 21 years and over	
DSM-IV-R diagnosis of ASPD (using SCID-II)	Neurodevelopmental disorder or significant cognitive impairment
Evidence of aggressive acts in the 6 months prior to assessment	Inadequate English or cognitive capacities to provide informed consent and participate in group therapy
Subject to statutory provision by the National Probation Service with at least 6 months remaining of their license or community sentence	

Despite the approach taken by the research team, three key groups were excluded

from the trial which limited the study team's ability to fully understand the effectiveness of

MBT for offenders with ASPD. Firstly, individuals without adequate levels of English

language skills were not eligible for the study as it was felt they would not be able to fully

participate in group therapy. In England and Wales, foreign nationals constitute

approximately 12% of the prison population (Sturge, 2018). Although service users with English as their second langue equates to a small proportion of the overall prison population, this group is reported to suffer even higher rates of both physical and mental health disorders compared to the general prison population and society at large (Till et al., 2019). Excluding this population creates a language barrier to rehabilitation, and potentially a reporting gap in mental health research. Secondly, only services users aged 21 years or older were considered for the study, despite anyone over the age of 18 years being treated as an adult in the criminal justice system. However, due to rates of maturity it was argued that this group of service users responds differently to treatment; engages in different types of offending behaviour from older adults and are at higher risk of reoffending and therefore should be treated differently (NOMS, 2015). Thirdly, the study only includes male service users. The exclusion of women was justified by the research team by the different and more complex needs profile of ASPD for women, which is different from the diagnostic profile for men (Petrillo, 2007). It was suggested that it would therefore not be possible to treat mixed gendered groups. Despite the clinical strengths of these arguments, there was no attempt by the research team to evaluate a separate women's only MBT group and further research is needed to explore the effectiveness of the approach for this group. The exclusion of these three groups limits the scope of the evaluation to fully understand the effectiveness of MBT for all service users under supervision by the NPS who meet threshold for ASPD.

3.3.3   Interventions

Randomised participants were allocated in a 1:1 ratio to receive PAU supplemented with MBT or PAU only. Both interventions are described in the sub sections immediately below, and a full description of the randomisation process is outlined in section 3.5.1 of this chapter.

3.3.3.1   MBT

Participants who were randomised to the MBT arm of the trial remained under the supervision of the NPS for the duration of their licence or community sentence, and attended MBT group and individual sessions. MBT is a 12 month psychotherapeutic treatment which was originally developed in the 1990s to treat borderline personality disorder (BPD) patients in a hospital setting. The programme aims to develop a therapeutic process in which the patient's mind becomes the focus of the treatment to enable them to understand more about how they think and feel about themselves and others, and how this influences their actions and behaviours known as mentalizing (Bateman & Fonagy, 2016). MBT has showed some promising preliminary results reducing personality disorder symptomatology by specifically targeting the ability to recognize and understand the mental states of oneself and others (Bateman & Fonagy, 2009). Over the last thirty years a number of adaptations of MBT have been developed for children (MBT-C), families (MBT-F), adolescents (MBT-A), chaotic complex and multiply comorbid youth (AMBIT) and adults with ASPD (MBT-ASPD) demonstrating a growing adoption of the approach. However, despite the potential of MBT across a wide range of clinical presentations further research is needed to increase the quality and the quantity of evidence beyond the treatment of BPD (Malda-Castillo, Browne, & Perez-Algorta, 2019). The MOAM study team aimed to make a contribution to the growing evidence base for MBT by building on the knowledge generated from the RCT of outpatient MBT versus structured clinical management for BPD (Bateman & Fonagy, 2009) to explore the effectiveness of MBT for ASPD patients currently under supervision by the NPS.

In the MOAM trial, research participants who were randomised to MBT attended 75-minute weekly group therapy sessions and one-hour individual MBT sessions on an ad hoc basis at the request of the participant or their therapist. Although it was compulsory for all participants to attend regular meetings with their offender manager, attending MBT sessions

for the majority of participants was not part of their compulsory licence conditions. The group therapy sessions were held in private meeting rooms in either a local probation office or approved premise attended by a maximum of six participants and led by at least two trained MBT therapists. MBT therapists explained why mentalizaing is important, and what can go wrong if someone is not able to understand how another person is feeling and thinking. Weekly group sessions would typically start with a check in to generate topics to be discussed during the meeting by the group members. As new members joined the group, established team members would contribute to introductory session thus supporting new members and developing their understanding of mentalizing (Bateman & Fonagy, 2016).

3.3.3.2   PAU

Participants who were randomised to the PAU arm of the trial remained under the supervision of the NPS for the duration of their licence or community sentence. Participants were free to be referred by their offender manager for any suitable and appropriate treatments available in their local area through the NPS or NHS services. Examples of PAU services included Building Better Relationships, Changing Lanes and Resettle. In order to address potential bias, site-specific strategies were put in place to ensure that MBT principles and practice did not directly influence the management of those randomised to PAU (Fonagy et al., 2020). PAU generally lasted from between six and nine months, after which participants who still had time remaining on their licence or community sentence remained under the supervision of the NPS for the duration. The decision was taken not to restrict the type of PAU services accessed by the participants to ensure the trial evaluated MBT in a real life setting. PAU services were tracked through a combination of self-report using the Secure Facilities Service Use schedule (Barrett & Byford, 2007) and collection of service use data from the OPD pathway database. This dual approach was adopted to reduce the limitations of self-report with forensic populations and NPS service use records.

3.3.4   Ethical approval

The trial protocol was approved by the London – South East Research Ethics Committee (14/LO/1696) and the HMPPS NRC (2014-315). Research and development approval was obtained from each NHS Trust and NPS lead in each geographical area.

3.3.5   Patient and Public Involvement

Patient and Public Involvement (PPI) was a central component in the design of the MOAM trial, as it was believed the involvement of researchers with lived experience would strengthen the findings of the study (Fonagy et al., 2020). A service user with lived experience of the criminal justice system was a member of the trial steering committee (TSC). The TSC were responsible for guiding and advising the study team throughout the research. The study team choose to include a service user as a member of the committee as it was believed they would be able to bring a different perspective by representing the views of the research participants. A review of the minutes indicate the service user attended 60% of the TSC meetings, suggesting they were an active member of the committee. In particular, the service user contributed to discussions about how to increase recruitment and engagement rates highlighting the importance of a flexible approach. This type of involvement could be considered "collaboration", the middle level on Boote's Level of Involvement Continuum, as there was an ongoing partnership between the traditional researchers and service user throughout the research process (Boote et al., 2002). However, although the service user attended over half of the committee meetings they did not set the agenda, and only one service user was invited to attend the committee alongside 14 traditional researchers, clinicians and service leads. Therefore it could be argued power was not redistributed as the service user's role was to "break down barriers", "consult" or "inform the design" of the research classified as "degrees of tokenism" on Arnstein's Ladder of Citizen Participation

(Arnstein, 1969). The research team also worked in collaboration with User Voice, a service user led organisation, to include researchers with lived experience as data collectors, known as peer researchers.

The principal activity of the peer researchers, who had served a custodial or community sentence, was to work alongside a team of traditional research assistants to collect baseline and follow up outcome measures. The research team chose to involve researchers with lived experience in the study design as they anticipated it would enhance the accuracy and validity of the data collected from a group of participants who often have entrenched distrust of authority (Fonagy et al., 2020). The study team suggested through their involvement the peer researchers would be able to access participants that traditional researchers may not be able to reach (Byng et al., 2012) and facilitate the development of trust with the participant through the reduction of power differentials leading to more honest answers (Milton et al., 2017). This type of PPI was different to the TSC membership, as there was an equal representation of researchers with lived experience and the five peers completed the same role as the traditional research assistants. The level of the participation of the peer researchers could also be classified differently depending on the impact of the experience on the service users, participants and key stakeholders involved. The subsequent chapters of the thesis aims to explore this impact.

3.3.6 Study oversight

The trial management group (TMG) was based at UCL and consisted of the chief investigator, programme coordinator and trial coordinator who met monthly. The TMG worked closely with the eleven principal investigators to oversee the coordination of the trial, and quarterly meetings were held to review progress. In line with NIHR guidance, a TSC was established to provide overall supervision of the trial made up of forensic clinicians;

academics with extensive experience of implementing RCTs; HMPPS and NHS England

OPD pathway leads and a service user representative. A data monitoring and ethics

committee (DMEC) was formed to provide independent advice on data and safety aspects of

the trial. Both the TSC and DMEC were led by an independent chair, and met between two

and four times a year as required. The composition of the oversight committees enabled the

research team to access independent and impartial advice from a range of expertise

throughout the life cycle of the study.

3.3.7   Research sites

The MBT service was designed to be delivered through existing community

partnerships between Probation Trusts and Health Service Providers through the OPD

pathway. Following an initial bidding process 13 RCT sites in England and Wales were

selected on the following criteria. Firstly, providers needed to be part of the National

Personality Disorder Offender Strategy to be eligible to join the project. Secondly, sites were

further selected on geography as well as demographic representativeness and availability of

participants for recruitment into the trial (Fonagy et al., 2020). The teams were based at either

a probation office, where service users would report to, or an approved premises that offered

accommodation for service users under supervision of the NPS. One MBT team was based at

each location and a peer researcher and research assistant were assigned to each site to collect

data. The five peer researchers were recruited locally at each site, as it was anticipated their

local knowledge of the probation and prison systems would enable them to access

participants more efficiently. The 13 sites were divided into four regional hubs: London,

South West, Midlands and the North of England with each hub consisting of between three

and four research sites.

Although each of the selected sites met the same inclusion criteria, there were limitations due to the geographical spread of the 13 sites selected which may limit the generalisability of the final findings of the study. Firstly, although the study was conducted across England and Wales, only one site was located in Wales accepting referral from across the southwest region. These geographical restrictions would have limited the number of service users who were referred to the study, and may have had an impact on engagement rates for treatment and follow up. Secondly, of the 13 RCT sites there was a disproportionate number in London, with 4 out of 13 in the capital, recruiting 27% of the overall total for the trial. In contrast to the situation in Wales, a larger number of sites in London may have positively affected engagement rates as participants had a shorter distances to travel, but also may have led to the results of the study being less representative of the entire population of England and Wales.

3.3.8   Clinical teams

The clinical teams based at each site consisted of a group of multi-disciplinary professionals from the NHS and NPS, led by a MBT clinical lead. The MBT clinical lead was either a clinical or a forensic psychologist at NHS grade 8a, working one day a week on the project and responsible for the coordination of the clinical team and overseeing the research locally. Each team included between two and three MBT therapists employed one day a week to work on MBT. The MBT therapists came from a range of professional backgrounds including clinical, forensic and counselling psychology as well as psychiatrists, specialist nurse practitioners and nurse consultants. An assistant psychologist working two days a week was based at each of the sites and was responsible for the administration tasks and data reporting to the central MBT coordination team. In addition, a specialist offender manager was also part of the team and acted as a link between probation and the clinical service.

During the trial, a central team based at the Portman Clinic in North West London coordinated the 13 MBT teams led by the MBT Director, a Consultant Psychiatrist in Forensic Psychotherapy, supported by an experienced NHS implementation project manager.

3.3.9   Data collectors

Two types of data collectors were involved in the trial; peer researchers with lived experience of the criminal justice system employed by User Voice and research assistants employed by UCL. The research team were aware of the challenges of engaging the target population for the MOAM trial and therefore decided to adopt the peer researcher approach. It was believed involving researchers with lived experience of the criminal justice system would be able to access participants and topics that traditional research and clinical staff might not be able to reach. The recruitment process for both groups of researchers was similar with both roles externally advertised, and shortlisted applicants attending a 40-60 minute face-to-face interview as part of the selection process. Both groups of researchers worked together in each of the 13 sites to collect data from male offenders who were either randomised to the MBT or PAU arm of the trial. The data collectors were managed by a UCL trial coordinator with support from a User Voice research and evaluation manager and coordinator who were all based in London. A project coordinator, a qualified clinical psychologists and senior lecturer at UCL, oversaw the entire research team. The sub sections below describe the requirements and responsibilities for each role.

3.3.9.1   User Voice peer researchers

User Voice recruited the first team of peer researchers by April 2016. Each of the successful candidates had already worked for User Voice in a variety of engagement roles through the prison councils and outreach work before joining the MOAM trial. In July 2018, a fifth peer researcher was employed who had previous experience of engagement roles but

had not worked for User Voice directly. All five of the peer researchers had lived experience

of the criminal justice system and had previously served a custodial or community sentence.

Four were male and one was female. The peers were not required to have a diagnosis of

ASPD, or to have committed an aggressive or violent crime. Therefore, the peer researchers

had similar but not the same lived experience as the MOAM participants.

The peer researchers were actively involved in the data collection phase of the study

and therefore it could be argued the MOAM trial enabled patients and members of the public

to carry out the research rather than the research being about or for them, meeting the Health

Research Authority's definition of patient and public involvement (Health Research

Authority, 2021). During the first phase of the project between January 2016 and December

2017 four peer researchers worked part time on the MOAM trial between two or three days a

week across one regional hub each. As caseloads started to reduce from January 2018

onwards, two peer researchers were employed full time on the project working across

multiple regional hubs. During the recruitment phase, the peer researchers were responsible

for meeting with the participant to complete the baseline assessment; notifying the clinical

team the participant was ready to be randomised and updating the User Voice research

coordinator. During the follow up phase the peer researchers were responsible for engaging

with the participant's offender manager and MBT assistant psychologist to identify where the

participant was; contacting the participant to engage them to complete the follow up

questionnaires; arranging the follow up appointment and completing the outcome measures

with the participant. Throughout the study, the peer researchers were also required to report

any immediate risk concerns to the trial coordinator and attend quarterly booster sessions. See

appendix D for the peer researcher job description.

3.3.9.2   UCL research assistants

Five research assistants worked alongside the peer researchers to collect data from the participants who consented to be part of the trial between April 2016 and September 2018. The research assistants were directly employed by the Anna Freud National Centre for Children and Families (AFNCCF) but based at UCL with the trial coordinator, and were recruited in January 2016 slightly earlier than the peer researchers. Two research assistants were in post at any one time across the four hubs working full time on the study. All five of the research assistants had not worked for UCL or AFNCCF before joining the study, but three had completed an undergraduate or master's degree at UCL before applying for the role. The research assistants completed the same tasks as the peer researchers as outlined in the section above, but they had broader range of involvement in the study and were responsible for database management, data entry and cleaning. Three of the research assistants were female and two male. They had no lived experience of the criminal justice system and a mean average age of 28 years old. The peer researchers were considerably older than the research assistants and were closer in age to the MOAM participants (peer researchers age M=39; MOAM participants age M=38). In addition to their lack of lived experience, the age difference between the research assistants and MOAM participants may have also been a barrier to engagement. See appendix E for the research assistant job description.

3.4   Study set up

The NIHR grant was awarded to UCL in November 2015 and the trial launched in January 2016. Following ethical approval from NRES Committee London – South East and HMPPS NRC local approval was requested from the research and development departments in each of the 13 NHS trusts to implement the study. Once the relevant approvals were in

place recruitment began. The sub sections below describe the study set up phase of the trial including site launch, research access and training as well as supervision.

3.4.1   Site launch

The sites entered the trial in four phases between January and September 2016 during the first year of the study, see table 2 below. The first participant was randomised on the 4th January 2016 in Merseyside, and the last participant joined the trial in Barnet, Enfield and Haringey/Portman clinic on the 31st August 2018.

Table 2: Phased site launch summary

Phase	Launch date	Research site	NHS trust
1	January 2016 - April 2016	Merseyside	Mersey Care NHS Foundation Trust
		Lincoln	Lincolnshire Partnership NHS Foundation
		BEH/P	Barnet, Enfield and Haringey Mental Health Trust
			Tavistock and Portman NHS Foundation Trust
		SLaM	South London and Maudsley NHS Foundation Trust
2	July 2016	Devon and Cornwall	Devon Partnership NHS Trust
		South West Wales	Bwrdd lechyd Prifysgol Hywel Dda University Health Board
		Leeds	Leeds and York Partnership NHS Foundation Trust
3	August 2016	Lancashire	Lancashire & South Cumbria NHS Foundation Trust
		Avon and Wiltshire	Avon and Wiltshire Mental Health Partnership NHS Trust
		Nottingham	Nottingham Healthcare NHS Foundation Trust
4	September 2016	Oxleas	Oxleas NHS Foundation Trust
		East London	East London NHS Foundation Trust
		Staffordshire	Midlands Partnership NHS Foundation Trust

3.4.2   Research access

Despite the Department of Health prioritising the involvement of patients and members of the public in research (Department of Health, 1998a), the MOAM trial found there were very few established systems to grant NHS access to researchers with lived experience. All researchers required an NHS Research Passport and Letter of Access for each NHS trust before they could collect data to ensure the researcher had received the relevant training to complete the role and adequate supervision systems were in place. Each member of staff was required to submit a copy of their CV; occupational health clearance documentation; Good Clinical Practice training certificate; DBS certificate and research passport application form that stated the nature of the research they would be working on. For a traditional research assistant with no criminal convictions, this was a relatively straightforward application process. However, for a peer researcher it was a more complicated process, as due to their lived experience, their DBS certificate contained information about their previous criminal convictions. To overcome this challenge for the MOAM trial, the trial coordinator worked in collaboration with User Voice to ensure the NHS requirements for the study were met, but the peer researcher's personal data was also protected. Following a discussion with all parties, it was agreed the peer researchers DBS certificates would only be reviewed by the MBT clinical lead and not shared with the Research and Development department at each trust. This was a significant adjustment to the research passport application process for the majority of the trusts involved in the trial, suggesting that although the policy for the involvement of patients and members of the public may be widely published more work is needed to adapt the systems and procedures on the ground beyond the traditional researcher approach.

3.4.3   Training and supervision for data collectors

The peer researchers and research assistants completed the same initial training led by the project coordinator; MBT director and trial coordinator. The training included research methodology, overview of ASPD traits and behaviours and guidance on the administration of the outcome measures. Both groups of researchers completed their Good Clinical Practice training and were given training to be able to enter the data directly onto the trial database through a web-based platform called Patient Owned Database (POD). During the trial every three to four months, the researchers met for a booster session at the User Voice London office. The agenda for the meeting was guided by the peer researchers and research assistants, and focused on peer support and shared learning. Despite the similarities, there were distinct differences between the type of training and support available to the peer researchers and research assistants even though they were required to meet with the same participant population to collect the same set of outcome measures.

In addition to the project specific training outlined above, the peers also completed their own User Voice peer researcher training which was developed and delivered by the service user organisation. The training covered research methods, confidentiality and the consenting process. The research assistants were able to access daily support from the trial coordinator in person as they were based in the same research office, and the peer researchers had the same access to support through telephone and email contact. The peer researchers were also able to speak with the User Voice research coordinator one day a week for guidance about specific User Voice systems and policies. The research assistants met with the project coordinator once a month for one to one clinical supervision and in the later stages of the project the peers had access to an employee assistance telephone service. It could be argued that the peer researchers needed access to a different type of training and support from

the research assistants because of their lived experience. However, it was unclear from the information available if the distinction between the two approaches was dependent on the needs of the individuals, or the resources and approaches of the two employing institutions. The potential impact of the different approaches will be explored in the subsequent chapters of the thesis.

3.5   Procedure

Participant were recruited between January 2016 and August 2018 across the 13 sites in England and Wales. The peer researchers and research assistants completed the baseline outcome measures with the participant prior to randomisation and then collected follow up data at three-month intervals for a 24-month period. The subsections below described the recruitment and data collection procedure for the study, and the role of the peer researchers and research assistants in this process.

3.5.1   Recruitment

The referral to randomisation process involved seven stages. (1) The first stage of the process involved an offender manager identifying a potential participant for MBT on their caseload who met the inclusion criteria for MBT on paper. (2) The offender manager would then send the details of the potential referral to the specialist offender manger or directly to a member of the clinical team to be considered. (3) If the specialist offender manager or MBT therapist felt the referral was suitable to be considered for the clinical service given the eligibility criteria they would ask the offender manager to briefly speak to the potential participant about the opportunity to take part in a research study and MBT. (4) Following this brief discussion the potential participant would be invited to meet with a member of the MBT team for a clinical assessment to explore their suitability for the trial, and to discuss the research study and treatment paths in more detail. During this meeting the participant was

given a copy of the MOAM participant information sheet, and the opportunity to ask any questions. (5) The potential participant was then given at least a 24 hours cool off period to decide if they would like to take part before the MBT assistant psychologist contacted them. If the participant decided they would like to take part, and they confirmed all their questions about the trial and the clinical service had been answered, the assistant psychologist would arrange a meeting with the participant to complete the consent, SCID – II assessment and OAS-M. If the participant met threshold for ASPD on the SCID – II assessment and scored at least 15 on the OAS-M they would then progress to the next stage of the process. (6) The participant met with either a research assistant or peer researcher to complete the baseline questionnaires. Once the questionnaires had been completed the participant was given £35.00 in high street vouchers to thank them for giving up their time to complete the research questions and would then progress to randomisation. (7) The research assistant or peer researcher would contact the MBT team to confirm the participant had completed the baseline outcome measures. A member of the MBT team would then enter the participant's randomisation information into the North Wales Organisation for Randomised Trial Clinical Trials Unit randomisation system. The participant was randomly assigned to either MBT or PAU services, and a member of the MBT team would then contact the participant and their offender manager to confirm which arm of the trial they had been allocated too.

During the recruitment process, the peer researchers and research assistants performed the same role. Both groups only met with the participant to complete the baseline outcome measures once they had given their consent to participant in the study and therefore were not part of the initial engagement process. It could be suggested this approach was a missed opportunity by the research team as one of the suggested strengths of the involvement of patients and members of the public is their ability to build a rapport an engage potential participants in the study (Livingston et al., 2014). Therefore, involvement of the peer

researcher at an earlier stage of the process may have enabled the research team to recruit participants who may otherwise have struggled to engage in a clinical trial.

3.5.2   Data collection

The peer researchers and research assistants both collected data from the MOAM participants. The baseline outcome measures were completed prior to randomisation, and the participant was then approached at three month intervals over a twenty four month period by either a peer researcher or research assistant to collect follow up data. The longer follow ups (baseline, 6, 12, 18 and 24 month) took between 60 and 90 minutes to complete depending on the participants literacy skills and were generally conducted in person. The shorter follow ups (3, 9, 15, and 21 month) took around 15 minutes to complete and were either conducted in person or over the phone. Depending on the participant's circumstances, follow up appointments either took place at the participant's local probation office or through a legal visit if the participant had reoffended or breached their licence conditions and been recalled to prison. Participation in the study was voluntary; participants were free to withdraw at any point and were not required to provide the research team with a reason for their decision.

For follow-ups completed in the community, the research assistant or peer researcher would contact the participant's offender manager to confirm they were still in the community and if there were any immediate risk concerns they should be aware of before they met with the participant. Following a response from the offender manger, the researcher would contact the participant directly to arrange a time to meet with them at the probation office to complete the follow up questionnaires. The meetings took place directly after the participant's routine meeting with their offender manager, or at a different time depending on availability. The offender manager or a member of the MBT team would then support the researcher with booking a private interview room at the local probation office for the follow up appointment to take place. Data collected in the community was entered directly on to the POD through

Samsung tablets via a 3G internet connection. At the end of the meeting, the participant

would be given £35.00 or £15.00 depending on the length of the follow up to thank them for

taking part. It was also possible to complete shorter follow ups over the phone with

participants in the community depending on the participant's preference and understanding.

The same approach was taken as outlined above for phone follow ups, but the high street

vouchers were posted out to the participant following the completion of the outcome

measures.

If the participant's offender manger confirmed the participant had re offended or

breached their licence conditions and been recalled back to prison the follow up meeting took

place in custody. Following confirmation from the offender manager about which prison the

participant was currently held the researcher would contact the prison to arrange a legal visit

to meet with the participant to complete the follow up appointment. The researcher would

enter the prison through legal visits and the follow up appointment would take place in a

private interview room. Due to restrictions placed on prison visits, it was not possible to take

the Samsung tablets into custody to enter the data directly on to POD. Therefore, all of the

data collected with participants who had been recalled or reoffended and been given a

custodial sentence was completed on paper. Once all the outcome measures had been

completed the participant could either request for the high street vouchers to be posted out to

a family member or friend, or they could be given to them upon release.

Although the research assistants and peer researchers collected the same data from the

trial participants over the 24-month period, their involvement in the management of the data

was different. The peer researchers were not involved in entering or cleaning of the data, but

the research assistants were actively involved in this phase of the study and entered all the

data collected on paper into the trial database. During the final phase of the study, the

research assistants completed accuracy checks of a randomly generated 10% sample of the

data entered onto the database and source verification checks. The data was then exported by the Clinical Trials Unit (CTU), cleaned and transferred to the trial statistician for analysis. The decision to not involve the peer researchers in these later stages of the research process may not have had a direct impact on engagement rates or the quality of the data, but it may have had an effect on other aspects of the study that the study team could not have foreseen. The potential impact of the approach will be explored in subsequent chapters of the thesis.

3.5.3   Risk management

In line with NHS REC and HMPPS NRC ethical approval, risk concerns were managed centrally by UCL. The confidentiality rules of the trial were explained to the participant by the MBT therapist before they gave consent to participate in the trial. The participant was informed all the answers they shared with the research team would be kept confidential, unless they shared any information that suggested they or another person might be at immediate risk of harm. The peer researchers and researcher assistants restated this guidance at the start of the baseline and follow up appointments to remind the participant of the study protocol. This approach meant that regardless of the type of researcher the participant met with, they were informed the information they shared with the research team would be handled in the same way. In addition, all of the peer researchers and research assistants received the same training and guidance about the management of risk. This approach ensured the trial was implemented in line with ethical approved received from the NHS REC and HMPPS NRC. However, the rational for adopting the peer researcher approach, and the hypothesis for this thesis was the peer researchers would be able to collect more accurate data because of their shared lived experience with participants. This may also have meant the peer researchers received a higher rate of risk disclosures from the participants. The study team did not appear to account for this possible scenario through the

training and support available to the peer researchers. The potential impact of the approach

will be explored in subsequent chapters of the thesis.

3.6   Findings and dissemination

The trial was the first ever large-scale trial of treatment for offenders with ASPD in

the community and aimed to provide key evidence to inform policy makers, commissioners

of services and professionals about the potential of MBT as an intervention for ASPD. The

sub sections below describe the findings and dissemination plan set out by the study team to

achieve these aims.

3.6.1   Findings

At the time of writing, data collection had been completed and the research team were

in the process of entering and cleaning the data ready for analysis. The findings of the study

are due to be published in July 2021 and therefore, it was not possible to describe them in this

thesis. However, a full description of the baseline characteristics of the recruited sample is

described below.

3.6.2   Participant characteristics

Between January 2016 and August 2018, 313 participants were randomised into the

trial. All participants were male with a mean age of 34 years old (SD=9.2). The majority of

the participants in both groups were white (n=237, 76%) and on licence under the NPS after

serving a custodial sentence (n=280, 89%). Two thirds of the population were on licence for

12 months or more (n=208, 66%) at the point of randomisation. The full characteristics of the

RCT recruited sample are described in table 3 below.

Table 3: RCT sample – MOAM participant characteristics at baseline

Characteristics		MOAM population (n=313)
Age (years)		34.2 (9.2)
Gender	Male	313 (100%)
	Female	0 (0%)
Ethnicity	White British/ White Irish/ White other	237 (76%)
	Black/ Black British	29 (9%)
	Asian/ Asian British	5 (1%)
	White and Black Caribbean/ White and Black African/ White and Asian/ Mixed other	27 (9%)
		15(5%)
	Preferred not to state	
Sentence type at baseline	Prison	280 (89%)
	Community	33 (11%)
Sentence length at baseline	>12 months	208 (66%)
	<12 months	105 (34%)

Data are n (%) or mean (SD)

3.6.3   Dissemination plan

The research team aim to disseminate the outcomes of the MOAM trial to policy makers, service commissioners, providers and users to support the rapid implementation of the service if MBT is found to be effective. The research team's planned dissemination strategy includes six main audiences. Findings from the study will be shared with members of the public through the national media. In collaboration with User Voice, a lay summary of the results will be written and shared with mental health and probation service users to ensure

they are able to access the result of their involvement. Practitioners and service managers in mental health and forensic settings will be invited to attend in-service seminars, pre-qualification and continuing professional development courses related to the findings of the study. Academics in public health, mental health, forensic psychology and criminology will be able to access the results through publications in peer-reviewed journals relevant to offender health and mental health services. Finally, a copy of the funders report will be shared with representatives from the Department of Health, Ministry of Justice and NHS following publication to inform policy makers about the potential of MBT as an intervention for ASPD. If the study team deliver on their proposed plan outlined above, they will achieve their aim to share the results of the RCT with a wide range of audiences, and contribute to the developing evidence base for the management of this high-risk population.

3.7   Summary

The MOAM trial aimed to evaluate the effectives of MBT for male offenders with ASPD in England and Wales. To ensure the study produced high quality generalisable results a single blinded randomised approach was adopted, and there were no restrictions on the treatment available to participants in the control arm of the study to ensure the intervention was evaluated under normal conditions. However, despite the strengths of the adopted methodology there were several limitations to the design of study. Not all service users who met threshold for ASPD were eligible for the study, and despite the involvement of 13 sites, not all geographical areas of England Wales were equally represented. Self-report data was collected from participants in environments associated with control and punishment, which may have affected the quality of the data collected. The involvement of researchers with lived experience was adopted to minimise these limitation particularly related to engagement and accuracy of the data collected. The peer researchers were involved in the collection of the data as employed members of the research team, conforming to the Health Research

Authority's definition of PPI (Health Research Authority, 2021). However, the peers were not involved in every stage of the research process and did not have the same access to training and supervision as the research assistants they worked with. The next chapter of the thesis will outline the methodology adopted for the thesis to explore these questions and the impact of the involvement of the peer researchers on the trial from the perspective of the MOAM participants, research assistants and offender managers who worked alongside the peer researchers and the peers themselves.

CHAPTER 4 Methods

This chapter describes the methodology that was adopted for the thesis and outlines the setting and overall design of the research. The author's perspective is declared, and the sub sections explain the qualitative and quantitative elements of the study. The chapter concludes with a description of the credibility and validity checks which were incorporated at all stages of the process including design, data collection, analysis and write up.

4.1   Setting

The study was part of a large-scale randomised control trial evaluating the effectiveness of Mentalization Based Therapy (MBT) in reducing rates of aggression amongst male offenders with Antisocial Personality Disorder (ASPD) on licence under the National Probation Service (NPS) known as Mentalization for Offending Adults Males (MOAM) (Fonagy et al., 2020). To be eligible for the MOAM trial, participants had to be male; aged twenty-one years or older; subject to statutory supervision by the NPS with at least six months remaining on their licence or community sentence and have a history of violent and aggressive behaviour. Referrals for individuals serving a conviction for child sexual offences or with a diagnosis of psychotic disorder were excluded from the study. All participants were required to have adequate English language skills and cognitive capacity to participate in informed consent and group therapy. Following the completion of the baseline measures, the participants were randomised to either Mentalization Based Therapy (MBT) or Probation as Usual services (PAU) and then followed up for two years at three-month intervals by either a User Voice peer researcher or UCL research assistant to complete a set of outcome measures. A full description of the MOAM trial is described in chapter 3.

The involvement of peer researchers with lived experience as data collectors was central to the methodology of the MOAM trial. The aim of this study was to explore the

impact of the adoption of the peer researcher approach on the randomised control trial from the perspective of the MOAM participants and key stakeholders involved in the study. This study does not attempt to compare the experiences of the participants who met with a peer researcher against those who met with a research assistant as it was not possible systematically make this comparison with the sample of participants available.

4.2   Study design

This study used a mixed methods design to explore the impact of the involvement of the User Voice peer researchers as data collectors on the MOAM trial. A mixed methods approached was adopted to provide the opportunity to qualitatively observe the participants, and then supplement the findings with a closed-end instrument to systematically measure certain factors which have been identified in the literature (Johnson & Onwuegbuzie, 2004). The adoption of only a qualitative or quantitative method would not have provided this opportunity.

4.3   Ethical approval

An application was submitted to request a substantial amendment to the MOAM trial study protocol (14/LO/1696; 2014-315). In February 2019 the amendment was approved by the trial sponsor and then the National Institute for Health Research (NIHR) who funded the main trial. A full protocol amendment was submitted to the NRES Committee London - South East and Heath Research Authority and Health and Care Research Wales for NHS ethical approval and to the National Research Committee for approval from Her Majesty's Prison and Probation Service (HMPPS NRC) which was granted in April 2019. Each of the thirteen NHS trusts involved in the trial were then approached for local NHS research and development approval which was granted for all sites by May 2019. See appendix F.

4.4   Author's perspective

I approached this study with a generally positive attitude towards the involvement of researchers with lived experience in clinical trials, but also with a caution due to my role within the MOAM trial as trial coordinator and my knowledge and experience of the complexity of conducting multi-site large-scale randomised control trials (RCT). My trial coordinator role involved training and oversight of the User Voice Peer researchers and I therefore played an active role in the implementation of the approach. Despite having no personal lived experience of the criminal justice system or accessing mental health services myself, I could still be considered to be an "insider" because of my role in the trial (Merton, 1972). It could be suggested that it might have been difficult or impossible for me to ask certain interview questions and therefore my role might have been a hindrance to trying to understand issues from the participant's point of view (Rabe, 2003). I also might have approached the research with my own internal biases and beliefs which might have shaped the conclusions I reached.

In order to overcome some of these potential challenges, I deliberately only conducted a small amount of the interviews myself and chose to involve researchers who were independent from the trial team to collect the majority of the data. The interview schedules and self-report scale were developed in collaboration with User Voice; the two supervisors and supported by the patient and public involvement literature. In addition, both PhD supervisors, as outlined in the credibility checks section of this chapter, guided the qualitative and quantitative analysis. Despite the limitations of the involvement of an 'insider' researcher, I believe the knowledge I bought to the study also generated a unique insight into matters that may otherwise have been over looked by others based on my understanding of the culture and language of PPI drawn from my own experiences of the MOAM trial.

4.5   Qualitative data collection

Forty-seven semi-structured interviews were completed with five groups of participants between April 2019 and March 2020. The aim of this part of the study was to gain an understanding of how the MOAM participants and key stakeholders made sense of their own experiences of interacting with a peer researcher and the impact of the approach on the trial. To provide the opportunity for the interviewees to express their opinions freely and not to be constrained or dictated by the researcher a qualitative approach was adopted (Marks & Yardley, 2004). To ensure comparable data was collected, but at the same time encouraging participants to think broadly though a series of prompts, a semi-structured interview approach was selected with standard questions asked to each interviewee (Marks & Yardley, 2004).

4.5.1   Sampling

A purposeful sampling approach was taken to meet the study aims (Smith & Noble, 2014). Five groups of participants who were directly involved in the RCT and therefore especially knowledgeable, were approached to be interviewed to explore a range of perspective (Cresswell & Plano Clark, 2011). The systematic strategy of selecting the participants to address the identified research question is described below.

4.5.1.1   MOAM participants

313 MOAM participants were recruited into the trial; the following five step approach was taken to identify a sub sample of the trial participants to be approached to complete the semi-structured interviews. Firstly, MOAM trial participants who had dropped out of the trial were removed from the potential sample pool of 313 as these participants had specifically asked not to be contacted by the research team (n=15). In line with the UK Policy Framework for Health and Social Care research participants have the right to withdraw from

a research trial at any point, and do not have to provide a reason (HRA, 2017). Secondly, participants who had died during the follow up phase were removed from the list of potential participants to be approached (n=5). Thirdly, to ensure participants were able to adequately recall their experiences participants who had completed the trial before April 2019 were removed from the potential sample pool (n=111). Fourthly, due to restrictions on taking recording equipment into prisons in England and Wales, participants who had been recalled to prison or reoffended and been given a custodial sentence at the time of data collection were excluded (n=70). This decision was taken to ensure the quality of the data collected was consistent across the sample. Lastly, participants who were on the run from the police were removed as they were uncontactable by the research team (n= 6). Once these five groups of participants had been removed from the potential sample pool, 106 were identified to be approached across the thirteen research sites. All 106 potential participants were contacted three times by phone and text message by the research assistants inviting them to participate in the study. Of those approached a total of 30 MOAM participants gave their consent to share their experiences of meeting with either a User Voice peer researcher or UCL research assistant to complete the follow up measures for the trial. The remaining 76 participants were either not contactable by the research assistants (n=53); initially agreed to participate in the study and then did not engage (n=17) or declined to participant in the semi-structured interview (n=6).

4.5.1.2   Key stakeholders

Four groups of key stakeholders were included in the study. Five peer researchers who worked on the project between April 2016 and September 2018 all gave their consent to share their experiences of working as a peer researcher on the MOAM trial. During the same period, five research assistants who worked alongside the peer researchers all agreed to participate. Two members of User Voice operational staff who were directly involved in the

trial and management of the peer researchers were approached and gave their consent to share their experiences of working with UCL and the peer researcher approach. Thirteen Specialist Offender Managers (SOM) worked on the project alongside the User Voice peer researchers and UCL research assistants between April 2016 and September 2018. All thirteen SOMs were approached, and five responded and gave their consent to be interviewed.

4.5.1.3   Sample size

In order to explore the identified research question in depth, a sample of 30 MOAM participants were recruited across the 13 research sites. In addition, 17 key stakeholders involved in the trial were interviewed to broaden understanding of the impact of the peer researcher approach. The analysis completed by Guest et al guided the decision of how many interviews to complete in order to understand the experiences of the different groups of individuals involved in the trial (Guest, Bunce, & Johnson, 2006).

4.5.2   Participant characteristics

The sub sections below describe the characteristics of each of the five groups of participants who participated in the semi-structured interviews and shared their experiences of the peer researcher approach.

4.5.2.1   MOAM participants

Two groups of MOAM participants were interviewed; those who had met with a peer researcher and a second group who had met with a research assistant to complete the follow up outcomes measures for the trial. The characteristics of the two groups of MOAM participants were very similar at baseline. Both groups of participants were male, with a mean age of 38 years old (peer researcher M=38.2 SD=10.9, research assistant M=37.9 SD=11.0). The majority of the participants in both groups were white (peer researcher 73%, research assistant 79%) and on licence after serving a custodial sentence (peer researcher 87%,

research assistant 87%). Overall, there was a slightly higher proportion of participants serving

a sentence of 12 months or more at baseline for the research assistant group (87%) compared

to those participants who met with a peer researcher (73%). The characteristics of both

groups of participants are described in table 4 below.

Table 4: Qualitative sample – MOAM participant characterises at baseline

Characteristics		Contact with PR (n=15)	Contact with RA (n=15)
Age (years)		38.2 (10.9)	37.9 (11.0)
Gender	Male	15 (100%)	15 (100%)
	Female	0 (0%)	0 (0%)
Ethnicity	White British/ White Irish/ White other	11(73%)	12 (79%)
	Black/ Black British	1 (7%)	1 (7%)
	Asian/ Asian British	1 (7%)	1 (7%)
	White and Black Caribbean/ White and Black African/ White and Asian/ Mixed other	2 (13%)	1 (7%)
Sentence type at baseline	Prison	13 (87%)	13 (87%)
	Community	2 (13%)	2 (13%)
Sentence length at baseline	>12 months	11(73%)	13 (87%)
	<12 months	4 (27%)	2 (13%)

Data are n (%) or mean (SD), PR=peer researcher, RA=research assistant

4.5.2.2   User Voice peer researchers

Five peer researchers participated in the semi structured interviews. Four of the peer researchers were male and one female, their educational qualifications ranged from NVQ Level 2 to bachelor's degree. Four out of the five peer researchers were involved in the recruitment phase of the trial, and all five collected follow up data. All of the peer researchers had personal lived experience of the criminal justice system either serving a custodial or community sentence and at the time of the interview were aged between 28 and 52 (M=39.2, SD=11.5).

4.5.2.3   User Voice operational staff

Two User Voice operational staff members participated in the research study. The first member of staff contributed to the development of the original grant application, and at the time of the interview had worked for User Voice for ten years. The second member of staff was directly involved in the day-to-day running of the trial and had worked for User Voice for three years. Both User Voice employees were educated to master's degree level and had no personal lived experience of the criminal justice system.

4.5.2.4   Research assistants

Five research assistants who worked alongside the peer researchers agreed to be interviewed for the study. Three of the research assistants were female and two male aged between 24 and 32 (M=27.8, SD=3.7). All five-research assistants had completed a bachelor's degree in psychology, and three had completed a master's degree. Similar to the peer researchers, four out of the five research assistants were involved in the recruitment phase of the trial, and all five collected follow up data.

4.5.2.5   Specialist offender managers

Five SOMs agreed to participate in the research study. Four of the SOMs were female and one male, and at the time of the interview were all employed by the NPS. The full range of academic qualifications of the recruited sample is unknown, but in order to practise as an offender manager all five SOMs would have completed at least an NVQ Level 4 in Community Justice. Three out of the five SOMs who shared their feedback were involved in the recruitment phase, and all five were in post during the follow up phase of the trial.

4.5.3   Interview schedules

Five interview schedules were developed in collaboration with User Voice supported by the findings from a systematic literature review, which is described in chapter 2 of this thesis. The schedules included a range of questions exploring motivation; definition of terms; training and support; involvement; data collection; engagement; boundaries; collaborative working; personal skills; development and empowerment. A full description of the development and a copy of each of the schedules is included in appendices G-L.

4.5.4   Procedure

The sub sections below describe how each groups of participants were recruited and the data collection process for the qualitative element of the study.

4.5.4.1   Recruitment

The MOAM participant was sent a text message by the researcher to introduce the study. At least 24 hours after the text message was sent the researcher called the participant to invite them to take part in the interview to share their experiences of meeting with a researcher for the MOAM trial. Following the phone call, a paper copy of the participant information sheet (PIS) was posted out to the participant, see appendix M. If the participant expressed an interest in taking part, the researcher would then arrange a time for the interview

to be completed over the phone. The MOAM participant interviews were conducted between July 2019 and March 2020.

Each of the key stakeholders was approached via email by the MOAM trial coordinator inviting them to participate in the study. The PIS was attached to the email and a short blurb was included about the project, see appendices N-Q. The potential participants were asked to respond to the email invitation if they wanted to take part. If the stakeholder agreed to be interviewed the researcher would contact them to arrange a time for the interview to be completed over the phone or in person. All of the peer researchers asked to complete their interview once they had left the project and therefore the interviews took place between May and December 2019. The research assistants, SOMs and User Voice operational staff member interviews were completed between April and July 2019.

4.5.4.2   Data collection

The interview process was the same for each of the five groups of participants. Following the recruitment phone call, the researcher arranged a time to complete the interview with the participant over the phone or in person. The researcher started the interview by re stating the purpose and the confidentiality rules of the study. The interviewee was then given the opportunity to ask any outstanding questions they might have about their participation in the project. Once the interviewee confirmed they were happy to proceed the researcher turned on the Dictaphone; took verbal consent and then the interview would start. The researcher asked each question in turn, prompting as needed. The participant was free to skip any questions they felt unable to answer. Before bringing the interview to an end, the participant was given the opportunity to share any feedback which might not have been raised by the interview schedule. Throughout the process all interviewees were reminded the answers they gave during the interview would be kept confidential; they could terminate the

interview at any time and their decision to take part in the optional interview would not affect

their employment or involvement in the MOAM trial now or in the future.

4.5.4.3   Setting and length of interviews

All the interviews were completed in a private meeting room at University College

London, either in person or over the phone. The interviews were conducted in one session,

except for one of the peer researcher's interview that was conducted over two 60-minute

sessions. The interviews ranged in length depending on participant group. The longest

interviews were completed with the peer researchers themselves and lasted between 60 and

180 minutes. The interviews with the other key stakeholders lasted between 60 and 90

minutes, and the shortest interviews were completed with the MOAM participants and lasted

between 10 and 60 minutes.

4.5.4.4   Recording and transcription

All of the participants gave consent for their interview to be recorded, apart from one

participant. The interviews were recorded on a Dictaphone and transcribed intelligent

verbatim. For the one participant who requested not to be recorded, detailed notes were taken

during the interview and typed up immediately after the meeting.

4.5.4.5   Participant payment

In line with the HRA guidance participants received a payment to thank them for

giving up their time to participate in the interview which was proportionate to the burden

imposed by the research (HRA, 2014). During the planning stages of the study, User Voice

highlighted the importance of taking a consistent approach to avoid tokenism by ensuring

everyone's contribution was valued equally (Ocloo & Matthews, 2016b). Therefore, it was

agreed the stakeholders and the MOAM participants should be offered the same amount to

reduce the imbalance of power, which may have occurred if an inconsistent approach had

been adopted. Following the interview, the researcher posted the PIS, consent form, self-addressed envelope, receipt and £35.00 in high street vouchers to the participant to thank them for taking part in the interview. A copy of these documents are included in appendices M-R.

4.5.5   Data collectors

All the interviews were conducted by researchers who were not involved in data collection for the main trial and had not met with any of the participants before. Four of the interviewers were female and one male. Each of the researchers had completed, or were in the process of completing, an undergraduate degree in psychology or related subject area. Before collecting data each of the interviewers received training in conducting semi-structured interviews and, in line with international ethical and scientific standards for conducting clinical trials, completed their NIHR Good Clinical Practice training (Vijayananthan & Nawawi, 2008). None of the researchers had personal lived experience of the criminal justice system.

4.5.6   Data analysis

The interview transcripts were analysed using thematic analysis to enable patterns of meaning to be identified within the participant groups, and across the entire data set to explore the potential impact of the peer researcher approach (Braun & Clarke, 2006). Braun and Clarke's six phase approach of thematic analysis was adopted. All 47 interviews were read and re read, and initial ideas were noted down. Initial inductive coding was completed by hand across the entire data set. Codes were then collected into potential themes. All themes were checked against the codes extracted and the entire data set was entered in to NVivo 12 qualitative data analysis software. Specific themes were then refined to develop an overall story of the analysis and a clear definition of each theme and name was created.

Finally, extracted examples of each theme were identified and included in the final write up (Braun & Clarke, 2006).

4.6   Quantitative data collection

76 participants across the 13 research sites completed a self-report scale between November 2019 and June 2020. 32 participants completed the self-report scale about their experience of meeting with a User Voice peer researcher to complete the outcomes measures for the MOAM trial, and 44 participants completed the self-report scale about meeting with a UCL research assistant. The aim of this part of the study was to gain an understanding of how both groups of participants experienced the interaction and how their experiences compared with each other.

4.6.1   Sampling

An opportunistic sampling strategy was adopted to generate the data. The study used the MOAM population who had already been recruited for the randomised control trial. The following procedure was adopted to identify a sub sample of the 313 MOAM trial participants randomised into the main trial to complete the 9-item self- report scale. Of the total randomised population (n=313) participants were excluded if they had dropped out of the trial (n=14). In line with the UK Policy Framework for Health and Social Care research participants have the right to with draw from the trial at any point, and do not have to provide a reason (HRA, 2017). The decision was made not to contact participants who had completed their last follow up appointment before August 2019 due to issues with recall (n=114). It was not possible to approach the participants who had died during the follow up period (n=5) or were on the run from the police and unlawfully at large (n=6). Once the excluded participants were removed, the data collectors were able to contact a total of 76 MOAM participants to

complete the self-report scale between November 2019 and April 2020, and all agreed to participate.

4.6.1.1   Sample size

The target population available determined the sample size for the quantitative element of the study. The aim of the data collection was to explore the experiences of the participants who met with a peer researcher or research assistant and therefore data was collected from 25% of the recruited MOAM sample using the strategy outlined above in section 4.6.1. 76 participants completed the self-report scale to share their experiences across the 13 sites, (n=32 peer researcher, n=44 research assistant).

4.6.2   Participant characteristics

Similar to the qualitative sample, the characteristics of the quantitative sample were very similar across both groups at baseline. Both groups of participants were male with an average age of 36 years old (peer researcher M=36.6 SD=8.6, research assistant M=36.4 SD=10.0) and the majority of participants who completed the self-report scale in both groups were white (peer researcher 78%, research assistant 75%). Although the characteristics of both groups were very similar, a larger proportion of the participants who met with a research assistant were on licence after serving a prison sentence (peer researcher 88%, research assistant 95%) and had less than 12 months left on their licence or community sentence at baseline (peer researcher 22%, research assistant 30%). The characteristics of both groups of participants are described in table 5 below.

Table 5: Quantitative sample – MOAM participants' characteristics at baseline

Characteristics		Contact with PR (n=32)	Contact with RA (n=44)
Age (years)		36.6 (8.6)	36.4 (10.0)
Gender	Male	32 (100%)	44 (100%)
	Female	0 (0%)	0 (0%)
Ethnicity	White British/ White Irish/ White other	25 (78%)	33 (75%)
	Black/ Black British	3 (9%)	6 (14%)
	Asian/ Asian British	1 (3%)	0 (0%)
	White and Black Caribbean/ White and Black African/ White and Asian/ Mixed other	3 (9%)	5 (11%)
Sentence type at baseline	Prison	28 (88%)	42 (95%)
	Community	4 (12%)	2 (5%)
Sentence length at baseline	>12 months	25 (78%)	31 (70%)
	<12 months	7 (22%)	13 (30%)

Data are n (%) or mean (SD), PR=peer researcher, RA=research assistant

4.6.3   Self-report scale

A 9-item self-report scale was developed for the study to explore the participant's

experience of meeting with a researcher or a peer researcher to complete the follow up

outcome measures for the trial. At the time of data collection, a validated scale specifically

designed to measure this type of interaction was not available, and therefore a bespoke self-

report scale was developed based on the validated Therapist Adherence Measure-Revised (TAM-R) tool used by Multisystemic Therapy services (Henggeler, Melton, Brondino, & Scherer, 1997; Henggeler, Pickrel, & Brondino, 1999). The MOAM participants were asked to rate each of the nine statements on the self-report scale in relation to their interaction with either a User Voice peer researcher or UCL research assistant on a 5-point Likert scale ranging from strongly disagree to strongly agree. The scale explored style of communication, trust and empowerment. A full copy of the self-report scale is included in appendix S.

4.6.4   Procedure

The sub sections below describe how the participants were recruited and the data collection process for quantitative element of the study.

4.6.4.1   Recruitment

At the end of the follow up appointment for the main trial, participants were approached to complete the optional 9-item self-report scale about their experiences of meeting with either a research assistant or peer researcher at their previous research appointment. The researcher explained the purpose of the self-report scale and asked the participant if they would like to share feedback about their experiences. The participant was reminded the answers they gave would be kept confidential, and their decision to complete the optional self-report scale would not affect their access to services or their involvement in the MOAM trial now or in the future. During the meeting, the participant would then confirm if they wanted to participate.

4.6.4.2   Data collection

If the participant agreed to complete the self-report scale, they were handed the document by the research assistant at the end of the follow up appointment. The participant was then given the option to hand the completed self-report scale directly to the researcher or

return the document by post to UCL using the stamped addressed envelope provided. To maintain anonymity the research assistant reminded the participant not to include any identifying information on the document.

4.6.5   Data collectors

One male and two female research assistants completed the self-report scale with the sub sample of MOAM participants. This group of researchers were involved in data collection for the main trial but did not work directly with the peer researchers. As was the case with the researchers who collected the qualitative data, each of the researchers had completed an undergraduate degree in psychology or related subject area and their Good Clinical Practice training (Vijayananthan & Nawawi, 2008) before collecting any data. None of the researchers had personal lived experience of the criminal justice system.

4.6.6   Analysis

In order to compare the experiences of the two groups of participants, an independent samples t-test was conducted for each of the 9 variable included in the self-report scale. This approach was adopted because the two groups were independent of each other and to explore the possibility of a significant difference between the experiences of the two groups. As the participants were being asked to give feedback about their interaction with a professional the data collected was anonymised to improve accuracy as anonymity is likely to improve reporting of stigmatizing behaviours or unpopular attitudes and opinions (Lavrakas, 2008). It was therefore not possible to complete any more detailed analysis on this data set.

4.7   Credibility and validity checks

In line with guidelines for research, credibility and validity checks were incorporated at all stages of the study including design, data collection, analysis and write up (Barker & Pistrang, 2005). The purpose of the study and its design were established and agreed with the

service user organisation and the two supervisors at the start of the project. Ethical approval

was obtained from NHS REC and HMPPS NRC in advance, and the Chief Investigator

oversaw treatment of the participants. During the data collection phase of the study, before

meeting with participants, all data collectors were provided with the same training to

maintain consistency. The procedure was explained to participants before they agreed to

participate and each stage of the research process is fully reported in the thesis. The interview

schedules were developed in collaboration with the service user organisation, supported by

the findings from a systematic literature review, and were piloted with a non-clinical

population during the planning stages of the study. Although the self-report scale was

developed specifically for the study, it was based on a validated tool that has been widely

adopted by clinical services. During the analysis phase of the study, the credibility of the

emerging qualitative themes and sub themes was reviewed through regular discussions

between the author and two supervisors until consensus was reached for each group of

participants (Hill, Thompson, & Williams, 1997). The author's perspective is disclosed in the

final write up to ensure transparency in how the data was collected and analysed. The

intention is to publish the results of the study to ensure the findings are publically available

and contribute to the development of knowledge in the subject area.

CHAPTER 5 Results - MOAM trial participants

This chapter describes the experiences of a sub sample of MOAM participants who met with either a peer researcher (n=15) or research assistant (n=15) to complete the follow up assessments for the trial. The first sub sample of MOAM participants participated in a semi-structured interview and were asked to describe their experiences of interacting with a researcher with or without lived experience. The analysis of this data does not attempt to compare the experiences of the participants who met with a peer researcher against those who met with a research assistant, but explores the experiences of both groups and the impact of the interaction. A second sub sample of participants completed a nine item self-report scale sharing their experiences of meeting with either a research assistant (n=44) or peer researcher (n=32) to complete the follow up outcome measures. The results from the qualitative and quantitative data collection for both groups of participants are described in this chapter.

Qualitative Analysis

5.1   MOAM participants – peer researchers

The first group of MOAM participants (n=15) met with a User Voice peer researcher who has lived experience of the criminal justice system (MOAM/PR). Analysis of the semi-structured interviews with this group of MOAM participants produced three themes: "Automatic common ground", Impact of common ground and The impact of seeing someone who has progressed. The participants described how they felt able to relate to the peer researchers because of the "automatic common ground" between themselves and the researcher due to their shared lived experience. The impact of meeting with a researcher with similar life experiences enabled some participants to feel more relaxed and, therefore, they felt more able to answer the questions honestly. The peer researchers were described as

"positive and inspiring individuals" and some participants explained how the experience encouraged them to reflect on their own past behaviour and gave them hope for the future. Despite the positive feedback, some participants described how they felt unable to relate to the peer researcher they met with because they may have been involved in a different type of offending behaviour, or trust them because they saw them as part of the probation or prison system. The themes and sub themes for the interviews conducted with the participants who met with a peer researcher are described in more detail below and are set out, by domain, in appendix T.

5.1.1   Theme: "Automatic common ground"

The first theme the MOAM participants who met with a peer researcher described, was how there was "automatic common ground" with the researchers because they knew both sides of the table. The participants explained that, because the peer researchers had similar lived experience to themselves, they felt understood, were able to relate and felt a connection with the researcher. The participants described how this experience led to the creation of "automatic common ground". However, some of the participants explained if a peer researcher had good communication skills and a polite approach this would also make them feel comfortable and engaged in the research process. Although the majority of the participants felt able to relate to the peer researcher, some described they may struggle to develop a connection if the researcher had been involved in a different type of offending behaviour. In particular involvement in a sexual offence was highlighted as a barrier. The four sub themes are described below and include: "They have been where I am", "It's having a connection with somebody who knows how you feel", "Well they explained stuff to me really well and "Everybody's crimes are different".

5.1.1.1 Sub theme: "They have been where I am"

The majority of the participants (n=11) described how beneficial it was to meet with a peer researcher to complete the outcomes measures for the trial. The participants highlighted the fact that the peer researcher's lived experience of the criminal justice system enabled them to understand both sides.

"They have been where I am like, if the tables were turned" (MOAM/PR1).

"I felt it was quite beneficial really because it was somebody that had sort of walked the walk if you like. You know, had experienced more or less the same sort of things that I was going through, as I was going through the probation system" (MOAM/PR 5).

Most of participants explained, because the peer researcher understood how the prison and probation environment operated they had a real understanding of how they were feeling compared to a probation officer or another professional who had never been or lived in that environment.

"They [offender managers] have not seen the other side of anything. They are just there to answer questions, sign off paper work and write risk assessments, and that is it. They [the peer researcher] knows what it is like to be, you know locked up" (MOAM/PR 9).

"People who have lived in prison, or been inside a prison environment, or have a criminal background have an insight into how people react, compared to people who have never been in that situation or lived in that environment" (MOAM/PR 10).

One participant explained how shared experience went beyond the criminal justice system, describing how the peer researcher's own experience of depression also helped them to engage in the research process.

"They were pretty helpful. They would have a chitchat and help a bit. I was going through depression at that time as well, so they did help a lot by just talking to me" (MOAM/PR 11).

5.1.1.2   Sub theme: "It's having a connection with somebody who knows how you feel"

The shared understanding between the two individuals enabled some participants (n=11) to feel able to relate to the peer researcher during the follow up meeting. "They could relate to the situation I am in, in terms of prison life, because they had been in themselves and they said that from the outset" (MOAM/PR 2).

"I think it makes more sense because they can relate to the questions themselves. They can, they can probably sympathise, or just kind of understand your answers a little bit more than someone who's never been in that situation" (MOAM/PR 3).

Some participants elaborated in more detail, explaining how their shared experience enabled them to not only relate to the peer researcher but they also felt a connection with the individual they met with. One participant described how the peer researcher's lived experience did not need to be stated, they were able to identify the connection by the way they communicated.

"You just have a connection to somebody; you know just by the way they speak to you and that. They don't have to tell you they've got previous experience, we can tell who's got previous experience and who's not, you know?" (MOAM/PR 4).

Being able to relate to the peer researcher, and in some cases having a connection, created an "automatic common ground" between the participant and the researcher. The overwhelming majority of the participants (n=13) described how this common ground meant they knew what to expect from the interaction with the peer researcher.

"Honestly it doesn't faze me in the slightest because I've seen, you know, they've been in the same or a similar situation. So, you know, that brings an automatic common ground of like, similar experiences" (MOAM/PR 6).

"If they had a past like me, they had past experience I would know what to expect off them" (MOAM/PR 7).

Despite a number of participants describing the importance of being able to develop a connection with the researcher because of their lived experience, some participants (n=4) explained it was not important, and therefore they did not have a preference for the type of researcher they met with.

"For me personally, I mean it doesn't matter to me. I am happy either way, it doesn't make a difference" (MOAM/PR10).

"I get on with them, on a personal level they seems all right. But, I don't think anyone's past for me personally really makes that much of a difference. Whatever their past is, I don't think it really counts" (MOAM/PR14).

Although others highlighted it would not make a difference to them, they recognised other participants might feel more comfortable meeting with a researcher with lived experience, particularly when answering sensitive questions.

"I think if someone wasn't used to doing that it may be an issue. But when you've been like through the prison system, and had to do loads of courses it's, its water off a ducks back really" (MOAM/PR14).

Two of the participants did not feel lived experience was a deciding factor, suggesting how the individual's character was more important than their personal lived experience.

"I did not really think about that to be honest. I was still as at ease with the second one as I was with the first" (MOAM/PR2).

"I'd be on the fence with that because, I wouldn't really mind either way. As long as the, as long as the character I was talking to was ok, you know?" (MOAM/PR5).

5.1.1.3   Sub theme: "Well they explained stuff to me really well"

In addition to shared experience, most of the participants (n=8) also highlighted the importance of soft skills when building rapport. The peer researcher's ability to explain the research tasks clearly by breaking down the process was considered important.

"Well they explained stuff to me really well when I asked questions. And if I didn't understand it you know, they could recognize that pretty quickly, and explained it a little bit more, without me really having to ask" (MOAM/PR 4).

"They explained everything clearly as well, like, you know, because I'm a bit slow at picking things up. They made me feel so at ease. They are a good person, they break it down for you really" (MOAM/PR8).

Other participants described a thoughtful, polite and helpful approach helped them engaged in the process.

"They were a really good person. They were very thoughtful, and they could talk to man! They would give me a call and we would have a little conversation. They would not just jump straight to 'alright we have got to do this, got to do that', you know?" (MOAM/PR3).

"Like cause personally good manners and that like" (MOAM/PR 14).

5.1.1.4   Sub theme: "Everybody's crimes are different"

In contrast, a few participants (n=3) highlighted depending on the peer researcher's previous offending behaviour they may find it difficult to relate to them. In particular, if the peer researcher had been involved in a sexual offence some of the participants explained they would find it difficult to build a connection.

"Yeah the only disadvantage that there would be on that side is the fact that everybody's crime is different" (MOAM/PR 6).

"I notice many of these questions are like, like about sexual, sexual offences. Yeah and I think, like maybe because we don't really like people like that. Maybe that would be a disadvantage if the person was like a sex offender" (MOAM/PR 14).

5.1.2   Theme: Impact of common ground

The second theme explored the impact of common ground describing how participants felt more relaxed, comfortable and at ease when meeting with a peer researcher. The peer researcher was able to calm some participants down during the meeting, and participants described how they felt less judged because the peer researcher had shared lived experience. The approach enabled some participants to be more honest, develop trusting relationships and broke down barriers to engagement. However, some participants described how they might struggle to be honest with a peer researcher if they thought they had not moved on from a life of crime or they gave the impression they were working for the probation or prison system. Mistrust of the system and the personal, sensitive nature of the research questions were also described as potential barriers to engagement not associated with the peer researcher approach. The three sub themes are described below and include: "I felt relaxed knowing that they'd been in my shoes", "I felt like I could be myself and answer honestly" and "I just didn't trust the process".

5.1.2.1   Sub theme: "I felt relaxed knowing that they'd been in my shoes"

The participants explained how this feeling of common ground affected how they engaged in the research process. Several participants (n=9) described how they felt more relaxed, comfortable and at ease when they met with the peer researcher because they had shared lived experience of the criminal justice system.

"There is no like, what are you on about and all that, you know, because they have already been in it, that situation. It made me feel a bit more relaxed, knowing that they had been in like my shoes and that" (MOAM/PR1).

"I felt good about it actually, because obviously they had past experience like me, and I just felt comfortable" (MOAM/PR4).

Some of the participants (n=3) described how, initially, they felt nervous about meeting the peer researcher, but over time they felt more relaxed after a couple of meetings.

"It felt a bit weird when I first met him and that, but after the first one or two sessions I felt relaxed" (MOAM/PR1).

"At first, I was a bit worried about it, but they were a good person. I got on very well with them. You could be yourself with them, so that was a good thing" (MOAM/PR12).

For one of the MOAM participants the feeling of automatic common ground meant the peer researcher was able to calm them down during the meeting when they felt worried and upset.

"It was when they said they had been in the same situation like, you know, and it more or less calmed me down really. It is always about a second chance like, you know. They made me feel at ease quite quickly" (MOAM/PR8).

5.1.2.2   Sub theme: "I felt like I could be myself and answer honestly"

Several of the participants (n=12) described how they did not feel judged by the peer researcher because of their shared lived experience and therefore they felt able to answer the questions they were being asked.

"If you are answering a question that only someone who has been to jail can kind of understand. If you get someone who's never been to jail, you'll feel more judgement against yourself so you probably wouldn't answer as many questions" (MOAM/PR3).

"You know you're not being judged either. Yeah, I felt comfortable" (MOAM/PR4).

Others (n=9) described how the experience broke down some of the barriers between the client and professional because the interaction was like a normal conversation.

*"*If I were to go see him, it was a bit like a normal conversation rather than a formal conversation" (MOAM/PR 10).

"[The peer researcher] was a really nice person. I never felt, felt like, there wasn't any kind of 'I'm the professional, you're the kind of the client' kind of thing it, it was really good" (MOAM/PR4).

The impact of the peer researcher approach meant several of the participants (n=8) felt able to be honest, and opened up when answering the questions because they felt at ease and comfortable during the research meeting.

"You can open up like more honestly with them and that, like they have already been in my situation and that. So I felt more like comfortable chatting about stuff" (MOAM/PR 1).

"I just think it was great, to be honest, because they were the first person that I ever opened up to. I am not the easiest person. As soon as they told me like, you know, I thought yeah, course you can, sit down!" (MOAM/PR8).

Nearly all of the participants (n=13) described how they felt able to trust the peer researchers because they could relate to them and they felt understood.

"Yeah, they made me feel like, like I said, like they weren't just some, how do you say like a, a desk person who's never been through it, who's just kind of judging you against your answers" (MOAM/PR3).

"To be honest I trust them more knowing that they have been in jail, because then that way I just feel that then they been through what I been through, and stuff like that" (MOAM/PR13).

A few of the MOAM participants (n=2) also shared examples of how their experience of meeting with a peer researcher enabled them to start to develop trusting relationships with

other members of the research team or their probation officer as they became more comfortable.

"The second person I had, that person. I did not, I did not really think about that. You know what I mean, and I think that was because I'd already got trust with [the peer researcher]" (MOAM/PR2).

"I couldn't, I couldn't speak openly to people about things in the past. But now, doing everything like this, it helps. It's helped me to talk to my family, friends, probation, anyone" (MOAM/PR7).

5.1.2.3   Sub theme: "I just didn't feel able to trust the process"

Despite the feeling of "automatic common ground" expressed by the majority of the MOAM participants, some (n=6) explained they still might not feel able to disclose honest answers during the research meeting. The MOAM participants described how they found it difficult to interact with the peer researcher if they had not fully moved on from participating in criminal activity.

"I think if they're still held onto their prison mentality or a criminal mentality, I think that would be a bit of a disadvantage really. You know because for me, I wanted to move on from the system and you know. I don't think sitting there talking prison talk as such would be so beneficial to me" (MOAM/PR 5).

"A disadvantage is maybe being too involved with someone who's mixed up, and that maybe if the participant is mixed up in criminal lifestyle still they could get dragged into it" (MOAM/PR 10).

One participant disagreed with the peer research approach explaining how they did not feel it was appropriate for someone who had been in prison to be collecting data for a research study.

"I don't think it's right if someone's sat in front of me who's been to jail, and then they're

asking me about my problems. I don't think that's right" (MOAM/PR 13).

Another raised concerns about the peer researchers no longer being peers, suggesting how

they could now be considered part of the prison or probation system.

"You know it wouldn't really matter I suppose, because even if they have been in prison they

can still you know change, and want to be part of that system" (MOAM/PR 9).

However, other participants (n=2) explained their response to the research process was not a

reflection of how the peer researcher interacted with them, they just did not feel able to trust

the research process because of their own experiences.

"I couldn't. It wasn't anything to do with the researcher. I just did not trust the process

because of my experience. I lied; I lied on every single question, to be honest"

(MOAM/PR4).

"I have bad paranoia anyways. So when they was asking me questions I was a bit like

anxious, because like I had an argument with my girlfriend and I was on bail" (MOAM/PR9).

For one participant the research questions brought back difficult memories. However, this

type of response to the study did not appear to be related to the experience of meeting with a

peer researcher.

"No it wasn't with the honesty element. It was just basically like bringing it all back up,

bringing it back to the surface" (MOAM/PR6).

5.1.3   Theme: The impact of being able to see somebody who's progressed

The third theme explored the impact of the peer researcher approach on the

participants. The participants described the peer researchers as "positive and inspiring

individuals" who had been given a second chance. Some participants explained how the

process gave them an insight into themselves, describing the experience of meeting with a

peer researcher to complete the research questions as an opportunity to reflect on their past, and concentrate on their future. The peers were an example that change was possible. The opportunity to give something back through participating in the trial and the peer researchers being an image of hope was important for some of the participants. However, others describe the process having little impact on them personally, as they were already in control of their lives. The three sub themes are described below and include: "I held them in high esteem", I reflected on my own behaviour and it has given me hope for the future.

5.1.3.1 Sub theme: "I held them in high esteem"

The majority of participants (n=10) who met with a peer researcher described the peers as "positive inspiring individuals" who were progressing in their lives.

"[The Peer researcher] was somebody that I looked up to, you know. That, you know kind of helped me decide that I really wanted to do this kind of stuff myself" (MOAM/PR4).

"I held them in, them in high esteem" (MOAM/PR5).

Some of the participants suggested how the peer researchers were an example that change was possible, and they had been given a second chance in life.

"The only positive impact is, you know, being able to see somebody that's working who's progressed. Which is what I'm trying to do, and struggling at the moment" (MOAM/PR6).

"You know what I mean, it's just to look at it [the peer researcher], you think fair play" (MOAM/PR2).

One participant described in more detail how they considered the peer researcher they met with as a role model, who has had a real, personal, positive impact on their life.

"It has just had a good impact on my life at the moment. It is sad, because I lost my dad when I was a young age, so I never had a male role model. So to have someone who is trying to tell me this and that, it's nice to know" (MOAM/PR12).

5.1.3.2   Sub theme: I reflected on my own behaviour

The experience of completing the research questions every three months with a peer researcher gave some of the participants (n=8) the opportunity to reflect on their past behaviour.

"Have you committed, have you threatened somebody in the last three months, for example? If you say 'no', you actually have not, and then three months later you have to go back and put 'once', it's kind of like you're letting yourself down. So in terms of that, looking at that, actually having that in front of you, you know it is quite eye opening." (MOAM/PR2).

"It has like made me like look at life. Some of them questions, like my criminal past and whatever. Like where I was going wrong and that, like the need for like direction and that" (MOAM/PR1).

Participants described how the experience of meeting with a peer researcher not only helped them to reflect on the previous behaviour, but also encouraged them to focus on their future and developing their skills.

"I suppose, because I've kept on top of my targets. So over the time. I've had my little set of targets to do since I've been out of prison, and I've hit all of them so far if not more" (MOAM/PR10).

"To do things properly in life, and there isn't no time for crying about things. I need to sort me life out. So that's, that's what it's helping me do" (MOAM/PR12).

However, one participant explained the process of answering the questions was difficult because it bought up feelings from their past describing how this was a helpful and unhelpful experience and they just really wanted to move on with their life.

"So, for some people it might work, but for me it doesn't. It just winds me up because, like it, just makes me more wound up because I am just talking about like all my past and that. I really want to move forward in my life, if you know what I mean" (MOAM/PR13).

For others (n=2), they did not feel the experience of meeting with the peer researcher had any impact on them, describing how the process was not for them but for the research team.

"No I don't think so. I don't think it had that kind of impact on me" (MOAM/PR5).

"It did not do anything for me. It was not for me, it was obviously for your research. You know, it was nothing off my back. I was just there to answer the questions, the same questions every few months" (MOAM/PR9).

5.1.3.3   Sub theme: It has given me hope for the future

The experience of meeting with the peer researcher to complete the questionnaires gave some participants (n=6) motivation to move on with their lives and hope for the future.

"It gives me hope that I can definitely get somewhere myself. Because I thought well after [the peer researcher] told me a little bit of, I am not sure of their whole life, but they did tell me a little bit. As I say it inspired me that I can, I can get to where [the peer researcher] is" (MOAM/PR4).

"It does give some form of hope. You know, that some have a career prospect" (MOAM/PR6).

The process of being involved in the research trial was also described as an opportunity to do something positive, by giving something back to a society that they might not have felt part of before.

"So it's, yeah, it makes a difference, you know? Trying to give something back to society that I've always just thought I could take from" (MOAM/PR3).

"For me the positive impact would be sitting through some uncomfortable questions, but being grounded around it, and you know realizing that I'm involved in a project that hopefully will be helping people" (MOAM/PR5).

However, one participant explained, that although meeting with a peer researcher may be useful for some people, they felt they already had a positive outlook on their future and felt in control of their life.

"I am on a life license so that is more than enough motivation for me to like not do anything. So I think it is good work, and it will benefit like a lot of people, even if I don't personally think it will benefit me, cause I'm kind of in control of myself" (MOAM/PR14).

5.1.4 Summary

The majority of the participants who met with a peer researcher described the experience positively. Meeting with a researcher who had similar lived experience to themselves, broke down some of the power imbalances between the interviewer and interviewee creating an "automatic common ground" as the participant felt able to relate to the peer researcher they met with. The creation of "automatic common ground" appears to be an important concept in aiding our understanding of how the inclusion of researchers with lived experience has the potential to improve the quality of the data collected. Through common ground, the participants described how they knew what to expect when they met with the peer researcher, which enabled them to trust the peer and disclose honest answers to the research questions supporting the hypothesis of the thesis. In addition to lived experience, soft skills including a friendly and polite approach were also valued. Lived experience alone did not appear to guarantee the participant would engage. Furthermore, some of the participants reported an additional impact of the approach describing how meeting with a peer researcher encouraged them to reflect on their past and focus on their future, reminding them change was possible. The peer researchers were described as "positive and inspiring individuals" who gave them hope for the future. The personal accounts shared by the participants suggest the interactions with the peer researchers did have

a powerful impact, especially for those participants who had not met with a peer researcher or an individual in a similar role before. However, this was not the case for all participants, and some highlighted the limitations of the approach.

The participants raised concerns about to which group the peer researchers now belonged. Were the peer researchers still a peer; had they really moved on from their criminal past or had they now become part of the probation system? In addition, some participants found the experience of meeting with a peer researcher to complete the outcome measures for the trial distressing. The participants explained how they found it difficult to talk about their past and wanted to move on from their offending behaviour and the systems associated with that part of their lives. It was suggested that struggling to develop a trusting relationship was linked to the participant's personal experiences. However, environmental factors including how the participant was feeling before the meeting and their experience of meeting in a probation or prison environment might have also affected how the participant experienced the interaction with the peer researcher. The next section of this chapter will explore the experiences of the participants who met with a UCL research assistant to complete the outcome measures for the trial.

5.2   MOAM participants - research assistants

The second group of MOAM participants (n=15) met with a UCL research assistant who had no lived experience of the criminal justice system (MOAM/RA). Analysis of the semi-structured interviews with this group of MOAM participants produced two themes; Experience of meeting with a research assistant and The peer researcher approach. The participants explained how before the meeting they felt apprehensive because they did not know what to expect from the interaction. However, once the participant had met with the research assistant they felt able to relax and described the researchers as "good people". The

participants suggested the interaction was as an opportunity to reflect on their own behaviour, but for others there was little or no impact. As well as describing their experiences of meeting with a research assistant, the participants were asked to share their thoughts about what it might be like to meet with a researcher with lived experience of the criminal justice system to complete the outcome measures. The participants described how a peer researcher might have a better understanding of their situation because they had also served a community or prison sentence. However, the participants highlighted the importance of the individual's communication style and their ability to control their own aggression as important skills in addition to their lived experience. Some participants suggested there might be no difference between the two types of researchers, whilst others were concerned that the experience of meeting with a peer researcher may lead to them reflecting negatively on their own personal circumstances. The themes and sub themes for the interviews conducted with the participants who met with a research assistant are described in more detail below, and are set out by domain in appendix U.

5.2.1   Theme: Experience of meeting with a research assistant

In the first theme, the MOAM participants who met with a research assistant explained how they felt before, during and after the meeting. The participants described feeling apprehensive and somewhat on edge before they met with the research assistant. The participants explained because they did not know the researcher they were worried about being judged and therefore found it difficult to trust them. Most of the participants suggested they felt more relaxed once they had met with the researcher, and the research assistants were described as "friendly, polite and respectful". The participants explained how the researchers communicated clearly and normally, and took the time to explain the research process to them. The ability of the researcher to look them in the eye was highlighted as especially

important to ensure they felt listened to and understood. Others suggested feeling understood was not important as they were just filling out outcome measures for a research study, which did not benefit them directly. The majority of the participants described how meeting with the research assistant to complete the outcomes measures had a positive impact on them, and gave them the opportunity to reflect on their own lives. For some, the process was therapeutic and enabled them to feel more positive about the future. Others highlighted the opportunity to give back and help others. However, not all of the participants found the experience of meeting with a research assistant and answering the questions had a positive impact on them, and others described little or no effect. The three sub themes are described below and include: "Initially, it was quite daunting for me", Everything was good in the room and It helped to talk to someone.

5.2.1.1   Sub theme: "Initially, it was quite daunting for me"

Some of the participants (n=8) explained how they felt before they met with the UCL research assistant for the first time to complete the outcomes measures for the trial. Some of the participants described feeling apprehensive and on edge before the meeting.

"I was a bit apprehensive at first so I didn't really ask that many questions" (MOAM/RA29).

"Yeah, like the first time I was really on edge, do you know what I mean?" (MOAM/RA16).

Others described the experience as daunting because they did not know the researcher, and therefore did not know what to expect from the interaction.

"It was a little daunting at first because obviously I didn't know them, you know I didn't really know what to expect" (MOAM/RA25).

"Initially, it was quite daunting for me" (MOAM/RA24).

One participant compared the feeling of meeting with a research assistant for the first time to a job interview, describing how they felt nervous and anxious because they did not know what the outcome would be.

"Well, the most difficult thing, as I said, it's like going for a job interview. So that whole anticipation" (MOAM/RA29).

One of the participants were worried about being judged by the research assistant they met because of the crimes they had committed.

"At first I was a bit nervous about what questions they were going to ask. You know like, meeting someone new and all that, and you are talking about your life and all about that, and the lifestyle I have lived" (MOAM/RA16).

Whilst another found it difficult to trust the research assistant because they saw them as part of the probation system.

"At first, not really, because I didn't really, because of this probation thing, because it was via probation. I just kind of thought something dodgy was going to happen to me, but eventually over a period of time I was able to sort of, yeah, came forth with answers" (MOAM/RA29).

Despite the concerns raised by some of the participants about meeting with the research assistant for the first time, several participants (n=5) described how they felt more relaxed once they had met with the researcher in person and they felt able to answer their questions.

"I think the difficult thing is when I met them for the first time you are talking about personal things, that's kind of, awkward. But, I met [research assistant] a few times, and the more times I met them and spoke to them over the phone, I became more comfortable with them" (MOAM/RA25).

"I wasn't too sure at first, but it was alright after I got into it" (MOAM/RA27).

One participant explained how they did not find the experience of meeting with the research assistant for the first time as daunting because they had experienced similar scenarios as part of the support they had received in prison.

"You know it is like, because I have done four years in therapy in prison. I've gone through that experience of being questioned, and you know giving answers. So you know it was not as daunting as what it was like being asked questions years ago" (MOAM/25).

5.2.1.2   Sub theme: Everything was good in the room

The majority of the participants (n=12) described the experience of meeting with the research assistants to complete the outcome measures for the trial as positive.

"Everything was good. They are a good person; do you know what I mean? Yeah it was great yeah. I got nothing bad to say about it, it was nice, it's had a good effect on me. I'm happy" (MOAM/RA18).

The participants suggested the research assistants they met with were friendly, good people who understood them and were easy to talk to.

"They were an absolute legend; I have no faults with them. They made me feel really comfortable, and were easy to talk too. They were a really nice person, really helpful, yeah, really good" (MOAM/RA26).

"It was really good, calm, they understood me do you know what I mean? They were really helpful and friendly" (MOAM/RA16).

The participants highlighted the researchers' respectful, clear and normal communication style as important because it made them feel as if the research assistant was interested in what they were saying.

"When I used to speak to them, they used to speak back to me normal. Yeah, pretty much, they were just asking me questions and I just felt OK. I didn't feel any pressure or anything" (MOAM/RA30).

"You know, never talked down to you. Listened. So yeah it was alright, it was good" (MOAM/RA20).

The research assistant's ability to look them in the eye and maintain real eye contact during the meeting was highlighted as important by two of the participants and a different approach from other professionals.

"They look at you in the eye, and what have you, you know what I mean. Most people in authority, you know obviously I am not saying everybody, but like you are doing a mundane job and you have to see someone, but really, they are not interested. When I get like that, I just clam up, and do not say nothing" (MOAM/RA17).

"You can tell when some people are actually listening and these people were actually looking at me, talking, they was taking it in, listening, so yeah they made me feel comfortable. I could actually talk; I could actually talk to them" (MOAM/RA23).

In addition to a clear style of communication, the participants described how the research assistants took the time to explain the research process to them and offered support if they struggled with any of the questions.

"You know, they explained everything and I just felt at ease with them you know what I mean, it's all good" (MOAM/RA17).

"I was allowed time to think about the questions and what answers were given. So it was a, a bit of a sensitive, but a good experience" (MOAM/RA25).

Nearly all of the participants (n=14) explained they felt listened to and understood by the research assistant they met with because of their engagement style.

"I felt it was all right with both of them. I felt comfortable. I would not do it mate, if I did not feel comfortable mate, believe me. Do you know what I mean, I'd have told them like fuck off I isn't doing it!" (MOAM/RA22).

"I felt at ease, you know. I did not feel on edge. I felt at ease, and it went okay" (MOAM/RA21).

However, one participant explained they did not need to feel understood because it was just a questionnaire.

"Yeah, I felt like they understood me, but it wasn't really, how can I put it? Because it was a questionnaire and that. It was, like, I think it wasn't really, it was more just to put down stuff on paper, wasn't it?" (MOAM/RA30).

For some (n=2), the high-street vouchers given to each of the participants at the end of the meeting to thank them for completing the outcome measures encouraged them to engage in the research process, regardless of whom they met with.

"The first time they said like come meet me and we will give you vouchers, and I thought I would not mind meeting a lady for 10 minutes and getting given money for it. That is sound as fuck like, you know what I mean" (MOAM/RA22).

"Yeah, it definitely worked when you are giving out free vouchers" (MOAM/RA20).

5.2.1.3 Sub theme: It helped to talk to someone

The majority of the participants (n=13) described how meeting with the research assistant to complete the outcomes measures for the trial had a positive impact on them.

"Someone else being there, listening. It does have some sort of positive impact on you. Even if you do not realise it. Later on down the line when you think about it, and you pull all those little memories together of all the times that you shut down with someone or this, that, and the other" (MOAM/RA20).

The participants explained how meeting with the research assistant every three months gave them the opportunity to reflect on their own behaviour.

"I think it's some of the questions that have stuck with me like, and they've made me like re-evaluate certain things" (MOAM/RA24).

"When they used to come to see me in jail and they used to ask me questions. I would sit there and I would be, like, 'Wow, I actually calmed down a bit and I'm not getting into so many arguments as much'" (MOAM/RA30).

Others (n=5) elaborated further, describing the process of meeting with a research assistant to complete the questionnaires at regular intervals as "therapeutic".

"I find it like therapeutic, like counselling do you know what I mean" (MOAM/RA16).

"So yeah it has helped me in getting it out sooner rather than later. Talking and stuff, because I've got an issue with it I close up and don't talk" (MOAM/RA23).

For some participants (n=4) the experience of meeting with a research assistant to complete the outcome measures had a positive impact on the way they saw their future.

"I think now, I see the future a little bit better than I did when I first met the researchers" (MOAM/RA23).

"It's definitely affected how I see the future. Basically, obviously I've got a lot of shit going on in my life, but I can't tell you certain things about me do you know what I mean. It's definitely had a good positive effect on me, yeah" (MOAM/RA18).

For one participant in particular, the experience supported his rehabilitation and helped him to stay out of prison.

"Well it has helped me. Well, when I think of the people that have helped me while I am out, outside of prison. It helps me to try and stay out of prison" (MOAM/RA19).

Two participants explained, for them, meeting with the researcher was more about giving back and helping others than having a direct impact on themselves.

"So like if it can help other people you know to get a better perspective and like, what we've been going through as like ex-prisoners or whatever. If that's what helps with all that then, it's got to be a good thing" (MOAM/RA17).

"It is going to help the next generation, and the youngsters obviously, because it is not going to help me is it? I'm too old now anyway" (MOAM/RA18).

In contrast, other participants (n=2) felt the experience had little or no effect on how they felt about themselves or their future.

"I do not know. I do not know how to answer that, sorry. I just don't see how it can affect my future by being asked a couple of questions" (MOAM/RA28).

"The way I see the future will always remain the same. The future, we are here, we are here for a short time and then we are gone. But yeah, me I just take each day, you know what I mean?" (MOAM/RA20).

5.2.2   Theme: The peer researcher approach

In the second theme, participants who had met with a research assistant described their thoughts and ideas about hypothetically meeting with a peer researcher who had lived experience similar to their own. The participants described how a peer researcher might have a better understanding of their situation and therefore they would feel able to relate to them. Some of the participants suggested the peer researchers had more experience than the research assistants did, and it was vital that a researcher who was collecting data from participants in the criminal justice system had personal lived experience. The participants highlighted the importance of picking the right people to become peer researchers. Explaining how a peer needed to have strong listening skills and the ability to control their own behaviour during the research meeting. There was a range of feedback from the participants about the type of the researcher they would prefer to meet with. Some valued the

idea of meeting with a researcher with personal lived experience because they thought they would feel more understood. Others felt, they would benefit from meeting with a research assistant to complete the outcomes measures because it was an opportunity for shared learning and preferred to keep their experience in prison separate from their life in the community. A third group of participants suggested they did not have a preference; it was the same outcome regardless of whom they met with. The two sub themes are described below and include: "They already know roughly the ins and outs about things" and "Well, it depend on what that sort of person is like".

5.2.2.1   Sub theme: "They already know roughly the ins and outs about things"

All the participants (n=15) explained that because the peer researcher had had lived experience of the criminal justice system, they would have had a better understanding of how they were feeling.

"You know people could have the best intentions in the world like you know what I mean? But until you actually walked in someone's shoes, it's like well you don't really know" (MOAM/RA17).

Two of the participants described how the shared experience of prison or the probation system would have enabled them to relate to the researcher, compared to someone with no experience of the criminal justice system.

"You can relate to them more obviously; do you know what I mean. Well, if they have been through the criminal justice system, you have some sort of fucking idea!" (MOAM/RA22).

"It gives you an insight into like their behaviours and things like that, which maybe they wouldn't have been pointed out like you know what I mean? Well, like your mood swings you know, and like why like you know you get frustrated with people" (MOAM/RA17).

For one participant they felt the shared understanding meant it would have been easier to have explained their answers because the peer researcher would already have understood how they were feeling.

"Well, yeah, definitely, because it makes it more easier to explain things. Not having to like go into detail about so many things you've done, because they already know roughly the ins and outs about things" (MOAM/RA28).

Some of the participants (n=2) suggested that because the peer researcher had had lived experience of the criminal justice system, they would have had more experience than a researcher who had not been in prison or under supervision by the probation system.

"Yeah, I think obviously they would be more experienced wouldn't they. Because someone who is going into prison for the first time will no doubt be very, very nervous" (MOAM/RA19).

"I think I guess it's having that option of all-round experience. Of that you know, to be able to get the most from these answers out of people, that's probably a good way to deal with it you know" (MOAM/RA24).

In addition to the advantages described by the participants, some (n=2) felt it was vital for a researcher who was meeting with participants who were in prison or under supervision by the probation system to have had lived experience to be able to understand the participants they met with.

"Yeah, I think it would be an advantage if someone has been to prison, because they know more about prison than a person who hasn't been to prison. You know, they have got more experience than people who haven't been to prison" (MOAM/RA21).

"I think it's vital to be honest. If you haven't got experience in life you're not going to have experience being able to deal with different sorts of people, so yeah, I think it's vital" (MOAM/RA26).

5.2.2.2 Sub theme: "Well, it depends on what that sort of person is like"

In the second theme, the participants (n=15) who had met with a research assistant highlighted the importance of the individual when thinking about involving peer researchers as data collectors for a research study. One participant explained it was important to pick the right kind of person to take on the role of a peer researcher.

"I can't see any issues around it, as long as you pick the right people" (MOAM/RA26).

Some of the participants suggested to be an effective peer researcher the individual must be able to listen to others, and be motivated to make a change in their own lives.

"So I think, I think in a way, you find the right people who come out and they want to change their lives and become researchers, then I think that benefits people like better" (MOAM/RA20).

"Well, it depends on what that sort of person is like, isn't it? Because as I said, someone that thinks they know it all can be very egotistic. So like, and when someone's got a big ego, they don't like to listen to other people" (MOAM/RA29).

If the peer researcher was not able to control their behaviour during the meeting this was described as problematic.

"Not for the people they're meeting but for themselves there could be. Well you never know what they went to jail for do you?" (MOAM/RA27).

"Well, just, if they can't really control their violence, or whatever it is that they were put in prison for in the first place, then that could be a disadvantage. Because sometimes it ends up getting messy or something and you just think 'AARGHH' and blows it, and ends up losing their job" (MOAM/RA20).

For others (n=3), the impact of the peer approach would also depend on the type of person being interviewed, and if they felt able to trust someone.

"It depends on their attitude, so their trust in other people and that. Someone who's being interviewed may trust someone who has been in a similar situation to themselves, you know" (MOAM/RA25).

"Some people don't like speaking about it. In my eyes I don't really give a fuck like, but other people might think 'ah I can't be fucked to see them' you know what I mean" (MOAM/RA22).

The importance of the individual was mirrored in the different opinions amongst the MOAM participants regarding the type of researcher they would have preferred to meet with to complete the outcomes measures for the trial. Some participants felt very strongly that they would have preferred to meet with a peer researcher.

"Yeah definitely, because they'd just understand more" (MOAM/RA20).

"It's like if you're doing drug awareness or anything like that, and you've got like, if they're a trainee who hasn't had any life experience really, talking to you about drugs and shit like that. It's like 'well, what the fuck do you know really?" (MOAM/RA17).

One participant felt, they benefited from meeting with a researcher who did not have lived experience of the criminal justice system similar to their own.

"To be fair, it's benefited me in many other ways speaking to the people that I spoke with previously" (MOAM/RA23).

Furthermore, some participants suggested meeting with a research assistant was a real opportunity for shared learning for themselves and the researcher.

"It's all a learning experience for everyone isn't it you know. You know someone who has been to prison on probation they have experienced that, but those who have not they then maybe get to see experience of other individuals, because some people get along with probation, others do not" (MOAM/RA25).

"It is like they're telling me things I don't know, and I can tell them things they don't know" (MOAM/RA28).

For one participant they suggested the interaction of meeting with a peer researcher might make them feel negatively about themselves because they may believe the peer researcher had achieved more in their life.

"I think you could possibly feel like, I don't know, in theory like that they've done loads better than you, you know" (MOAM/RA24).

Another suggested they would prefer to meet with a researcher assistant, explaining how they tried to keep their experience of prison separate to their life in the community.

"I like to try to keep prison; I'm out of prison now so. I like to keep them separate" (MOAM/RA19).

In contrast, several participants explained that it would make no difference to them if the researcher they met with had served a prison or community sentence, and they suggested they would feel comfortable meeting with either a peer researcher or a research assistant to complete the outcomes measures.

"With me, if they have been to prison or not been to prison. It would not bother me either way. Yeah it wouldn't make much difference at all if you've been to prison or not been to prison" (MOAM/RA21).

"It is same end result, I suppose. I wouldn't feel any different" (MOAM/RA27).

5.2.3   Summary

Before the participants met with a research assistant they described feeling apprehensive, worried about being judge and unsure about the meeting. Some participants described the first meeting as "daunting" and another compared the experience to attending a job interview because they did not know what to expect from the interaction. In addition,

some of the participants were worried about the research assistant being part of the probation system, and therefore were uncertain if they could trust them. These initial feelings of apprehension, because the participant did not know what to expect from the interaction with the research assistant, could be understood as a potential barrier to engagement. However, once the participant had sat down with a research assistant and started to complete the outcomes measures they described feeling more relaxed. The research assistants' positive and friendly approach was important, as well as a clear and "normal communication style". The participants described how they felt listened to and the meeting had a positive impact on them as it was an opportunity to reflect on their own behaviour, with one participant describing the process as "therapeutic". However, despite the positive feedback some participants suggested the experience of meeting with a research assistant had little or no effect on them and they were just there to answer research questions. Others described the process of completing the outcome measures as similar to the courses they had completed in prison and therefore already felt comfortable participating in the study. The offer of vouchers and the opportunity to give something back to society was a powerful engagement tool for some of the participants, not the type of researcher they met with. The range of reported impacts of the experience might have been related to the participant's personal circumstances at the time of the meeting, and this should be considered when interpreting these findings.

In contrast, the participants suggested if they had met with a peer researcher, it would have been a different experience because they would have felt able to relate to the researcher. The participants described how they thought it would have been easier to explain their answers because the researcher would understand because they had also serviced a custodial or community sentence. Despite the overall positive feedback about adopting the approach, the participants highlighted the individual peer researcher's skills were important and to what degree they had moved away from engaging in offending behaviour or associating with

individuals in the criminal justice system. These individual characteristics were not suggested to be as important for the research assistants. When asked to compare their actual experience of meeting with a research assistant to a hypothetical experience of meeting with a peer researcher the responses were mixed. Some participants felt strongly that they would prefer to meet with a peer researcher because of their shared lived experience, whilst others suggested they would prefer to meet with a research assistant, as it was an opportunity to learn from someone who had different life experience to themselves. Some participants described how meeting with a peer researcher whom they considered to have moved on with their lives might make them feel negatively about their own progress and others suggested they did not have a preference. The range of different preferences could have been affected by the different engagement styles adopted by the research assistants the participants met with. Furthermore, the fact the interviews were completed for this study by researchers with no lived experience may also have had an effect on the answers the participants gave. The next section of this chapter will bring together the experiences of the participants who met with a research assistant and the participants who met with a peer researcher to complete the outcome measures for the trial to identify patient and public involvement and non-patient and public involvement impact.

5.3   Qualitative summary

When interpreting these results, it is important to remember that both groups of researchers followed the same study protocol. All 313 trial participants met with the researcher in either a probation office or prison to complete the outcome measures for the randomised control trial. The same set of outcome measures were completed with the participant and at the end of each meeting both groups received the same amount of high street vouchers to thank them for giving up their time to participate in the study. The

description of the qualitative analysis included in this chapter does not attempt to compare the experiences of the participants who met with a peer researcher against those who met with a research assistant. However, as previous studies have highlighted (Crocker et al., 2018), it is important to review the qualitative accounts from both groups of participants in order to identify the experiences specifically related to meeting with a researcher with lived experience, as to the impact which may have occurred anyway as a result of meeting with a traditional researcher. The differences and similarities between the qualitative accounts from the two groups of participants are explored in the summary below.

The participants who met with a peer researcher described how there was "automatic common ground" between them and the peer they met with because of their shared lived experience. This common understanding of language and the realities of the criminal justice system, for some, led to the development of a trusting relationship between the participant and the peer. The ability of the peer researcher to break down barriers to engagement, particularly during the initial meeting, were specific to the researchers with lived experience. However, the qualitative reports from both groups of participants who either met with a peer researcher or research assistant also highlighted the importance of soft skills. Both groups of participants described a friendly, polite and clear communication style as key in encouraging them to engage in the research process. These soft skills were not related to individual researcher's lived experience of the criminal justice system, but were still described as an important engagement tool by the trial participants. Some of the qualitative accounts from the participants who met with a peer researcher or a research assistant also described how they struggled to trust the researcher they met with, but the reasons for this reported lack of trust differed across the two groups.

Some of the participants who met with a research assistant suggested they found it difficult to trust the researcher, particularly in the initial meeting, because they did not have

shared lived experience of the criminal justice system. On the other hand, the participants

who met with a peer researcher described how they might struggle to trust a peer, as they

were not sure which group they now belonged to. Had they really moved on from their

criminal past or had they now become part of the probation system? The participants who

met with a research assistants, but were asked about what they thought it might be like to

meet with a peer, supported these qualitative reports highlighting the importance of an

individual's characteristics. The different reasons for why some of the participants struggled

to trust the researcher they met with are specific to the type of researcher, and therefore these

findings indicate the potential limitations for researchers with and without lived experience as

data collectors. Beyond the impact on rates of engagement, the qualitative reports from the

trial participants who met with a peer researcher or research assistant also described the

personal impact of the experience.

The peer researchers were described as "positive and inspiring individuals", and for some

participants the experience of meeting with them every three months encouraged them to

reflect on their own behaviour, and gave them hope for the future. Some of the qualitative

accounts from the participants who met with a research assistant also described the

interaction positively and explained how the participants benefited from talking to someone

at regular intervals over a two-year period. However, although most of the participants who

met with a research assistant described the experience in a positive light, the qualitative

accounts from this group did not suggest the research assistants were seen as role models and

therefore this impact was specific to the peer researchers. In addition to the positive reported

impact of the experience, both sets of qualitative accounts described how the research

questions could cause distress and some participants found the process upsetting regardless of

the type of researcher they met with. The next section of this chapter will explore the

quantitative results from the participants who met with a research assistant or a peer researcher to complete the outcomes measures for the trial.

Quantitative analysis

5.4   MOAM participants - peer researchers and research assistants

A third group of MOAM participants completed a nine item self-report scale sharing their experiences of meeting with a research assistant or peer researcher to complete the follow up measures. At the end of the follow up meeting, the MOAM participants were asked to rate nine statements on a self-report scale using a 5-point Likert scale ranging from strongly disagree to strongly agree in relation to their interaction with either a peer researcher or research assistant at their previous meeting. The scale explored the researcher's style of communication; if the participant felt able to trust the researcher and the potential impact of the interaction. An independent samples t-test was conducted to compare the participants' experience of either meeting with a peer researcher or research assistant to complete the follow up outcome measures. There was no significant difference in the scores across both groups.

5.4.1   Results

There were no differences between participants seen by an RA or PR. Participants in both groups described how the researcher made them feel relaxed during the meeting, (peer researcher M=4.56, SD=.564, research assistants M=4.73, SD=.451; t(74)=-1.46, p=0.15, d=-0.34) and they felt able to ask the researcher questions if they did not understand (peer researcher M=4.72, SD=.457, research assistant M=4.66, SD=.479; t(74)=0.55,p=0.578, d=0.12). The participants who met with the peer researcher or a research assistant both explained how they felt able to trust the researcher they met with (peer researcher M=4.13, SD=1.070, research assistant M=4.39, SD=.754; t(74)=-1.23, p=0.224, d=-0.29) and therefore

felt able to give honest answers (peer researcher M=4.59, SD=.499, research assistant M=4.68, SD=.471; t(74)=-0.81, p=0.421, d=0.19). The participants indicated how both types of researchers listened to them (peer researcher M=4.66, SD=.483, research assistant M=4.55, SD=.589; t(74)=0.88, p=0.38, d=0.2); they felt understood by the researcher (peer researcher M=4.44, SD=.801, researcher assistant M=4.43, SD=.661; t(74)=0.05, p=0.952, d=0.01) and the researcher communicated with them in a way they could understand (peer researcher M=4.63, SD=.492, research assistant M=4.64, SD=.487; t(74)=-0.09, p=0.929, d=0.03). The participants suggested they would feel comfortable meeting with the peer researcher or research assistant they met with again to complete another batch of questionnaires (peer researcher M=4.63, SD=.492, research assistant M=4.66, SD=.479; t(74)=-0.27, p=0.788, d=0.07) and described the experience of meeting with the researcher as positive and empowering (peer researcher M=4.38, SD=.793, research assistant M=4.34, SD=.680; t(74)=0.23, p=0.814, d=0.05). See table 6 below for a summary of the results.

Table 6: Results of participant self-report scale

	PR	RA	t-score(df)	p- value
	Mean (SD)	Mean (SD)		
Felt relaxed	4.56 (.564)	4.73 (.451)	-1.46(74)	0.15
Able to ask questions	4.72 (.457)	4.66 (.479)	0.55(74)	0.58
Felt able to trust the researcher	4.13 (1.070)	4.39 (.754)	-1.23(74)	0.22
Felt able to give honest answers	4.59 (.499)	4.68 (.471)	-0.81(74)	0.42
Felt listened to	4.66 (.483)	4.55 (.598)	0.88(74)	0.38
Felt understood	4.44 (.801)	4.43 (.661)	0.05(74)	0.95
Clear communication	4.63 (.492)	4.64 (.487)	-0.09(74)	0.93
Would feel comfortable meeting again	4.63 (.492)	4.66 (.479)	-0.27(74)	0.79
Positive and empowering experience	4.38 (.793)	4.34 (.680)	0.23(74)	0.81

PR = peer researcher, RA= research assistant, SD=Standard Deviation

5.5   Quantitative summary

In contrast to the qualitative data, both groups of participants reported a positive experience of meeting with either a peer research or research assistant to complete the outcome measures for the trial. Out of a total score of five, the participants who met with a peer researcher or research assistant rated each statement with a mean average of at least 4.13. The participants who met with a peer researcher rated 'able to answer questions' the highest (M=4.72, SD=.457) and 'felt able to trust the researcher' the lowest (M=4.13, SD=1.070). Those participants who met with a research assistant rated the statement 'felt relaxed' the highest (M=4.73, SD=.451) and 'positive and empowering experience' the lowest (M=4.34, SD=.680). Although there was no significant difference between the two groups, the participants who met with a research assistant felt more able to give honest

answers during the follow up meeting (peer researcher M= 4.59, SD= .499, research assistant M=4.68, SD=.471). However, the rate of standard deviation between the two groups varied, with a higher rate of variance in the answers given by the participants who met with a peer researcher for seven out of the nine statements compared to a research assistant. In particular, there was a greater range of variance between the two groups when the participants were asked if they felt able to trust the researcher they met with (peer researcher M=4.13, SD=1.070, research assistant M=4.39, SD=.754); felt understood (peer researcher M=4.44, SD=.801, research assistant M=4.43, SD=.661) and described the experience as positive and empowering (peer researcher M=4.38, SD=.793, research assistant M=4.34, SD=.680). The higher rate of variance amongst the answers given by the participants who met with a peer researcher rather than a research assistant may have been related to individual's stronger opinions about a new data collection approach compared to a traditional method. Other factors beyond the data set should also be considered when interpreting these results.

The group of participants who were approached to complete the self-report scale may not have been a representative sample of the 313 participants who participated in the MOAM trial across the 13 sites. 25% of the recruited population completed the self-report scale, but this sample did not include participants who had dropped out of the study or disengaged which may have led to the reporting of mostly positive responses. The lack of significant results could have been because of the type of questions included in the self-report scale were not appropriate. As the scale that was used was a non-validated instrument this may have contributed to a possible ceiling effect (Salkind, 2010) with the majority of the answers falling within the upper limits of the scale. If the qualitative data had been analysed prior to the collection of the quantitative data, these findings could have been used to inform the design of the self-report scale. This approach should be considered for future studies to strengthen the quality of a quantitative data collection tool. However, despite these suggested

limitations of the approach adopted, the reported experiences of the two groups of participants could have been very similar regardless of the type of researcher they met with and although the results were not significant, the participants who met with a research assistant may have felt more able to give honest answers during the follow up meeting. The next chapter of the thesis will explore the qualitative results from the interviews with the peer researchers and User Voice operational staff members about their experiences of working on the MOAM trial.

CHAPTER 6 Results - User Voice peer researchers and operational staff

This chapter describes the experiences of the five User Voice peer researchers who met with the MOAM participants to complete the follow up assessments for the trial, and the two User Voice operational staff members who were directly involved in the trial and line management of the peer researchers. Both groups participated in semi-structured interviews. The peer researchers were asked to describe their experiences of meeting with the research participants in probation officers or prisons to collect the outcome measures. The operational staff members were asked to share their observations of the peers researchers' experiences, as well as their own reflections of the impact of researchers with lived experience on a randomised control trial. The results from the semi-structured interviews for both groups of participants are described together in this chapter.

Qualitative analysis

6.1   User Voice peer researchers and operational staff

Analysis of the semi-structured interviews with the peer researchers (UVPR) and operational staff members (UVOS) produced four themes: The peer researcher approach, Collecting data in the criminal justice system, Impact on the participants of meeting with a peer researcher and Impact of the role on the peer researcher.

In the first theme, the User Voice staff members described why the peer researchers were motivated to take on the role, suggesting it was an opportunity to give something back but also an opportunity to develop their research knowledge. For others the role was an accessible source of income to someone with a criminal record. Shared experience with the research population was described as being important to being an effective peer researcher,

but one also needed a range of other skills to be able to engage participants in the research process.

In the second theme the peer researchers described some of the challenges of accessing prison and probation offices to meet with the participants to collect the outcome measures. Some challenges were similar to those faced by the research assistants, for example booking a room, others were related to their lived experience specifically as staff members were sometimes suspicious of their motivates. Meeting participants in prisons was the preferred environment as appointments at probation offices were described as often chaotic and unpredictable. The importance of managing boundaries between the peer researchers, participants and staff members without lived experience to ensure everyone's safety was highlighted. The peer researchers explained how they were generally treated with respect by the criminal justice staff members they interacted with whilst working on the study, but this was unfortunately not always the case which could have been distressing for the peers and brought back painful memories.

The impact of the approach on the participants and the peer researchers themselves is explored in themes three and four. The peer researchers suggested the participant felt more able to give honest answers to the questions because they were able to break down barriers to engagement through their shared lived experience. The participants responded well to the peer researchers and saw them as role models and someone to aspire to be like. The User Voice staff members suggested how the peer researchers gave the participants hope as they were an example of breaking the cycle of reoffending. The peers themselves reflected on the impact the role had on them personally, explaining how they felt valued and it was an opportunity to reflect on their own journey. The peers described a number of skills they had developed in the role and also explained how the experience was an opportunity to share their knowledge with the research team at UCL. However, the peer researchers highlighted if they

had been more involved in the initial planning stages of the study and decisions about the analysis of the data their knowledge could have strengthen the study design, and this was a missed opportunity. The peers also highlighted it was important to remember that because of their lived experience, a peer researcher would face more challenges than a traditional research assistant without lived experience, and adequate training and support was needed to support individuals. The themes and sub themes are set out by domain in appendix V, and are described in more detail below.

6.1.1   Theme: The peer researcher approach

The first theme described by the User Voice staff members (n=7) explored why the peers were motivated to apply for the role, and the characteristics and skills of an effective peer researcher. Some the peers were looking for an opportunity to give something back, whilst others were interested in developing their research skills. For some their motivation was purely financial, and a role which was accessible to them despite their criminal record. Shared lived experience with the participant was described as essential to enable the researcher to understand the participant's perspective. However, it was also important this experience was relevant to the population, and should not be too recent. Although experience of either serving a prison or community sentence was required for the MOAM trial, some of the peers explained that they had not engaged in the same type of offending behaviour as the MOAM population and therefore suggested they could not be considered true peers.

The operational staff members explained lived experience was not enough to be an effective peer researcher; one also needed a range of other skills to engage participants and collect data for a research study. The ability to clearly communicate, listen and take an interest in what the other person was saying was suggested to be important. Strong leadership skills as well as the ability to maintain boundaries provided the opportunity for the peer

researchers to build rapport with the MOAM participants they met with. A patient and flexible approach with individual participants and the criminal justice system was also required. The three sub themes are described below and include: Motivation, Having that shared experience and Skills required to be an effective peer researcher.

6.1.1.1   Sub theme: Motivation

The first sub theme described by the User Voice staff members suggested a range of reasons as to why an individual may be motivated to become a peer researcher. One of the peers explained they were motivated to give something back to society and to improve the quality of services available for people in the criminal justice system.

"I'd been there, and I've been on the other end of some really poor service over the years. So anything I could do to help I think was a motivation for it" (UVPR1).

Others (n=2) explained, they did not want to become a peer researcher specifically, but wanted to work within the criminal justice system more generally to help others and contribute to the work of User Voice.

"I wouldn't say I wanted to be a peer researcher. It's more like, I wanted to work within the criminal justice system, to help others that have gone through similar situations" (UVPR5).

"A couple of the peer researchers didn't necessarily apply specifically to be a peer researcher, a lot of people get involved in User Voice because of something wider of that. User Voice, yes, delivers services and contracts and peer research, and the councils and all of that, but actually it's a movement as well" (UVOS2).

In addition to giving back to society, one User Voice staff members suggested the role of the peer researcher also demonstrated that it was possible for someone with a criminal record to make a positive contribution to society.

"To want to sort of show, that that you know ex-service users, ex-offenders are not kind of forlorn, not kind of lost and they are not just kind of a burden on society" (UVOS1).

One peer researcher, applied for the role because they were specifically interested in working on a research study in collaboration with a university in an academic setting. "For me, I've done bits of research projects for the university and assisted them previously. I wanted to get back more into the research I was in, the data side of things to validate points, policies and things in prison, with actual data and research to back it up" (UVPR3). Another was encouraged to apply for a position at User Voice by their offender manager as they felt it would help them to reintegrate into society. "For my community service, the supervising officer that I got on with really well flagged User Voice and encouraged me to apply" (UVPR2).

In contrast, some (n=2) explained their motivation was more practical, and they applied for the role of peer researcher at User Voice as a source of income; it was a position accessible to them despite a criminal record. "So it was kind of, we've got this position that you could apply for otherwise you are back on the dole queue" (UVPR4). "Participating in that kind of work is a way to pay the bills for them in the society which kind of prevents them, or puts up obstacles for them to be able to find other employment" (UVOS1).

6.1.1.2   Sub theme: Having that shared experience

All the User Voice staff members (n=7) described the definition of a peer researcher as someone with similar lived experience as the population being studied. "My definition is someone that's come through similar circumstances, or they have experience, lived experience of the subjects being researched" (UVPR5).

"You are supposed to have a similar or similar life experiences to the interviewee as possible. You have some understanding of what it's like to walk a mile in their shoes kind of thing" (UVPR4).

The peer researchers and operational staff members expanded on this idea, explaining how peer researchers with lived experience could come from a range of backgrounds. For example, they shared examples of how the peer researcher approach could be adopted for a research study about football or immigration.

"Like you could be a football coach, for instance, but you would have had to have been a footballer. So they are peers of each other because they are footballers" (UVPR1).

"It might not only be sort of an offender status it might be, I don't know, immigration status. Something that enables them to kind of strike a connection in that way" (UVOS1).

Having lived experience to build the connection with the participant was essential. However, one peer researcher also highlighted not all lived experience was relevant, but there might be some cross over between different populations.

"So if I'm a peer to people within the justice system it wouldn't necessarily mean I'm a peer to people who are homeless, but there might be a lot of crossover" (UVPR1).

A User Voice staff member also highlighted the importance of the lived experience not being too recent to ensure the peer researcher was able to separate the two experiences.

"It's just you know within reason, and probably not somebody who's experiences were dead recent. I mean it's I think yeah, you have to be able to kind of take a step back from it. I think that that kind of leads to the bias kind of scenarios, if it's too close and it's too sensitive" (UVPR4).

For the MOAM trial, the User Voice staff (n=6) described how a peer researcher needed to have a personal lived experience of the criminal justice system either serving a

community or custodial sentence. However, this also often meant experience of homelessness, poverty and accessing mental health services.

"I suppose it's having a lived experience in this context with justice services, and psychological services with MOAM particularly" (UVPR1).

"You'd say I've got a shared lived experience in the User Voice context, and our entry point is the criminal justice system. But also then all of the associated stuff that comes with that, whether that's mental health, homelessness and poverty" (UVOS2).

Despite the peer researchers and operational staff members providing a clear definition of what a peer researcher was, some of the peer researchers (n=2) explained they had similar lived experience, but they did not feel they had the same experiences as the MOAM participants they met with.

"With MOAM, I've never been convicted of a violent crime for instance, and most of these participants have. So I'm not a peer in that respect" (UVPR1).

"Although we say we're peer researchers none of us probably had direct, none of us fitted into that client group. So we're close. We've got similar shared experiences, but they're similar they're not the same" (UVPR4).

6.1.1.3   Sub theme: Skills required to be an effective peer researcher

The majority of the User Voice staff members (n=5) described a range of specific skills that an individual would need to be an effective peer researcher. Strong communication skills and an ability to engage a range of audiences was highlighted as important to enable the peer researcher to be build rapport with others.

"I think communication is really important. So I think that's the reason why it's important. So it's kind of, its one thing having that kind of common status, but it's another thing to be able to kind of communicate it" (UVOS1).

"People that have got degrees, down to people that have never touched the education system. Being able to build a genuine rapport with someone, but communicate on different levels (UVPR3).

Ability to listen and take an interest in the research participant was described as a key skill when encouraging participants to complete the outcome measures for the trial. "Very often it's about those listening skills, analytical skills. The things that you would be looking for in a researcher more generally on top of the lived experience" (UVOS2). "So it's taking an interest in that person as well. So before giving them the follow-up, just having a chat with them first, see how they were doing, because it's kind of went a long way" (UVPR3).

The User Voice staff members (n=2) explained a patient and resilient approach was also an important skill needed in order to be an effective peer researcher. "So yeah you do have to be quiet sort of patient, and I don't know if laid back is the right expression, but just kind of let them talk through that what they want to say rather than interfere" (UVPR4). "You're not a normal researcher, and therefore you're going to come up to a lot of red tape because the institutions are not used to usually dealing with you in that capacity, usually you are kind of seen as posing risks" (UVOS1).

One User Voice staff member explained strong leadership skills encouraged people to trust the peer researchers, and believe in what they were saying. "I guess the leader as well within that peer group as well. The people are able to trust you and believe in what you're saying, but also sit down and see that what you're trying to do is to make a difference" (UVPR3). Being non-judgemental; able to understand and maintain boundaries was also highlighted as important in building trust and encouraging the participant to share honest answers.

"Ultimately, it's being able to use your own lived experience to be able to talk about that in an appropriate way, but in a way that inspires and motivates other people to open up, to make them feel, in a space, comfortable, space in which they can be honest" (UVOS2). "Non judgemental, understanding boundaries." (UVPR2).

One User Voice operational staff member explained how all of these skills were important, in addition to having shared lived experience to enable the peer researcher to be able to build rapport and connect with the research participants they met with. "It's kind of like the idea that anyone with the experience can therefore play a role. Absolutely wrong. People need the skills in order to do that" (UVOS2).

6.1.2 Theme: Collecting data in prisons and probation offices

The second theme described by the User Voice peer researchers and operational staff members (n=7) explored the experience of collecting data in prisons and probation offices when one has a criminal record. The peer researchers described a range of difficulties when trying to access participants in prisons and probation offices explaining how some staff members could be suspicious of their motives. However, this was not the case for all establishments. The peer researchers shared examples of how developing relationships with local staff members enabled them to overcome barriers to accessing these spaces. The peer researchers explained the majority of the participants engaged well in the research process. However, some participants did feel uncomfortable meeting with a peer in a probation office, and in some cases, the participant's cautious attitude towards the environment was transferred to the peer researcher and the participant found it difficult to trust them. Participants who completed the follow up appointments in prison were generally well engaged in the process because it provided an opportunity for time out of their cell. However, the User Voice staff explained if the participant felt they had been recalled unfairly this would be a barrier to

engagement. Meeting with participants in prisons was the preferred setting compared to a probation office as it was considered to be safer with less distractions. Despite the challenges of collecting data in prisons and probation offices described by the peer researchers, the majority agreed these environments were the most appropriate place to meet with the participants for everyone's safety.

The importance of maintaining boundaries was highlighted, and the potential risks to the participant, peer researcher or other research staff without lived experience if these professional boundaries were not maintained. The User Voice staff members suggested that because of the peer researchers' lived experience they may be more vulnerable in these types of scenarios. The peers explained that they were mostly treated like any other professional in the prisons and probation offices and they faced the same challenges as the research assistants. However, the peers did share some examples of more challenging situations where the prison staff spoke to them directly, and sometimes they struggled to access buildings or participants because of their criminal record. The four sub themes are described below and include: Getting in, Levels of engagement, Managing Boundaries and Being treated like an ex offender.

6.1.2.1   Sub theme: Getting in

The peer researchers (n=5) described a range of experiences when they tried to arrange meetings with participants in prisons and probation offices to collect the outcomes measures. If the participant was recalled or re offended and was given a custodial sentence the follow up appointment would take place in prison through the legal visits system. For some prisons, the peers (n=3) described how difficult it could be to arrange a legal visit to meet with a participant.

"I mean you try like a legal visit, and because the majority of the legal visits are for like police or lawyers or probation. If it comes up as someone from User Voice or UCL, and it [the prison] didn't really like that, I didn't really understand that" (UVPR5).

"Despite the fact that you know obviously MOJ are supposed to have the overall say. It was very difficult. I mean I had to get the trial coordinator to intervene with that prison" (UVPR4).

In addition to overcoming the barriers of accessing the prisons, one peer researcher explained the amount of time they were given to complete the follow up was often problematic. Legal visits were restricted to a set period of time in prison, which did not always give the peer researchers enough time to complete the outcome measures with the participant and listen to what they had to say. The peer described how they felt they had to sometimes rush the appointment.

"It might be like an hour or two hours something like that, I can't remember, each prison varies. Sometimes like, you would have to, in a sense like rush it, and then you want to listen to them as well at the same time" (UVPR5).

In contrast, other prisons were easier to access. The peer researchers (n=3) highlighted the importance of developing a relationship with the prison and the staff, which established their credibility and authority in the setting.

"You know, once you'd established your credibility or the authority, that they had the authority for like the data there, then they were quite compliant really" (UVPR1).

"I had a really good relationship with one prison where I could literally ring them up and go. I want to see so and so, on such a such a date, at such and such a time and the visit would be booked, no sweat" (UVPR4).

The peer researchers also described a range of experiences when meeting with participants in probation offices to complete outcome measures for the trial. Some of the peers (n=2) explained how staff were very suspicious of anyone coming into the building. "I don't know, it just felt like 'oh here he is', and I wouldn't say interrogate but you feel like that yeah" (UVPR5).

"A receptionist questioning what you're doing there, sitting around for ages or OMs not being there, and then you scramble around to introduce yourself to someone else to try and get a room for the client that's turning up" (UVPR3).

However, it was not clear from the descriptions the peer researchers gave of their experiences of accessing probation offices if the barriers they come up against were because they had lived experience of the criminal justice system, or because they were visiting the building from an outside agency.

"I think the whole nature of that building is set up for everybody to be suspicious of everybody else. Yeah, it's such a lousy setup" (UVPR4).

The staff at other offices were described as generally open, friendly and accommodating as long as the peer researcher was in communication with the participant's offender manager in advance, the process was generally straightforward.

"Mainly, they were generally open, friendly and accommodating, in most of the places. If you got some agency receptionist, sometimes you would have to jump through a few more hoops to get some access, but generally I always got access when I needed it" (UVPR1).

"For me it was always communicating in advance to make sure the OMs were there or if not, there was another specific point of contact that I could have so that when I do get there, there was no confusion" (UVPR3).

Similar to the peer researchers' experience of accessing prison, the importance of establishing relationships with the local staff was described as important. The peer

researchers (n=3) explained it was easier to develop these relationships if they were regularly

visiting the same office, or if User Voice already had a pre-existing relationship with staff in

the building.

"I mean depending on if you go to a probation office quite regular, the staff would get to

know you and kind of, they'd almost treat you like a member of staff" (UVPR5).

"Most of the sites have been, well because I was operating in that environment anyway with

User a Voice, so I knew most of the reception. Particularly in [name of city] which is one of

my sites, I knew all the receptionists anyway" (UVPR1).

Overall, the peer researchers (n=4) explained they preferred meeting with participants

in prison to collect the follow up data because they were generally given a confidential room

in which to meet the participant and the environment felt more controlled and safer with less

distractions.

"Prison was a controlled environment, it was a positive experience. People weren't expecting

us in probation. We had to argue to be given rooms, just to get in, and that was difficult"

(UVPR2).

"In the community, obviously, people are trying to get away, or trying to get to another

appointment, or obviously have got something else going on that they need to be somewhere

by a certain time. With prison, once you're on the legal visit you're there until the end of it,

or if you finish earlier, then you can go back, so it was more of a relaxed atmosphere"

(UVPR3).

Despite the challenges described by the User Voice staff, most of the peer researchers

(n=4) agreed meeting with the participants in prison or at a probation office was the most

appropriate setting as the environment was safe and protected both the participant and the

peer researcher.

"There was no way you could meet in the community. There are two sides, this way protects the participant and protects the researcher" (UVPR1).

The probation office was also a convenient location for participants as they were already visiting the office once a week to meet with their offender manager.

"I'd always just try to just piggy back their regular appointments where possible or once you've built a relationship with the offender manager, they'd piggy back what was convenient for me, particularly if I'm travelling some distance" (UVPR1).

Although the peer researchers agreed, probation and prisons were the most convenient and safe location to meet the participant, one peer researcher felt it might have been beneficial for the research meetings to have taken place in a different environment following a similar approach adopted by User Voice for other research projects and engagement work. "We [the peer researchers] would meet these same people for User Voice and quite happily take them out and take for a cup of coffee and its part of my job. You know we kind of, have to do our own risk assessments by the people with on the fly. We were used to it. I think a certain amount could have been taken advantage of to use other premises" (UVPR4).

6.1.2.2 Sub theme: Levels of engagement

In the second sub theme, the User Voice staff members (n=4) reflected on participant engagement and the potential impact of meeting with a researcher with lived experience similar to their own in a prison or a probation office to participate in a research study. One peer researcher explained the majority of the participants engaged well in the process, especially when they continued to meet with them if they had returned to prison to serve a recall or custodial sentence.

"I think the majority of them enjoy doing the follow-ups. I think they were quite surprised, like they didn't think they'd see you when they've gone inside. They think like, they

thought it'd be over kind of thing" (UVPR5).In prison, the peer researchers (n=4) explained

the participants were generally more willing to engage in the research process because it gave

them time outside of their cell, and they knew they would be able to collect their vouchers for

participating in the follow up appointments once they were released.

"Unless they refused to see me, or refused because something had gone on in the prison or

due to regime, they were glad to get out of their cell. Glad to engage and knowing

the vouchers would be clocking up for them when they got out, there'd be something for

them to come out to as well" (UVPR3).

"I think for the majority of them; it gave them a bit of a break from their daily routine. They

might not be in work or they'd be in their cell for however many hours in the day, so it kind

of broke the day up" (UVPR5).

However, for some participants who had been recalled or sent back to prison one peer

researcher explained this was a barrier to engagement because they felt let down by the

system.

"I had the kind of experience that once they got put behind bars they didn't want to see us.

You know I've been recalled, and I'm not participating in anything at this point" (UVPR4).

As previously outlined in this theme, the peer researchers described access to

probation offices as being challenging. The peers also explained engaging participants in this

space was equally as difficult. Attendance was often unpredictable and some participants did

not arrive on time for their appointment. Despite these challenges, one of the peer researchers

explained most of the offender managers at the offices were accommodating and provided the

peers with a working space while they waited.

"In terms of the participants, then it was hit and miss if they'd be there. If they're not, if

they're running late, but even when they were running late, anything between two minutes

and an hour, we were always allowed to stay within the probation office and sitting at the desk or catching up on emails" (UVPR3).

Engaging participants during the following up meeting at a probation office could also be challenging. The peer researchers (n=2) explained some of the participants did not feel comfortable meeting in a probation office because this was the same space they met their probation officer.

"I think like maybe they thought they were being listened to, even though you'd explain it to them. Sometimes they didn't feel comfortable" (UVPR5).

For some participants the negative feelings they had towards a probation office were transferred to the peer researcher because they were concerned about being judged.

"I think there was definitely some barriers to overcome, because they just thought you're another probation officer or another sort of somebody else there to judge them and make your mind up about them" (UVPR1).

In order to be eligible for the trial, a participant had to have at least 6 months remaining on their licence at the point of randomisation. This meant that some participants would no longer be under supervision by the national probation service during the follow up period. The peer researchers explained that some participants would disengage completely when they were no longer under supervision, and therefore they were difficult to follow up. However, one of peer researchers also explained the participant's disengagement was not always related to the approach adopted by the research team. Often the participant just wanted to move on with their lives.

"You know it was not that they were unwilling, but it was 'well I'm working now, and probation is behind me as it were. I'd rather get on with my life and forget about it'" (UVPR4).

6.1.2.3   Sub theme: Managing boundaries

The User Voice staff explained in the previous theme how lived experience could enable a peer researcher to build rapport and engage participants in the research process. However, all of the User Voice staff members (n=7) also explained it was important for a peer researcher not to become too familiar and to treat everyone in the same way to maintain the quality of the data collected.

"We always come from a perspective of our own lived experience, but there is a potential for there to be an over-familiarity, and for people to over-identify with the subject. That can have an adverse impact, therefore, on the results that come out of it" (UVOS2).

"So to be firm but fair, friendly and not their friends, but you can see issues where things have gone wrong. People are too over-friendly, or sympathise too much with them and then you might favour one person over another person" (UVPR3).

If the peer researcher did not maintain clear professional boundaries between themselves and the participant there was a risk to the participant and the peer. Concerns were raised about the peers not reporting risk concerns or colluding with a participant if they struggled to maintain the boundary between themselves as a professional and the participant. "There are lines. That are, that can never be kind of overstepped in the sense you know. Let's say if a participant revealed suicidal ideation, or wanting to kill themselves today that needs to be reported or things like that." (UVOS1).

"Colluding with people and just having an inappropriate relationship between the two of you, like maybe too banter and having to stipulate we are professionals and confidentiality [comes into] play" (UVPR3).

Due to their lived experience, the User Voice staff members (n=2) suggested the peer researchers may be more vulnerable to higher rates of disclosures from the participants

compared to the research assistants and it was therefore even more important for researchers with lived experience to maintain boundaries between themselves and the participant. "There was a lot of times when we were put in risky situations compared to the RAs [research assistant]. Having a peer element did lead to disclosures which were difficult. I hadn't been prepared for this which I then had to figure out" (UVPR2).

"There is a lot, there is more trust involved between the peer researcher and the participant more than they would usually be otherwise. I'm suspecting that may be true, more than you know a research officer or assistant might experience with participants" (UVOS1).

Secondly, there was also a risk to the peer researchers themselves. The User Voice staff members (n=3) highlighted the importance of the peer limiting the amount of information they shared with the participant for their own safety, especially if their experiences were very similar to the participant.

"It is okay to talk about your kind of shared experience with probation, which is what your kind of there for. But you know you should limit the bit that's personal to you in that." (UVPR4).

"If you've got someone sitting in front of you that's gone through that, and you've got a similar experience, it's quite heavy" (UVPR5).

One of the peer researchers also suggested there was a potential risk of the participant responding negatively if too much mutual information about lived experiences was shared. "You know this is where as a peer researcher you have to be very careful about what you say about yourself. Because I think the more of those kind of intimate details of yourself that you put across, the more you may have somebody that might react negatively to them" (UVPR4).

Thirdly, one operational staff member explained how it was also important for clear boundaries to be maintained between the peer researchers and staff members without lived

experience as well as service users, to avoid the risk of a dysfunctional relationship developing.

"I think [it is] potentially more difficult for people or organisations, let's say, without lived experience because, there's confusion about whether a peer researcher is a peer or a researcher, ie, are they a service user or are they a professional? They're a professional and need to be treated as such, and sometimes a dysfunctional relationship can start to build without any motivation, with all the best of intentions" (UVOS2).

Although there was agreement as to the importance of maintaining boundaries, one peer researcher explained they were sometimes unsure about how much personal information they should share with the participant, and where to draw the line.

"When you're doing prison visits or whatever it's always been a bit, how much do you tell them? You know that boundary?" (UVPR1).

Another peer researcher described how they felt they needed more training to support them with managing these boundaries.

"The training? To be fair it was quite limited [laughs]. To be fair, things like that was where I just felt my own way into the boundary line really" (UVPR1).

However, one peer felt they already had an understanding about where to draw the line because of the training they had received in previous roles, and the skills they had already developed before joining the MOAM trial.

"Obviously, I'd done a fair bit of that by the time I was working on the trial, and was kind of used to where the line needed to be drawn" (UVPR4).

Regardless of the amount of training required, it was suggested that it was always going to be challenging for the peer researchers to manage these boundaries because they had shared lived experience with the research participant they were meeting with.

"You can't get away from the fact that they are a peer, and I think it's a difficult line for those individuals to hold, and it's been something that they have to be very much aware of. But equally, they're people, they're human and if someone asked them a question, then I think it's difficult not to answer it or to give some advice about where to go and how they moved on in their journey" (UVOS2).

6.1.2.4   Sub theme: Being treated like an ex offender

The peer researchers (n=4) described a range of different reactions from the criminal justice professionals they met and interacted with as they followed up the MOAM participants. Generally, the peers (n=3) explained they were treated like anyone else who was working in the environment.

"You know in most of the places we were fairly quickly treated like people that were working there, and it wasn't a problem" (UVPR4).

"The probation offices overall on the whole have in my experience, and the feedback that I've got have been cooperative" (UVOS1).

If there were any processing issues with entering a prison or probation office, it was suggested by one peer that these were the same challenges the research assistants at UCL faced.

"I mean there were some process problems but I don't think that that was any different from, from what I understand, from the UCL researchers as opposed to the peer researchers?" (UVPR1).

Another peer researcher elaborated further by explaining the prison and probation staff were probably not even aware that they had lived experience of the criminal justice system and did not feel as if they experienced any animosity towards them.

"So in the prisons, it was fairly manageable. I never really got any sense of that, because I

was an ex-offender, or animosity towards me or anything like that from anybody. They probably didn't even realise or know to be fair" (UVPR1).

However, the User Voice staff did share some experiences of the peer researchers being treated differently because they had served a community or custodial sentence.

The peer researchers and operational staff (n=3) explained that sometimes prison and probation staff could be very direct and other times the barriers were not always as obvious but equally challenging to navigate and overcome. Criminal justice professionals not trusting the peer researchers was highlighted as problematic when trying to arrange a meeting with a participant, especially if the participant was no longer on licence under the national probation service.

"In prison, you'll get told that, people will be very upfront with prisoners, 'You're an ex-con, you shouldn't back in here', whatever. In probation services, we generally find, and this has been my experience with the feedback I've had from the peer researchers, that it won't be so blatant and obvious, but there will be a lot of barriers put in front of you in terms of getting access, in terms of having a room on your own with the individual" (UVOS2).

"I don't think they ever got their head round the kind of a peer researcher is somebody that has been on probation kind of scenario" (UVPR4).

6.1.3   Theme: Impact on the participant of meeting with a peer researcher

In the third theme, the peer researchers and operational staff members (n=7) shared their reflections about the impact on the participants of meeting with a researcher with lived experience similar to their own. The peer researchers suggested that because of their shared lived experience they were able to break down barriers to engagement, leading to most of the participants feeling more able to share open and honest answers. For some participants levels of honesty also increased over time as rapport developed between the participant and the peer

researcher. Despite a number of examples of increased rates of honesty due to shared lived experience, the User Voice staff members also described other factors which may have affected the participant's ability to open up about their experiences. Some participants were worried the answers they gave may be shared with their offender manager, whilst others were concerned about being judged by the peer researcher if they had relapsed. The peer researchers and operational staff members suggested for some participants it may not have been a conscious decision to give false or contractionary answers, they may just not have been engaged in the process or felt unable to engage because of how they were feeling at the time. The operational staff members also highlighted it was important to remember many of the MOAM participants may have struggled to trust others because of their own lived experience and having a diagnosis of anti-social personality disorder (ASPD). Everyone is an individual and it is not possible to engage everyone, regardless of how much shared experience one has.

The User Voice staff members suggested how some of the participants saw the peer researchers as role models, as they were a real example of breaking the cycle of reoffending. The peer researcher and operational staff members suggested how the peers gave some of the participants real hope for the future, especially if they had met with them in a prison to complete the outcome measures. The participant recognised the level of trust the peer researcher must have gained to be allowed back into the prison in a professional capacity. It was suggested there may not be an immediate impact, and some participants may not reflect on the experience until days, months or even years after the event but the impact of the experience could have been just as powerful. The peer researchers explained, because of the potential impact the role could have on a participant, it was important that they conducted themselves appropriately. However, despite the positive example of the impact of the approach it was suggested meeting with a peer researcher who had similar lived experiences

may have led to some participants feeling demoralised because they felt they had not achieved the same level of success. For one peer researcher they did not believe their role had any impact on the participants they met with as their job was to just collect the outcome measures at each time point. The sub themes are outlined below and include: Levels of honesty and The peer researchers as role models.

6.1.3.1   Sub theme: Levels of honesty

In the first sub theme the User Voice staff members (n=7) described their observations of how the participants responded to the peer researchers during the research meetings, and if shared lived experience affected the level of honesty of the answers the participants gave. One of the peer researchers described how the participants responded positively to them during the research meeting because of their shared lived experience. "We sit down and explain it to a couple of people [participants], who were, particularly like the ones that just came out of prison would pick me to work with. I say, I don't know, that's not obviously, I mean [the research assistant] was lovely, and it's not a reflection of [the research assistant], it's just the fact that if you are going to have to say this stuff to somebody, it may as well be to somebody that understands what it means" (UVPR4).

Shared lived experience provided the opportunity to break down some of the barriers to engagement because the peer researchers understood the participant on an emotional level. "It's so that they can relate to the fact that they can open up and be honest with me, and they can appreciate the fact that I do understand what they're saying to me on an emotional level" (UVPR1).

"I've had a few kind of situations where peer researchers would come back from a visit and say that the participant was really open with me, and they actually specifically told me that

they wouldn't have told this information to anyone else because they wouldn't have trusted

them, or definitely not too their offender manager" (UVOS1).

One of the peer researchers described how lived experience gave you an "edge" that someone

without lived experience may not have.

"You've got an edge that somebody that hasn't had that lived experience can't have. You

know, through no fault of their own. But yet it gives you a definite it's kind of like that toe

through the door thing" (UVPR4).

The ability to break down these barriers to engagement enabled the peer researchers

to engage participants leading to more open and honest answers being shared.

"It's interesting because I think in some ways generally, I think, I hear, and I sense that

participants are very open with peer researchers" (UVOS1).

"I think it just allows people to open up more, be able to be more honest, give data and talk to

them on a level where they'd struggle" (UVPR3).

One User Voice staff member suggested shared lived experience enabled the peer

researchers to create a safe space for the participant to share their experience.

"There's an element of the skill of the individual in being able to, like I said, create that safe

space for people to feel that they can open up" (UVOS2).

The study protocol supported the creation of safe space as the peer researcher only had

contact with the participant during the research meetings. One peer compared the experience

to a therapy session because they only interacted with a participant in a structured

environment.

"People were largely honest. I don't think there was a benefit to them really lying. It was

refreshing, you weren't going to see the researcher out of the session, so people used is as a

therapy session" (UVPR2).

User Voice staff members (n=2) suggested honesty may also increase over time for some participants as the level of rapport developed between the participant and the peer. "I suspect that most of them are, they probably become more honest the longer you get to know them" (UVPR1).

"They see you in some cases as like a constant picture as opposed to some of the other services they're working with as well, so it would be like, 'I'm always going to see you in three months' time'. I think a lot of the cases; they become just more honest and more raw as well" (UVPR3).

However, one operational staff member suggested that although they would expect rapport to develop over a time, this may not be the case for every participant the peer researchers met with.

"It's not going to happen for all individuals, and sometimes individuals don't click for whatever reason. But I think in general, a rapport is built" (UVOS2).

Although the User Voice staff members shared several examples of the participants feeling able to share honest answers with the peer researchers, they also suggested this may not have been the case for everyone. To illustrate this point, four peer researchers described situations when the participant's answers were inconsistent.

"What they wrote on the form and reality was very different. They would take a call from their partner in the meeting, but then tick the box to say they weren't in a relationship" (UVPR2).

"I mean there were definitely days when I was sitting opposite participants and I knew dam well they were lying to me. Sometimes it's very apparent because they contradict themselves a lot" (UVPR4).

The User Voice staff members (n=3) shared their thoughts about why some of the participants may have found it difficult to open up during the research meetings and share

honest answers. The peer researchers suggested some of the participants were concerned about other members of staff, particularly their offender manager, being able to hear the answers they gave, or the peer researcher may report the information to their offender manager which could affect their sentence.

"I mentioned before about the chap that was worried that he was being listened to, reporting back to his probation officer" (UVPR1).

"Some of them just wouldn't feel comfortable. They'd think like it might impact their sentence or stuff like that" (UVPR5).

One peer researcher described how some participant's concerns were based on their own experience of the criminal justice system when they believed their private conversations had been recorded.

"He was quite open with me and says, 'I'll give you as much honesty as I can, but if I've committed a crime of some kind, then I'm not going to tell you, because I am worried that there are microphones in this room'. Mistakenly or not, they have that perception that it's happened to them in the past" (UVPR1).

The peer researchers (n=3) explained some of the participants may struggle to give complete honest answers if they had relapsed.

"One guy, you could see he was suicidal, but when I asked the question he wouldn't put it on the form. But when I saw him again he had been" (UVPR2).

"You would get to like maybe I think the audit section, and it's like 'have you had a drink in the last week or last 3 months?' or whatever it might be. And they'd say 'no', but you already know they've had a relapse and they've been drinking quite heavily, or you might smell it on them" (UVPR5).

One of the peer researchers suggested the participant may have struggled to share this type of information with the peers because they were worried about being judged by someone who had lived through similar experiences.

"I think with the peer research element to this as well is. That if they think you're like one of them, because, then they might not want to be honest and admit to things that they think you might judge them for" (UVPR1).

The peer researchers (n=2) explained some of the participants may not make the conscious decision to not provide honest answers during the baseline or follow up meeting. They may just not have wanted to engage in the process.

"I mean what I've just mentioned there about them just replying just to get through it, just to get to the end without really thinking about what actually applies to them. It's not that they're being dishonest; it's just that they don't want to engage in the process" (UVPR1).

"I wouldn't say for all of them, but I mean it's like you get through maybe halfway through the longer follow-ups and they they'll start losing concentration, or like they'd have to because some of them are quite lengthy and they get fed up" (UVPR5).

For others, their level of honesty may have had nothing to do with the type of researcher they met with, but related to how they were feeling at the time. However, one User Voice staff member explained because of the peer researchers shared lived experience with the participant there was a reduced risk of these types of barriers to engagement.

"Sometimes it might just be circumstantial as well, because a particular thing has happened that week or that day or whatever, that a person doesn't want to touch that subject. I think that's reduced because they are a peer researcher. So the likelihood of that happening is less, but it still absolutely is there, and a peer researcher doesn't mean that all of the barriers are removed, it just means that a large part of the barrier is removed" (UVOS2).

The operational staff members (n=2) highlighted it was important to remember the characteristics of the MOAM population, and how an individual who had experienced very difficult and sometimes traumatic experiences in their lives who also had a diagnosis of ASPD may have found it difficult to trust someone, regardless of their shared lived experience with the participant.

"I think it might be because we're kind of dealing with you know participants diagnosed with anti-social personality disorder. You know, it's I think because someone is a peer researcher it doesn't change the kind of the nature of the people you're dealing with" (UVOS1).

"I think, no matter who you are, whether you're a peer researcher or anyone else, there are always going to be those individuals where some things are just too challenging to go into" (UVOS2).

6.1.3.2   Sub theme: The peer researchers as role models

The peer researchers and operational staff members (n=6) suggested for some of the participants the experience had a positive impact on them as they saw the peer researchers as role models. This impact was described as a natural by-product of the role by one operational staff member.

"I think what they've also done as a by-product, because of the very nature. I think that goes for any researcher, but absolutely peer researchers [because] there's also an element of support that happens very naturally" (UVOS2).

The peers described themselves as positive role models, who had the ability to encourage the participants to reflect on their own actions.

"I think they were able to see, within the four of us, positive role models as well. I think it enabled them to open up more, talk more as well and look at themselves and their actions" (UVPR3).

The peer researchers (n=4) described how they were an example that it was possible to break the cycle of reoffending, and succeed outside of the criminal justice system. "You know you think you're going round and round in circles, and it's never going to stop. Actually, it's quite a major thing. People speaking from personal experience, it's quite amazing to meet somebody that has actually got off, has managed to stop that cycle" (UVPR4).

"So, although they might set themselves up and fail numerous times, sooner or later they want to believe that they have got a chance to do something like what I'm doing. So, you can inspire them to change as well, I suppose" (UVPR1).

The peer researcher's ability to demonstrate change is possible could give a participant who may be really struggling with their lives, real hope for the future. "Sometimes it is maybe just giving them a bit of hope as well. Doesn't mean because you've gone to prison that your life is over, do you know what I mean. You can turn it around, and just being there in front of them it's like living proof kind of thing" (UVPR5).

"They could see that consistency in terms of the same peer researcher showing up to see them every three months, to show them they can make a change" (UVPR3).

The positive impact on the participant was described by one User Voice staff member as even more powerful if the peer researcher met with the participant in custody as the participant recognised the significance of someone with a criminal record being allowed to visit a prison.

"There's that greater level of, 'bloody hell, you're one of [me] and you're back in here and the governor has let you come back in'" (UVOS2).

Although there was general agreement amongst the User Voice staff members that the peer researchers had a positive impact on the participants they met with, it was suggested by two staff members the impact may not be immediate, and in some cases, it may take a long

period of time for the experience of meeting with a researcher who has similar lived

experience to themselves to have an effect on the participant.

"You're not necessarily saying it's going to have an immediate impact, but it might be the

next day, the next week, the next month that then someone then actually thinks back on it and

thinks, 'bloody hell', the enormity of what has happened" (UVOS2).

One of the peer researchers shared their own experiences of meeting with someone who had

similar experiences to themselves, and the impact this had on them as an individual.

"For me the person that changed my life the most was the first guy I ever met that had

stopped and gone out and got a regular job, and kind of got one with his life. He had a huge

impact on my life. Probably far more than he ever realized, and actually some of that impact

wasn't immediate either" (UVPR4).

Due to this potential positive influence, one peer researcher highlighted they had a

real responsibility in their role and it was important to conduct themselves appropriately

when they met with the participants to collect the outcome data.

"Hence you know that's why it's so important the way that we behave and present ourselves

when we're going out as peer researchers because actually, you have got be very conscious

that for that one person that might be meeting you might be the one thing that does make a

difference" (UVPR4).

Despite the examples of the positive impact a peer researcher could have had on a

participant they met with, there was a risk that some participants may have felt demoralised

by the experience, as they felt they had not been able to move on with their lives and achieve

the same level of success.

"It's inspirational or motivational, but also challenging to say, 'Well actually, why haven't I

been able to achieve that?' (UVOS2).

In contrast, one peer felt the role of the peer researcher was limited to data collection and they did not feel their role had had an impact on the participant themselves.

"The role was data collection; it wasn't much more than that" (UVPR2).

6.1.4   Theme: Impact of the role on the peer researcher

The fourth theme explored the impact of the approach on the peer researchers themselves. The User Voice operational staff described how the role of a peer researcher could have a positive impact on the peer, as they felt valued and the experience provided an opportunity to reflect on the progress they had made in their own lives. For some the experience improved their confidence in their own abilities, and was an opportunity to develop a more positive view of probation and offender managers as the experience gave them a better understanding of their role. The peer researchers explained how they developed a range of new skills; improved their existing skill set and increased their understanding of research. However, one of the peer researchers felt they had not developed any new skills from the role. The experience of working in multi-agency teams was described positively and an opportunity for researchers at UCL to learn from the peer researchers about the realities of the criminal justice system. The peer researchers explained how this transfer of knowledge was like "providing a bridge" between service users and providers.

Despite the positive feedback about their experiences, some of the peer researchers also described the challenges of the role. Firstly, the peer researchers explained they did not always feel part of the entire study and suggested their lack of involvement at other stages of the research process was a missed opportunity. The peers felt given the opportunity, they would have been able to strengthen the design of the trial by increasing engagement and reducing the number of dropouts. Secondly, the peer researchers highlighted how emotionally challenging it was as a peer researcher to meet with a participant in prison or a probation

office to collect outcome measures for the trial. The peers suggested how this was especially

difficult if the participant's experience was very similar to their own, and they witnessed

them being unfairly treated by the criminal justice system. The peer researchers described

how they sometimes felt they had limited opportunities to process some of these more

challenging situations and it was difficult not to become personally involved. Operational

staff members suggested how these experiences could be especially challenging for the peer

researchers because of their own lived experience, but despite these challenges the peers had

developed their own coping mechanisms. The four sub themes are described below and

include: Feeling valued and time to reflect, Skill development, Not feeling part of the entire

process and Having that lived experience meant it was more challenging.

6.1.4.1   Sub theme: Feeling valued and a time to reflect

In the first sub theme, the peer researchers (n=5) explained how their involvement in

the trial has had a positive impact on themselves. One User Voice staff member described

how the role made them feel valued because they had been trusted to carry out this important

work.

"In a positive way. I think it is just, it's a good feeling, like doing the work. Felt kind of

valued, felt quite important as well" (UVPR5).

One peer researcher described how the experience improved their confidence in

themselves because of the amount of independence and autonomy they were given in the

role.

"My own personal confidence has grown. I loved the independence of the role" (UVPR2).

The peer researchers (n=3) also explained the role improved their confidence when

interacting with people in authority because they felt valued and therefore able to present

themselves as an ex-offender.

"I guess because it improved my own kind of self-worth. How I felt about my own self-image when I'm stood in front of like authority figures" (UVPR4).

"So I think it's shown me, in a positive way, that I was able to do that. And then it's impacting on the work I do now with multi-agency working, and having the confidence to go into a room full of people and present to them as an ex-offender" (UVPR3).

The role provided the opportunity for the peers to reflect on their own journey and remind them of how far they had come.

"There's almost like, I don't want to say excitement, but it's like I'm going back inside. Like I've turned my life around you know that kind of stuff. Kind of a positive thing" (UVPR5).

"The experience of interviewing and meeting participants who have profound emotional issues themselves has really helped them to be more reflective, and think about their emotion. It's almost like you know secondary MBT you know, secondary mentalization" (UVOS1).

For one participant, the process encouraged them to reflect on their own personal journey through the criminal justice system, and the labels associated with that system.

"Even just thinking about those labels, like ex offender. I didn't consider myself as an ex offender, but it made me think about what made me vulnerable and put me at risk of the criminal justice system" (UVPR2).

For another peer they felt the role allowed them to develop a more positive view of probation and offender managers as they now had a better understanding of their role.

"It is quite nice to work with other professionals and it's kind of like changed my views. When I was on probation, and you get like a short period of time with your officer and you'd be thinking like I want more time or, it feels a bit rushed. When you work on the other side, you see how much they've actually got a lot of work to do" (UVPR5).

6.1.4.2   Sub theme: Skill development

In addition to the personal impact the role had on the peer researchers outlined in the previous sub theme, the User Voice staff members (n=7) described a range of new skills the peer researchers developed. The peers (n=5) described how the experience of working on the trial developed their knowledge and understanding of research.

"I knew like the kind of the basics really, but I did not know how like everything got to be like ethically approved, and about the consent and all of those kinds of things. How many hoops you have to jump through to get to the stage where you can actually sit down in front of a participant" (UVPR5).

"It's understanding that there's a goal to what you're doing, and because you kind of understand the goal it's much easier to see why you're taking the steps that you are" (UVPR4).

For others who may have been involved in research studies in previous roles, MOAM was an opportunity to develop specifically their understanding of randomised control trials.

"Definitely with the controls trial. I've done research projects in the past, whether it's focus groups or interviews, like group work, but to work on a randomised trial where I was blind to it, that was definitely a new experience for me (UVPR3)".

"I learnt, when you read something that says 'new research says' not to just trust it! I do know RCTs are the gold standard, and they tell us a lot of good things" (UVPR2).

One of the peer researchers described how the role developed their knowledge of services, explaining how the experience broadened their ideas about clinical support for service users who have committed violent or aggressive crimes.

"Some people will perceive that as, 'why should they get all these services when they've committed crimes and they're in the wrong?' But you got to think of other victims really.

That's what I think about to keep me from being judgemental is if the service can help them be less violent, then that's creating less victims" (UVPR1).

Communication skills were also highlighted as an area for skill development. The peer researchers were required to not only engage participants in the research process, but also actively listen to them. One of the peer researchers suggested the engagement technique was similar to counselling skills that encouraged the participant to reflect on their own behaviour.

"I think, as well to be able to enhance my counselling techniques as well with participants in terms of actively listening, in terms of paraphrasing, reflecting" (UVPR3).

For another, skill development related to written forms of communication and writing emails.

"I'd say like I didn't really use emails prior to like doing the job, and learning like how to word them in the correct way" (UVPR5).

The peer researchers (n=2) suggested how the role was an opportunity to develop their organisational and time management skills, as they were required to work independently and manage their own caseload.

"Suppose like time management as well. Screening like each person and working out the times of getting into [name of probation office] and [name of probation office], whatever it might be and getting there on time" (UVPR5).

"Logistics as well and geography! Definitely skills there, and how to get things done really" (UVPR1).

Working in a multi-agency team was a new experience for some of the peer researchers (n=2), and provided them with an opportunity to develop their skills of working with people from different kinds of backgrounds to achieve a shared goal.

"Definitely multi-agency working, having to liaise with so many different people for a shared goal" (UVPR3).

"Yeah massively being a kind of and being a part of a team that's not just comprised of fellow colleagues from one organization. So being able to sit with team members from UCL, and kind of research assistants and research officers but at the same time the coordinators, clinicians, academics and being able to ask poignant questions and think about information relevant to that particular person, that particular team." (UVOS1).

The Peer researchers (n=4) described how not only they learnt from the experience, they enjoyed the role and working on the MOAM trial.

"I always felt welcome, well respected. I didn't feel like there was a level where 'we're researchers, you're peer researchers' a hierarchy or anything like that. I think we're able to learn from each other as well, so I might learn something from [the research assistant] and then vice versa, they might learn from me about the way I speak in front of the clients as well" (UVPR3).

Operational staff members also described the positive impact of the experience for User Voice as an organisation.

"It's been a really good to feel that User Voice can be a part of a project that big, and that's significant" (UVOS2).

Despite the range of skills described by the peer researchers, one felt the experience did not provide them with new skills, only developed the skills they already had.

"I'm not sure it equipped with new skills, it certainly sharpened some of the ones that I have" (UVPR4).

For another peer they felt the role did not provide them with an opportunity to develop their skills, although they explained they enjoyed the role.

"In terms of skill development, I don't really see it. I did really enjoy the role though. Maybe team work and communication. I am sure there was, but I can't see it [skill development]" (UVPR2).

In addition to their skill development, the peer researchers and User Voice operational staff members (n=4) described how the UCL research team might have learnt new skills and knowledge from them. The peer researchers described how the experience of working with User Voice may have changed the research assistants' view on people's experiences of the criminal justice system by providing them with an insight into the process from a different perspective.

"Say for example, you could have a family member that's gone to prison but turned their life around, and you can see that, that can actually happen. Others might have a different experience like they've had a negative experience, then seeing staff at User Voice actually making a change within the criminal justice and prison as well. I suppose would have a positive impact" (UVPR5).

I think just a different way of thinking about something or the knowledge of the criminal justice system in terms of 'this is how it normally is'. Whereas that kind of knowledge wouldn't necessarily have been there, so I was like an insight, how it would work from the other side" (UVPR3).

The User Voice staff described how this insight could lead to a different way of approaching research in the criminal justice system and how protocols could be adapted for future studies.

"I think just a different way of looking at things or interacting with prisoners, like ex-offenders, the way to approach things" (UVPR3).

"That's nothing to do with what their emotions or their disorder maybe, it's an environment that's causing this person to behave this way" (UVOS1).

One of the peer researchers described the process of the User Voice peer researchers and User Voice sharing knowledge and skills with the UCL researchers as "providing a bridge", because there is often a gap between service users and service providers.

"We tend to provide a bridge between the service users and the service providers, because often there's a gap between that and we try to be that gap in between. Fill that bridge so that there can be a co-productive approach to developing services" (UVPR1).

6.1.4.3   Sub theme: Not feeling part of the entire process

Despite the positive examples described by the peer researchers of working with the researchers at UCL, they also shared examples of not feeling fully included in trial (n=7). The peers explained they were not given the opportunity to contribute to every part of the research process and share their knowledge of the criminal justice system. Some felt this was a missed opportunity, and if they had been more involved their knowledge could have increased retention of participants and the quality of the data collected.

"A large part of being a peer was about giving someone a voice, but there was nowhere for our [the peer researchers] voices to be heard. It was a real shame that we weren't integrated in a more meaningful way" (UVPR2).

One User Voice operational staff member explained it could have been beneficial for the peer researchers to be involved in the design of the study during the planning stages of the process.

"Maybe not strictly research design, but perhaps research methods design. To have their insight into that, and I think that would be, that could be quite beneficial for any future sort of trials" (UVOS1).

One of the peer researchers suggested that if individuals with local knowledge of the probation and prison systems had been involved in the planning stages of the study, more cost-effective systems could have been developed.

"I think having researchers on the ground who are used to operating in that environment, and involving them in that decision-making process in the set up would have been probably more

helpful. In terms of geography of where places are, how far they are and how much it's going to cost to get to them" (UVPR1).

However, one staff member explained that although the peer researchers who collected data for the study may not have been involved, other User Voice staff with lived experience did contribute to the initial planning stages of the study.

"So, it wasn't like a group of people without lived experience sat in a room and decided what people with lived experience should be doing. So, although the peer researchers themselves, at the beginning, weren't involved, yes. User Voice, by its very nature of being user-led, there was therefore an element of lived experience right from the very beginning" (UVOS2).

The peer researchers first met the participants at the baseline assessment. Prior to this contact, the participant would have been screened into the study by an offender manager; attended a clinical assessment with a psychologist and completed a diagnostic assessment with an assistant psychologist. Several of the peer researchers (n=3) suggested how the peer researchers could have supported this recruitment process which may have meant fewer participants dropping out before randomisation.

"You know, so if I guess if we'd have had that earlier involvement in the recruitment stage that might have prevented some of the dropouts, particularly some of the earlier dropouts because you wouldn't have got so many unwilling" (UVPR4).

However, another felt it was not important for the peer researchers to be involved in the process until the baseline assessment.

"We were not involved in the initial, obviously like identifying the men, you know what I mean. I mean, I don't feel like we really needed to be involved until baseline to be honest" (UVPR5).

Several of the peer researchers (n=3) highlighted that if they had been more involved in the decisions about the analysis of the data they had collected this would have aided them

in engaging the participants and probation offices in the study. The peers suggested how a better understanding would have enabled them to explain what was going to happen to the information the participants shared with them.

"Yes, I think being closer to the data, because it's something we'd always be asked by psychologists or probation officers. So, it felt like if we had something, it would have come across a bit more reputable, if you see what I mean, as opposed to being 'we have no idea'" (UVPR3).

"It would have been interesting to be involved in the analysis, gaining knowledge and experience, but also this would have cascaded back to the role because participants would ask us about where does this data go, what happens to the data" (UVPR2).

One of the peer researchers explained not only did they feel they had skills and knowledge that could have been capitalised on to support the other stages of the research process beyond data collection, it would have also been an opportunity for them to learn and they were genuinely interested in developing their research knowledge.

"It's easy just to operate in your little silo, mining away at your data mining. Digging it out for everybody else to do something with. So, seeing how that works in a broadest spectrum would be interesting for me" (UVPR1).

6.1.4.4   Sub theme: Having that lived experience meant it was more challenging

In the final sub theme, some of the peer researchers and operational staff members (n=4) described the possible emotional impact of the role on the peer researchers who collected the outcome measures for the trial because of their own lived experience. The operational staff members explained listening to the answers from some of the participants might have been an intense experience for the peer researchers as it could bring back difficult memories of their own experiences of the criminal justice system.

"Participants who participated, who disclosed a sort of serious sexual abuse from their childhood, some sort of abuse. That was very kind of intense and profound, and it was a very sort of intense disclosure. I remember the peer researcher feeling very, kind of affected by that" (UVOS1).

One of the peer researcher suggested there was an increased risked of distress if the participant's experience was very similar to their own because they knew what the next steps of their journey would involve.

"Disadvantages it can be quite stressful on a peer researcher at times, particularly if the person you're interviewing has got life experience that's quite negative and it's very similar to your own. You know particularly if they are at their stage much further down the line, and you kind of know what the next steps are" (UVPR4).

One User Voice staff member described how the experience of working in a prison or probation office could be challenging for the peer researchers because of their own lived experience and the peer may sometimes struggle to separate the two experiences.

"I kind of almost like breathe when I get out of prison. It's almost, it is trauma kind of thing when you're reliving what you've gone through and the process of being around the officers" (UVPR5).

For others they described how challenging it could be to observe how some of the participants were treated by their offender managers, particularity when they felt a participant had been unfairly recalled.

"Like particularly like the recall rates in one area were particularly high. Some of the reasons were utterly ridiculous. I mean, it is you know the way one circumstance it all most brought me to tears" (UVPR4).

In some instances, one peer researcher described how difficult it could be when the participant did not want to talk because of shared experience.

"There's always the danger that they don't want to talk to you because, you know it's kind of like they don't view you as a professional because you have that shared experience. I'd say that a very very small minority that will take that opinion" (UVPR4).

The peer researchers (n=3) described how they sometimes felt they had limited opportunities to process some of these more challenging situations. The peers suggested they were not always given the opportunity to de brief and it was difficult to not become personally involved.

"No supervision. No consistent line management which was difficult" (UVPR2)

"We've gone through prison, and like I mentioned earlier, and probation and I think there could be a lot more work done around that. Because it is trauma, and at the same time it is therapy as well" (UVPR5).

One operational staff member explained how the emotional impact of these meetings could be more challenging for a peer researcher compared to a traditional research assistant because of their owned lived experience, but the peers had also developed their own coping mechanism as well.

"I think it plays on it, it [the role of a peer researcher] can feed into some of their prior issues. But I think, you know they [the peer researchers] generally. I think on balance, kind of considering these issues I think they [the peer researchers] also have kind of this capacity to kind of to cope with that somehow" (UVOS1).

6.2   Qualitative summary

The majority of the peers explained they were motivated to apply for the role in order to give something back to society and help others, but this was not the case for all. Some of the peers wanted to develop their research knowledge, whilst others' motivation to apply for the role was purely financial as it was a job accessible to them even though they had a

criminal record. The range of reasons reported by the peer researchers for why they applied for the role challenges the assumption that individuals are only motivated to become involved in this work to help others. User Voice staff members described how in order to become a peer researcher one needed to have shared lived experience to be able to engage participants that traditional researchers may not be able to access, supporting the rationale for adopting the approach. However, the peer researchers suggested their lived experience was similar but not the same as those participants whom they met with, and therefore they could not be considered true peers. This is an important point to consider when involving patients and members of the public in health care research to ensure study teams do not categorise lived experience too broadly. Despite the value of being able to understand what it is like to "walk a mile in their shoes", shared lived experience alone was not enough to build rapport with a participant. The peer researchers needed well-developed communication skills; the ability to maintain boundaries and strong leaderships skills to be an effective peer researcher as well as the ability to work flexibly in often busy and unpredictable environments. The range of skills described by the User Voice staff members demonstrates the importance of these additional skills.

The participants generally engaged well in the process, but some did struggle to relax, particularly when meeting with a participant in a probation office because they associated the environment with meeting their offender manager. Collecting data in probation offices was described as chaotic, and the peers preferred to meet with the participants in prison describing the environment as more controlled and therefore easier to navigate. The consistency in the reported experiences from the peer researchers suggests consensus on the preferred data collection environment. Overall, the peer researchers were able to access the participants in prison and probation services, and the general challenges of booking a room were similar to those faced by the research assistants the peers worked alongside. Good local knowledge and

building connections with staff was described as essential to ensure one could access participants to collect baseline and follow up outcome measures. However, due to their lived experience, the peers experience of meeting with participants to collect outcome data was different from those researchers who had not served a custodial or community sentence. Some members of staff were suspicious of the peer researchers' motives and restricted their access, treating them as if they were still an offender under supervision. The User Voice staff members described how the peer researchers were more vulnerable to the potentially negative impacts of when boundaries are crossed between themselves the participant and other staff members without lived experience. The importance of the peer researcher being able to manage boundaries between themselves and the participant, could be suggested as not that different from the experiences of the research assistants. However, the importance of managing boundaries with other staff members and the responsibility of those individuals without lived experience in these scenarios is particularly noteworthy. Despite the challenges, the peer researchers agreed a prison or probation office was the most appropriate environment to complete the outcome measures, but they did encourage the UCL research team to explore other more informal environments commonly used by User Voice for possible future studies.

The participants responded well to the peer researchers because of their shared lived experience and were mostly honest and open, supporting the hypothesis of the thesis. The peers described how lived experience broke down the barriers to engagement and gave one an "edge" that someone without lived experience did not have. The peer researchers were able to build rapport with the participants over time, which supported the creation of "safe space" where the participant felt able to open up about how they were feeling and their experiences. However, the User Voice staff members also explained that it was not possible to engage every participant regardless of how much shared experience one may have with the other

person, and it was important to think broadly about the potential barriers to engagement. For example, some participants were concerned about the information they shared being passed on to their offender manager, whilst others were worried about being judge by the peer researcher especially if they had relapsed. Other barriers may not have been related to the type of researcher but reflected the participant's levels of engagement generally, or how they were feeling about other aspects of their life at the time. It was also important to remember the impact of their experiences of the criminal justice system and a diagnosis of ASPD may have affected the participant's ability to trust others. These findings demonstrate the breadth of knowledge of the peer researchers and User Voice, suggesting not only lived experience but also knowledge of the criminal justice system was key to understanding the barriers to engagement for this population.

In most cases, the peer researchers shared examples of how the role had a positive impact on them and the participants they met with. These findings demonstrate how the approach had a broader impact on individuals than suggested by the hypothesis of the thesis. The role was an opportunity to learn new skills; share their knowledge with others and reflect on their own journey and the progress they had made. The impact of the experience for the peer researcher made them feel valued and improved their confidence in their own abilities. For the participants, the peer researchers were seen as role models and a real example that it was possible to break the cycle of reoffending, giving them hope for the future. These findings also fit with the feedback from the participants who met with the peer researchers, described in the previous chapter. The User Voice staff members suggested that for some the impact was immediate whilst for others it may happen, days, weeks or even years after the event but it was just as powerful. However, the impact of the experience on the peer researchers and participants was not always positive, and in some cases caused distress.

Some peer researchers struggled to process the information the participants shared with them because of their lived experience, and found working in probation offices and prisons difficult. The peer researchers described how the experience could be particularly challenging if the participant's experience was similar to their own, and witnessing the participants being treated unfairly by the criminal justice system was upsetting. Levels of distress did differ across the team, and therefore the individual's circumstances should be considered when interpreting these results. The experience of meeting with someone with similar lived experience to themselves who was employed as a trusted member of society was challenging for some participants as they felt they had not been able to achieve the same success in their lives. Some found it difficult to trust someone with lived experience because they were not considered "a professional". This feedback from the peer researchers raises further questions about how and why society has developed an image of what a professional is and how we value knowledge. The peer researchers highlighted the importance of providing adequate training and support to help them navigate some of these more challenging aspects of the role and maintain boundaries for the safety of the participant and themselves. Despite the concerns raised about the potential emotional impact of the work on the peer researchers, the qualitative accounts shared by the User Voice peers and operational staff members were predominantly positive. These findings are encouraging and support the hypothesis of this thesis that the involvement of researchers with lived experience can enhance the quality of the data collected and facilitate the transfer of knowledge between peers and traditional researchers. However, other factors should be considered when interpreting these results.

It could be argued that if someone has decided to work for a service user organisation they already have their own beliefs and ideas about the importance of involving researchers with lived experience in clinical trials, which may have influenced their accounts of their

experiences of working on the MOAM trial. As the peer researchers and operational staff members were representing a particular organisation they may have felt it was important to report their experiences positively to ensure the findings from the thesis reflected well on the service user organisation. In order to reduce these risks of bias the peer researchers were interviewed at the end of their involvement in the study, and throughout the process, all interviewees were reminded the answers they gave during the interview would be kept confidential. However, it was not possible to eliminate these external factors, and therefore these points should be considered were interpreting these results. Despite these possible limitations, the experiences of the User Voice staff members may have been predominately positive as the results reported in this chapter suggest. The next chapter of the thesis will explore the qualitative results from the interviews with the UCL research assistants and specialist offender managers about their experiences of working on the MOAM trial alongside the peer researchers.

CHAPTER 7 Results - Research assistants and specialist offender managers

This chapter describes the experiences of the two groups of professionals who worked alongside the peer researchers to recruit and follow up each of the 313 MOAM participants. The UCL research assistants (n=5) and offender managers (n=5) were asked to describe their experiences of working with the peer researchers, and their impressions of how the MOAM participants interacted with a researcher with lived experience similar to themselves. The results from the semi-structured interviews for both groups of participants are described in this chapter.

Qualitative analysis

7.1   Research assistants

The first group of professionals who worked alongside the peer researchers were a group of UCL research assistants (RA). The research assistants were involved in the peer researchers training and worked alongside the peers to collect baseline and follow up data in each of 13 sites. The interviews with this group of professionals produced four themes: Engagement style, Levels of engagement, Shared learning and Support and supervision. The research assistants suggested the peer researchers' engagement styles varied. The peers used their shared lived experience to identify with the participants and encouraged them to engage in the process. Other techniques included adopting a more informal communication style or a more direct approach to encourage the participants to complete the outcome measures for the trial. However, the research assistants explained from their observations, levels of engagement varied and to what degree the participant engaged was dependent on the individual. However, despite the differences the participant's experience of meeting with a

peer researcher was describe as more authentic because of their shared lived experience, enabling them to develop a trusting relationship and collect more detailed honest answers.

In addition to the impact of the approach on engagement, the research assistants highlighted the opportunity for shared learning. The experience of working on a large scale, randomised control trial, provided the opportunity for the peer researchers to develop their research, communication and organizational skills. The research assistants also shared positive examples of developing their own knowledge and skills of the criminal justice system by learning from and working alongside the peer researchers. Working together to collect the data was an important theme. However, despite the positive examples of both groups of researchers supporting each other, the research assistants also described examples of poor teamwork. The research assistants shared their observations of the potential negative impact of the work on the peers, as it sometimes triggered painful memories from their pasts. Questions were raised about the amount and quality of the supervision and training the peer researchers received. It was suggested that because of their lived experience the peer researchers required more support than the researcher assistants did. The themes and sub themes are set out, by domain, in appendix W and described in more detail below.

7.1.1   Theme: Engagement Style

The first theme the research assistants (n=5) described was about how the peer researchers engaged the MOAM participants in the trial. They highlighted three approaches that were adopted. Firstly, the peers used their understanding of the participant's situation through their own lived experience to build rapport and break down barriers. Secondly, the research assistants described how the peer researchers would adopt a friendly informal engagement style to enable the participants to feel at ease during the follow up appointment. Thirdly, the research assistants explained how some of the peers adopted a slightly forceful

direct approach to encourage the participants to engage. The three sub themes are described below and include: "Someone they can identify with", "A bit more informal, a bit more lay" and "We are seeing you end of story".

7.1.1.1   Sub theme: "Someone they can identify with"

In the first sub theme, all of the research assistants (n=5) described how the peer researchers' lived experience enabled them to engage the participants in the research process. It was suggested by some of the research assistants that because the peer researcher was able to understand the participant's circumstances, this enabled them to empathise with the participant because they understood their situation and the challenges they may be facing. "I think they probably were more able to sympathise, or empathise is the right word and recognise the situation they are in and what they're going through" (RA1).

"The way they could interact with them interpersonally, they had like a shared understanding of what they were going through in terms of like going through prison and probation services" (RA3).

Two research assistants explained how the shared understanding of the participant's current situation was particularly helpful if the participant was aggressive during the research meeting, or became upset. The research assistants explained that the peer was able to calm the participant down.

"The peer researchers turned up and just by introducing themselves, you could see the participant physically relax and was more open to the questionnaires" (RA5).

"I remember you know going for visits and participants would get quite upset, and the peer researcher was able to kind of really empathize and mentalise with that individual, and kind of really settle them down to engage with the measures" (RA3).

The majority of the researcher assistants (n=4) explained how shared experience enabled the peer researchers to break down barriers between the participant and professionals. This approach reduced power differentials between the participant and the researcher, which encouraged the participant to engage in the research process.

"I think, the philosophy of the us and them culture, and the peer researchers kind of breaking that down and was really helpful in the data collection of the trial" (RA5).

"I think, when they first meet me they may be paranoid about me, I get 'you look like a lawyer or a police officer' type situation" (RA4).

Some of the research assistants (n=3) explained how the peer researchers' ability to engage with the participants through their shared experience meant the participant felt more able to be honest in the answers they gave during the follow up appointment, particularly regarding rates of offending behaviour.

"One way of making it easier for people to engage would be for the people doing the research with them, to be people they could identify with a bit more" (RA1).

"They [are] more like comfortable sharing certain, perhaps information with the peer researcher" (RA3).

The majority of the research assistants (n=4) described how they were not able to engage the participants in the same way as the peer researchers because they did not have that personal lived experience of the situations and potential challenges they were facing.

"We haven't been in custody, and I think it's really hard to work with people that have been in custody, been through the probation system, when you have no idea what that's like" (RA2).

"We can empathize with participants and kind of think that must be really difficult, what you have been through. But I think the peer researchers have a really in-depth understanding of what it's like to be on the other side" (RA5).

7.1.1.2   Sub theme: "A bit more informal, a bit more lay"

In addition to using their shared experience, some of the research assistants (n=3) described how the majority of the peer researchers adopted an informal approach to engaging the participants in the research process. They described how the peers' interaction with the participants was softer, more informal and casual.

"I reckon it's like the same way we do it to be honest, apart from maybe perhaps a bit more informal. Maybe a bit more lay I should say actually, probably [a] more lay approach" (RA3).

"So we've had situations where the peer researchers have gone for like a cigarette with a participant afterwards, or sent messages like 'How are you doing and follow up will be due soon, I just wanted to check', kind of more of a casual conversation" (RA4).

One research assistants described how the same approach was taken in written communication with the participants.

"I know from some of the letters I've received, thinking that I was one of the peer researchers, that it was very very informal kind of colloquial language compared to maybe how I would interact with them" (RA4).

Another research assistant described how the informal approach put the participant at ease and increased engagement rates over the follow up period.

"They are very, very, very friendly. Very easy to get on with, and probably will make them feel extremely comfortable. That particular person is often able to meet participants every three months, and does not lose engagement because they probably find that they will actually have a chat with them" (RA2).

7.1.1.3   Sub theme: "We are seeing you, end of story"

In contrast to the informal approach described in the previous sub theme, the last engagement strategy adopted by some of the peers was described as more direct and abrupt by some of the research assistants (n=2).

"It would be more like 'you're due your follow up can you come to probation on Thursday or I'm coming to prison'. So it's more like, we're seeing you. End of story" (RA2).

"I think some of the peers are actually quite forceful as well, for some of them. Like kind of this idea that 'oh no you really should, you should give back' like we're [research assistant] very much, like if someone says 'No we're not keen on doing it at the moment', we're like 'Okay sure'" (RA4).

Some of the research assistants (n=2) described this direct engagement approach as an effective strategy for some of the participants who may need that extra encouragement to engage in the research process.

"For some participants, being very kind of straightforward, to the point, not having any additional chat" (RA2).

"Maybe being quite forceful sometimes with some of the guys helps as well, because it's almost like they need a push to be engaged, rather than being naturally engaged" (RA4).

Despite the suggested advantages of this direct engagement approach, the research assistants did raise some concerns about voluntary participation and if the peer researcher was giving the participant a choice to engage.

"Sometimes when they are on the phone I think are you giving that person a choice, and are you're making it clear that this is voluntary? Perhaps it can get a bit lost, which can be a bit of a worry. But they get the full lot, maybe I need to be more abrupt!" (RA2).

"I think some of the peers are very much like, really go hard on the engagement. So it is kind of, a little bit kind of, getting close to the line as to what ethically we should do" (RA4).

However, one of the researchers did suggest that the direct engagement style could be described as less authoritative and more an example of friendly peer pressure to encourage them to engage.

"Maybe being a peer allows you to kind of, be on a more kind of friendly kind of peer pressure type style of engaging, rather than kind of being coercive and kind of almost kind of punitive" (RA4).

7.1.2 Theme: Levels of Engagement

In the second theme, the research assistants described the impact of the peer researcher approach on engagement levels. The research assistants suggested how the involvement of the peer researchers had a positive impact on engagement levels and, because of their shared lived experience their approach was more authentic. The peer researchers were able to foster and develop relationships with the MOAM participants enabling them to collect more detailed and honest answers. Importance of consistency and the role of the peer researcher not being perceived as part of the criminal justice system was highlighted as important. However, the research assistants described how engagement levels were going to vary, suggesting some participants might not have responded differently to the researcher because of their lived experience. Each individual was different; they trusted you or they do not. The three sub themes are described below and include: "It's more authentic", Developing a relationship over time and "It is going to vary".

7.1.2.1 Sub theme: "It's more authentic"

Overall, most of the research assistants (n=4) described how the peer researcher approach had a positive impact on engagement levels.

"Yeah, I think [it] could make that whole experience for the participant much more positive, much more helpful, much more rewarding and therefore be rewarding for the researcher as well I hope" (RA1).

"To be honest, when I've inherited cases that have been with [the] peer researchers they have been generally very engaged" (RA4).

The research assistants (n=4) described how the participants felt able to be open and honest with the answers they gave the peer researchers during the research meetings.

"Hopefully they have been more honest, and felt more able to be more open" (RA1).

"You are asking the questions, and you are getting an answer that is on a sheet. They [the peer researchers] get more; get good quality data from participants in terms of the honesty at times" (RA2).

In some cases, two research assistants explained the peer researchers were able to collect more detailed answers from the participants they met with than the research assistants were, particularly during the diagnostic interview at the 12 and 24-month follow up appointments.

"Using peer researchers who can really relate, and really get the best out of [the] participants' experiences, and sharing that information and that data that, they can really get in there much more personally than other researchers could" (RA1).

"I think when we meet up every couple of months we always go through a SCID together which is really helpful, and we kind of think about what information we've got. I definitely think they seem to get more. That's probably in terms of that they feel more able to, or maybe more trustworthy" (RA2).

7.1.2.2   Sub theme: Developing a relationship overtime

Nearly all of the research assistants (n=4) commented on how the peer researchers were able to engage and build rapport with the participants during the two year follow up period.

"If people have projects or things that they were working on, I think they were able to kind of go back, and yes I think the engagement would have definitely improved over time" (RA5).

"From the ones I've seen, and where the person has been doing the follow ups that they do kind of seem to be very engaged with follow ups. Almost kind of, don't want to say looking forward to, but kind of anticipating them and not feeling negative about them" (RA4).

However, one of the research assistants highlighted the importance of consistency to develop and maintain this engagement over time.

"I know one of the peer researchers has been on the trial for a couple of years now and their follow-up rates are the highest of anyone's. I am convinced that it is because they have been there from the beginning, so there has been no hand-over to anyone else" (RA2).

To help explain these levels of engagement, two of the research assistants suggested the participants did not see the peer researchers as a threat as they were not part of the criminal justice system.

"It's quite important that they see you not as a threat, and you know it's very important that the peer researchers are able to make it clear that this is all confidential we're not going to hand anything over. I think if you're able to get that information across, in a way they trust you, that, you'll get so much more data" (RA1).

"I do think they seem to get more information, so I'm more likely to get a 'yes I've done something illegal but I'm not telling you what it is'. Whereas they are more likely to get 'yes I've done several things illegal: this, this, this, this'" (RA2).

7.1.2.3   Sub theme: "It is going to vary"

Despite the examples of good participant engagement, most of the research assistants (n=4) described how it was difficult to conclude if the peer researchers were able to engage participants more effectively than the research assistants were, as they were not in the room during the meeting with the participant.

"Again, I've never directly observed it. It is hard because I think it is going to vary. I hope that they're probably more honest with a peer researcher, that is my assumption and my hope I guess because of the experiences they've had" (RA1).

"I think in terms of like offences and things like that, they might say something different in front of a peer researcher. I'm not certain to be honest" (RA3).

Two of the research assistants suggested there may not be any difference between how the participants responded to the two different types of researchers because the protocol for both was the same, and they are either trusted you or they did not.

"The peer researchers follow the same protocol as the other researchers. So I think as long as they're letting the participants know at the start, which I'm sure they were, their confidentiality only goes to a certain extent. I think then quite honestly [the peer researchers] would probably be the same to be honest as the research assistant" (RA5).

"I think they either trust you to not hand over [the information] or they don't. I do not know whether being a peer researcher would really play that down that much, because it's still the same structure, in terms of interview and the way it's taken place" (RA4).

7.1.3   Theme: Shared learning

In the third theme, the research assistants (n=5) described how working alongside the peer researchers was an opportunity to share learning and for everyone to develop their skills. The research assistants explained they observed how the peer researchers developed their

research as well as their organizational and communication skills, which led to the peers feeling more confident. For others the experience enabled them to develop a more positive relationship with prison and probation staff. The research assistants highlighted the experience also provided the opportunity for the peer researchers to recognize the skills they already had due to their own lived experience. The research assistants described the experience of working alongside the peer researchers as positive, as it enabled them to develop their research and engagement skills, as well as their understanding of the criminal justice system whilst maintaining boundaries. For one of the research assistants the experience of working alongside the peer researchers solidified their own decision to follow their chosen career path. The research assistants described several examples of equal joint working explaining how both the peer researchers and the research assistants would work together to cover the caseload. The peer researchers' local knowledge was described as very important, and the role was a real opportunity for the peers to give back. However, some of the research assistants shared examples of poor team work and concerns about data quality. The three sub themes are described below and include: Learning experience for the peer researchers, "We learnt so much from them" and Working together.

7.1.3.1   Sub theme: Learning experience for the peer researchers

All of the research assistants (n=5) described how the experience of being a peer researcher gave the peers the opportunity to develop their skills.
"I think it's a good idea because if they want to kind of expand their repertoire of skills and experiences. I think, they can say 'I was a peer researcher on this project'" (RA3).
Although all of the peer researchers had previous experience of engagement roles, most of them had not worked on a research study. All of the research assistants (n=5) described how the experience of working on the MOAM trial provided the peer researchers with the

opportunity to develop their skills in interviewing participants and administering outcome measures.

"Collecting quite sensitive data for this kind of, a massive clinical research trial like, it's completely different to what I think the majority of them would be doing had they not signed up to do it. So I think in that way it gives them skills that they just wouldn't get from another job" (RA4).

"Yeah, hopefully that's been an opportunity for them to learn some new skills in that way, and feel really a sense of mastery of a new area or a new skill of collecting data" (RA1).

In addition to research skills, the research assistants (n=3) described how the role also provided the opportunity for the peers to learn other skills. Organisational skills were highlighted as a key area of development for the peer researchers.

"I think the amount of organization and management that they were given, the same responsibility as us" (RA5).

"They're not going to text you and remind you that you're seeing them on Thursday, it's not going to happen. So you have to be really organized" (RA2).

One of the research assistants explained how as part of their role the peers were also required to communicate with a wide range of professionals whilst working on the trial.

"For example, one of the peer researchers gave a presentation about the research trial to an office of London probation managers, quite a lot of people who were quite high up. It gave them new opportunities; I think which could be exciting and a bit nerve wracking" (RA5).

The research assistants (n=2) described how the experience also increased the peer researchers' confidence. They suggested how empowering the role was and how the peer felt a buzz of excitement because they had achieved.

"Because of the way their DBS is used, they probably would not be able to get that job. Because they would just be screened out for that reason. So I think it's very empowering to kind of give them that opportunity, but also because no one else would give it to them" (RA4).

"I think one of our best days on the research trial was after myself and one of the peer researchers did a training event to a big group of people. Just the absolute happiness and buzz and excitement of the peer researcher's face that they had achieved that, because they were really nervous about it beforehand" (RA5).

For some of the peer researchers, the impact of the role may have led to them developing a more positive relationship with some of the prison officers and offender managers as they felt more confident in the space.

"Hopefully getting a different experience of the relationships with people there, like prison officers and things, and actually being able to experience that in a different way it could be quite helpful for them as well" (RA1).

"I mean there's one site where actually, you know, when there are quite a few times I'm guessing, [the peer researcher] kind of built up a good relationship with some of the team or most of the team I hope. Then that way it kind of gives them a different experience of probation services from the one when they were on the other end" (RA3).

Although all of the research assistants (n=5) agreed, the role provided the peers with the opportunity to develop their skills, one of the research assistants suggested the role may also support the peer researchers with recognizing the value of their own lived experience.

"I also reckon not just developing their skills, but recognizing the unique kind of extra skill they have from their own lived experience" (RA1).

7.1.3.2   Sub theme: "We learnt so much from them"

In the second sub theme, all the research assistants (n=5) described the skills they had developed from working alongside the peer researchers. The research assistants spoke very positively about their experiences.

"I thought it was very innovative and was kind of really exciting that we were able to do this. I feel like with big organizations there's normally a lot of rules and it was all well managed or well organized, and it was done properly" (RA5).

"So I think that's been probably, one of the best parts it's just a general learning experience that I feel like you wouldn't have been able to get from anything else" (RA4).

Several of the research assistants (n=4) described how they really valued the opportunity of working with someone who had personal lived experience different from themselves. They described how different the study was compared to other projects that often just recruited psychology graduates.

"So when you do like a team meeting and you have people and one of them says something like 'the month I came off her heroin was the worst month of my life, I wouldn't recommend that to anyone'. Another one saying 'yeah well when I was selling drugs I went to HMP wherever this happened' and another one saying 'when I was on probation I was recalled for not even turning up'. Like it was, it's like amazing to have colleagues which have that background and you learn so much from that in a way" (RA4).

"Actually, working alongside the peers has taught me so much about working with people that are very different and have different life experiences. So it's been really good" (RA2).

Two of the research assistants highlighted how the experience developed their own engagement and research skills, as they were able to learn from the peer researchers' approach.

"So I've learned a lot from them in terms of you know that kind of engagement, and when they are talking about when they meet, meeting with participants" (RA2).

"Having their experience as well and their views on how to kind of maintain engagement" (RA3).

Others described how the experience had broaden their own understanding of the criminal justice system as they explained how the peer researchers were able to describe what prison or reporting to a probation office was really like.

"Probably just like a better understanding of the criminal justice process, and understanding their experiences of what they'd been through" (RA3).

"That was an interesting thing actually that they taught us. Just how much, how much the prisons have changed as well over the years and how much more understaffed they are" (RA5).

The importance of maintaining boundaries and recognising that some people may require more support than others was an important skill two of the research assistants explained they had developed whilst working alongside the peer researchers.

"Patience definitely! Thinking about how those boundaries are different, and how you're working with a different kind of individual that perhaps needs a bit more support, or needs a bit more help with things" (RA2).

"I think definitely kind of training, and kind of training and supervision qualities I think probably. I've developed kind of like vicariously not kind of deliberate, but I think it's just stuff I've picked up" (RA4).

For one of the research assistants the experience of working alongside the peer researchers solidified their own decision to follow their chosen career path.

"I do think working alongside the peer researchers has really solidified that for me, and made me think actually this is what, this is why I'm doing this. These people have had often, not always, shit stuff happen to them, shit lives, awful things that they do not deserve" (RA1).

7.1.3.3   Sub theme: Working together

In addition to the skills the research assistants felt they and the peer researchers had developed from working alongside each other, all the research assistants (n=5) also described a range of examples of working together to engage and collect data from participants.

"So before there was quite a lot of flexible working where peer researchers would pick up cases where they would do a follow up for you, and then they would kind of do the paperwork and send that back to UCL, and obviously have done the follow up well" (RA4).

"They would work with the research assistants equally to provide the training to probation services to promote the research trial, which helped with recruitment" (RA5).

In particular, the research assistants (n=3) described examples of when the peer researchers shared their knowledge to support the research assistants with navigating the prison and probation system.

"They knew the system very well and would be able to say 'oh that prison's a nightmare, best to call them or it's best to do this', so it is very useful just for their knowledge and for their experience of the regional areas that they worked in" (RA4).

"I remember like, yeah, if they knew the service or the probation officers it went much more smoothly" (RA3).

Through the examples of shared learning, one research assistant highlighted how the involvement of the peer researchers was a real opportunity for them to give back to society and the study was an example that the peer researcher approach could be successfully adopted.

"It just seemed like a great opportunity really for people who have been through this process, to then feed back into the process of the research, around supporting people who have been in a similar situation who have offended" (RA1).

Despite several examples of both groups of researchers working together, one research assistant also described some examples of poor teamwork.

"It was like that with a few appointments, and then kind of turning around maybe trying to blame others for why things hadn't happened was kind of a negative experience that I've kind of experienced" (RA4).

7.1.4   Theme: Support and supervision

In the fourth theme, the research assistants (n=5) described the importance of adequate support and clinical supervision for the peer researchers. The research assistants described how the experience of meeting with a research participant in a probation office or prison was too close to home for some of the peers and it bought back painful memories. Visiting prisons was described as particularly triggering, especially when the peer visited a prison where they had served their sentence. Interacting with criminal justice staff or meeting with a participant who had been involved in a similar type of offending behavior was highlighted as particularly difficult situations for the peer researchers to navigate. These experiences meant the peer researchers had to carry an extra burden compared to the research assistants. However, the research assistants explained the experience did affect the peer researchers differently depending on the degree to which they had moved on with their lives.

There were mixed opinions amongst the research assistants about the amount of supervision the peer researchers received during the trial. Although opinions varied, all of the research assistants felt the peers needed more support, describing how the amount of training and supervision the peer researchers received for the role was not sufficient. The unequal distribution of support amongst the researchers was highlighted as particularly problematic. Not only did the peer researchers receive less support, the research assistants felt the peers needed more support because of their lived experience as their role involved more lone

working. The research assistants highlighted it was important that not only should the peer researchers be able to access more support in the future, but also that the support was specifically tailored to their needs. The two sub themes are described below and include: "It was too close to home for some of the peer researchers" and Clinical supervision.

7.1.4.1   Sub theme: "It was too close to home for some of the peer researchers"

Nearly all of the research assistants (n=4) explained the role of a peer researcher was enjoyable, but it could also be painful for some of the peers who worked on the trial. Interacting with participants who were either in prison or on licence could bring up painful memories from their past.

"So I guess it's frustrating at times, and I guess it is hard being somewhere where you've had bad experiences. But I think on the whole they seemed to, I think that they enjoyed it" (RA2).

"You know if it brings up stuff for them that they've not had a chance to kind of think about in a while, or it's still quite painful for them I think it could be quite difficult" (RA1).

One research assistant explained the experience of going back into a prison to meet with a participant might have been particularly challenging for some of the peer researchers, especially the process of being searched on entering the prison.

"Maybe like going into prisons. Not just the experience but also like the process. Wonder what that was like for them. The whole pat down. I don't know if it was like, I don't know if they identified it or like any entry forms or things like that" (RA3).

During the course of the trial, some of the peer researchers met with participants to complete the follow up measures in the same prison they had served their sentence. One research assistant explained how the experience could bring back very difficult memories for some of the peer researchers.

"I can imagine having to go back into a prison and having been in prison yourself could bring back an awful lot of really difficult experiences and memories. Dealing with that whilst remaining professional, whilst managing the role of being a peer researcher and going in and getting the task done that you need to do" (RA1).

How some of the prison staff interacted with the peer researchers was described as triggering by the research assistants (n=3) as it reminded the peers of the way prison staff had spoken to them whilst they were serving their sentence in custody.

"They mentioned they've [the peer researchers] had trouble with certain prisons being, they can be, they can ask questions that they don't want to be asked. I know one of the peer researchers said they were worried that the prison would ask what their background in offending was" (RA2).

"I've had one example where I was shadowing a peer researcher and the way the prison officer spoke to them brought back ways that a police officer treated them back in the day, and obviously there's no way really for them to share that at the time" (RA4).

One research assistant described a particularly negative interaction with a member of staff in a prison, explaining how one of the peer researchers described how they did not feel safe.

"It can sometimes be they can feel kind of like the process is repeating. I think one of the peer researchers that has actually left now said that they didn't feel safe going back into the prison without more support" (RA4).

In addition to the challenges of meeting with participants in prison, two of the researcher assistants described that if the participant had a similar offending history the peer may find it difficult as the participant's answers could bring back difficult memories.

"So if they have a similar offence or similar history. So if they're doing measures and that kind of stuff is coming out and thinking 'oh this feels quite similar to what I've been through' I imagine that could be quite difficult" (RA1).

"I guess it depends on the nature of the crime they were in custody for as well and you know. If you say it's drugs, and then you're interviewing someone who is a drug dealer it might be difficult to bring up a difficult past" (RA2).

One of research assistants described how this experience may lead to the peer researchers projecting their own experiences onto the participant.

"I think it is important that someone does not just project his or her own experience onto everything. If someone has had a negative experience of the service, not necessarily everyone else will have that same experience. Someone that can see their experience is kind of part of a bigger jigsaw, not just the only experience" (RA4).

The degree to which the peer researcher had moved on from their previous life affected how successfully they were able to navigate these situations.

"I guess it depends on the person and if they have completely put their past behind them, and are able to talk about these things, and not be triggering or upsetting" (RA2).

"There may be some peer researchers that have issues with that regard that they have still yet to work through" (RA4).

It was highlighted by one research assistant how these experiences could lead to the peer researcher taking on an extra burden, and it was important to consider this when structuring support for the peer researcher role.

"In a professional you know, in a professional way, but they are taking on an extra burden. I think it is important that's considered, the impact for the individual peer researchers and how they are supported with that" (RA1).

7.1.4.2   Sub theme: Clinical supervision

All of the research assistants (n=5) described the importance of clinical supervision for the peer researchers to support them with processing their experiences of meeting with male service users with ASPD.

"You hear a lot of stories of men, who really haven't been given much chance in life and have had a really crappy life from when they were kids, and you hear some stories and they are uplifting. So to have that clinical supervision, it makes a massive difference and that's something that the peer researchers just don't get" (RA2).

"So I think they would probably need regular supervision to kind of process their own experiences, and also to keep them engaged and keep them focussed on getting follow ups completed. Not bogged down" (RA4).

However, there were mixed opinions about the type of support the peer researchers received during the trial.

One of the research assistants felt User Voice were very supportive, describing how they were real advocates for the peer researchers.

"I mean I think User Voice really stuck up for the peer researchers as well. In terms of communicating like theirs need or, advocating for them" (RA3).

Two of research assistant highlighted that the quarterly booster sessions, which involved User Voice and UCL research staff, were an opportunity for the team to support each other. During the meetings, the researchers reviewed how to overcome challenges and difficulties they may have faced in the last couple of months.

"So the UCL researchers and the peer researchers meet together and we discussed general things that are happening in the trial, kind of challenges, difficulties and also things that were going well" (RA4).

"So UCL and User Voice would meet up for like a joint meeting. I cannot remember, every three months maybe, I cannot remember. But that was really good so we could all meet up together because obviously we're all kind of spread across the region" (RA3).

However, some of the research assistants (n=2) were unsure about the amount of informal support the peer researchers received in addition to the quarterly booster sessions to talk about their experiences and how they were feeling.

"I wonder what, how informal that peer support was between them. Whether there was more opportunity for them to kind of meet and talk and things separate from this, from the stuff that was mandatory for the study I guess" (RA1).

"I did wonder about like you know reflection space and like how they kind of felt about it. I think maybe they talked about it within User Voice, but you didn't have super open conversations about you know what it's like for them" (RA3).

Although there were, mixed views about the amount of support the peer researchers received, all of the research assistants felt the peers needed more support supervision and training for the role.

"People should be given the opportunity to thrive. If they are struggling then they should be given the support to rectify that. And I don't think that's been there really" (RA4).

One research assistant highlighted that due to lack of support for the peer researchers a situation had been poorly managed which resulted in one of the peers leaving the trial, despite performing very well in the role.

"One of the peer researchers that's left through really an incident that was quite severe really, like they were brilliant at the job, but I think it was just the way that the whole situation was managed pushed them out" (RA4).

Changes within the management structure at User Voice were described as possibly contributing to the amount of support the peer researchers received.

"I think with User Voice, I think they had quite a few changes of management during the trial which was a bit tricky. I think that might have had an impact on the amount of support that the peer researchers receive" (RA5).

"I think where kind of service user led organizations maybe falls down, and I can't comment on all of them, but where User Voice may be falls down it's just, it seems to be a bit all over the place in terms of the way it was managed. So sadly, it has not worked as well as it should have done because of that" (RA4).

One of the research assistants felt they received more support and training than the peer researchers whilst working on the project, describing how they were able to access clinical supervision sessions every three weeks, and worked in the same office as the trial coordinator.

"I don't feel they've had the same support that my colleague and I've had. In terms of, so for example my colleague and I who obviously work at UCL, we have clinical supervision every three weeks, or more if we want it, where we meet and we talk clinically about our cases with a clinical psychologist" (RA2).

The unequal distribution of support amongst the researchers was highlighted as particularly problematic because not only did the peer researchers receive less support, the research assistants felt the peers needed more support because of their lived experience.

"They [the peer researchers] might need more supervision and support, or space for that because of the parallels there might be between them and the person that they are doing the research with" (RA1).

In addition, one research assistant described how the peer researcher's role involved more lone working than the research assistant role as the peer researchers worked in separate offices in different parts of the country.

"Like myself and my colleague will ask each other questions and kind of like support each other when we're in the office together, whereas they are a lot more separated. When we do meet up I do wonder if they would benefit more from having someone that they can you know, even if they were in the same office together like once a week so they could go through those kinds of things together" (RA2).

Although the research assistants agreed the peer researchers needed more support, some of the research assistants (n=2) highlighted that it was important to tailor that support to the needs of the peer researchers and not to assume that they all needed the same type of support, or the same support offered to the research assistants working on the trial. "Also that there's different options for that, because I guess it might not always be easy to talk to an academic kind of type of supervisor. So whether it is another peer support option, or a peer supervisor" (RA1).

"I think that they need support from people in their own organization, because a lot of people at User Voice obviously have the same background in the criminal justice system" (RA5).

7.2   Qualitative summary

The research assistants who worked alongside the peer researchers to collect the outcome measures for the study reported a range of positive effects due to the involvement of researchers with lived experience on the participants and themselves as researchers. The peer researchers adopted different engagement techniques to encourage the participants to complete the outcome measures that enabled them to develop relationships over time. Through these engagement approaches, the research assistants described how they observed how some participants were able to identify with the peers because of their shared experience and therefore gave more detailed and honest answers supporting the hypothesis of this thesis. The research assistants explained the engagement approaches adopted by the peer researchers

were not accessible to them, as they did not have the shared lived experience with the participant. These findings suggest the peer researchers' approach was more authentic. Although the research assistants shared several examples of how the peer researchers were able to engage the participants more effectively, there were limited opportunities for them to observe these interactions. Therefore, these opinions would have been generated from secondary information from the participants and the peer researchers themselves, which may limit the accuracy of the finding.

An unexpected impact of involving researchers with lived experience was the opportunity for shared learning for both groups of researchers. The role provided opportunities for the peer researchers to develop their organisational and communication skills the research assistants described how over time they also observed the peer researchers' confidence in their own abilities grow, leading to improved self-worth. All of the research assistants described how they really enjoyed the opportunity of working with someone who had a different life experience to themselves, and valued the opportunity. Working alongside the peer researchers enabled the research assistants to develop their engagement skills. The research assistants also highlighted how much knowledge the peer researchers shared with them about navigating the criminal justice system. The range of specific examples shared by the research assistants strengthens this finding, suggesting the approach does create the opportunity for shared learning.

Despite the positive experiences described by the research assistants, they explained that not all of the participants felt able to identify with the peer researchers and having shared lived experience did not guarantee engagement. The participant's personal circumstances effected engagement levels, as well as the meetings being held in a probation office or prison setting. In addition, some concerns were raised about poor data collection and the potential negative impact on the peers of working in prisons and probation offices may trigger painful

memories from their pasts that should be considered when evaluating the full impact of the approach. The qualitative reports from the research assistants highlighted the need for the peer researchers to be able to access clinical supervision to support them with managing the emotional burden of the role. The next section of this chapter will explore the experiences of the specialist offender managers who worked alongside the peer researchers in each of the 13 sites.

7.3   Specialist Offender managers

The second group of professionals who worked alongside the peer researchers were a group of specialist offender managers (SOM) who were part of the MBT team and provided a link between the clinical service and the wider probation system. Analysis of the interviews with the specialist offender managers produced three themes: "Bridging the gap", "Challenging the stereotype" and "The therapeutic effect". The offender managers described how the peer researchers were able to "bridge the gap" between the participant and professional because of their lived experience, breaking down barriers to engagement. The peer researcher role was described positively, and the specialist offender managers explained how the involvement of the peers enriched the study because they brought a new perspective and challenged the negative stereotype of being an ex-offender. They were trusted professionals, and real examples of rehabilitation for the participants as well as probation staff. The specialist offender managers suggested meeting with a researcher with lived experience could also have a therapeutic effect on the participant as well as the peer researchers themselves since the experience provided hope and they felt valued. However, the specialist offender managers highlighted the importance of maintaining boundaries and the ability of the peer researcher to be empathetic, but not sympathetic raised concerns. The specialist offender managers also suggested the potentially negative impact on the peer

researcher of the experience of going back into prison or a probation office to meet with a research participant currently under supervision. The peer researcher may potentially be drawn back to a life of criminal behaviour or re enforcement of those ideas and lifestyles or the experience may bring up trauma from their past, particularly when meeting with a participant in custody. The themes and sub themes are set out by domain in Appendix X, and are described in more detail below.

7.3.1   Theme: "Bridging the gap"

The first theme the specialist offender managers (n=4) described was how the peer researchers were able to bridge the gap between the MOAM participants and the offender managers, UCL and the clinical services through their shared lived experience. They highlighted how beneficial this role was for the research trial as the peers were able to break down the barriers to engage participants in the research process suggesting "it feels like us and them if not". The specialist offender mangers also suggested there were other benefits to the approach including shared learning for the peer researchers, offender managers and the research team at UCL. However, they highlighted there was a risk of a peer researcher being drawn back to a life of criminal activity if they were unable to manage the boundaries between empathy and sympathy. The offender managers stressed the importance of the peer researcher having a degree of separation between their old and new life to minimise this risk for their own protection. The three identified sub themes are described in more detail below and include: "It feels like an us and them if not", "Any study is just enriched by involving service users" and "Being empathetic but not sympathetic".

7.3.1.1   Sub theme: "It feels like an us and them if not"

Some of the offender managers (n=3) suggested the MOAM participants could be suspicious of authority figures because they found it difficult to trust professionals because of their previous experiences.

"When I think about the people on MBT particularly. I think they are very suspicious and very mindful of people in authority, because that's the kind of experience they've had" (SOM1). This mistrust could lead to the development of the 'Us and Them' culture between service users and professionals, especially for those working in the criminal justice system. The specialist offender managers (n=3) explained the peer researcher approach was able to break down some of these barriers.

"I think the more service user that you can have the better, because I just feel like it feels an us and them if not" (SOM1).

"I think it does. Yes, because again it bridges the gap. It cuts it being 'us and them'. You know there not people in authority or offenders, but there you know, people who straddle that line" (SOM2).

It was highlighted how barriers could be broken down through shared learning, as the peer researchers were able to bring a different perspective and an appropriate level of challenge to the table.

"You know we learn from each other. You know the resilience and that; sometimes they carry on in the face of all sorts of shit you know what I mean. So I have learned from them, and I think that we learn from people all the time" (SOM3).

"So I think they offer an appropriate level of challenge, which I think is really helpful and a different perspective" (SOM1).

7.3.1.2 Sub theme: "Any study is just so enriched by involving service users"

Shared learning enabled some of the specialist offender managers (n=3) to
communicate more effectively with the MOAM participants as the peer researchers supported
them to understand the language the MOAM participants used.

"These are people who understand the language. So you know I've worked in probation twenty
years, and even I occasionally say 'what on earth does that mean to people?'" (SOM4).

"It's you know been very helpful I think in some ways. I think it's good to use people who have
lived experience" (SOM5).

The offender managers explained how the approach helped bridge the gap between
some MOAM participants and the trial, suggesting that because the UCL research team had
limited experience of the criminal justice system they might have struggled to understand the
reality of reporting weekly to a probation office or serving a prison sentence. The
involvement of the peer researchers provided an opportunity to bridge this gap of
understanding.

"That is how it works. What the terminology is, how the system works and yet what goes on. I
think they have bridged the gap the other way, and kind of been like 'actually that's not how
things are'" (SOM4).

The involvement of the peer researchers in the trial also enabled the MBT team to
engage some service users more effectively by bridging the gap between the clinical service
and some of the MOAM participants.

"One case, he was very sort of, he was a little bit anti MBT, he did come, and he was motivated,
but anyway. But when the peer researcher went in we got information from the peer researcher
they were really, really keen to come back and do MBT" (SOM1).

"It became really hard to maintain that contact with him. It was almost when he spoke to the
peer researcher, it reminded him that he wanted to talk to us [MBT] as well" (SOM4).

One of the offender managers suggested the peer researcher approach might have strengthen the trial's methodology because the peer researchers were able to support UCL to understand the service user experience.

"I think it is also important because, people who are involved in academic research at somewhere like UCL are probably a fairly privileged group. I think well 'how can someone from a really privileged group really know what's important?' What we've got to do is learn, and think about in terms of a service user's experience, and what might help them" (SOM1).

In addition, one of the offender managers described how the experience of working with the peer researcher in their site, furthered their own self-development and understanding of their role within the probation system.

"They remind me of the fact that my experience and my values, and the way I think about things will only take me so far. I need to be curious about things, how they [service users] feel, in order to do my job better" (SOM1).

Despite the positive examples of when the peer researchers had successfully bridged the gap between different agencies, some specialist offender managers (n=2) described scenarios where probation staff were suspicious of the peer researchers' motives and were concerned they had not changed their behaviour.

"I think some people still could be quite judgemental and think oh, you know, I better cover up my computer, I better do this, I better do this, you know. I better not leave my handbag on the thing, and some people are absolutely fine" (SOM1).

"Maybe a bit suspicious. What is their motive, what are they doing this for?" (SOM5).

One offender manager felt the only way to overcome these suspicions was to involve more services user with lived experience in their work.

"I think there are still a lot of prejudices within the probation service about service users, and that's not just on the MBT, but across the pathway. These people are just, critical and quite a

few sort of, you know, yeah, a bit kind of suspicious. So that's why I think we need more"
(SOM1).

7.3.1.3   Sub theme: "Being empathetic but not sympathetic"

Some of the offender managers explained (n=3) for some participants the involvement
of the peer researchers increased their engagement in the trial because they knew they would
be meeting with someone with similar experiences to themselves.

"It's just bridged that, especially around the start of the program having the peer researcher to
come and speak to them has just bridged that gap around engagement" (SOM4).

"I think it's huge because again I do not think we can overestimate the impact that it's had on
somebody who's been there and done that. Can offer you an opinion, a thought, a word of
support" (SOM2).

In particular the offender managers (n=2) explained that the peer researchers understood how
chaotic the participant's lifestyle may be and the way their current situation may be a barrier
to them engaging in the trial.

"I think they need the empathy, the ability to connect to people" (SOM4).

"You know empathy with them you know for the way their lives turn out and things. You know
you do not mind chasing around after them so much. Whereas somebody like me might get a
bit pissed off" (SOM3).

The offender managers (n=3) explained how empathising with the participants
through their shared lived experience enabled the peer researcher to engage the MOAM
participant in the research process and bridge the gap between the service user and the
professional.

"I think it's really helpful that they're empathetic. So they put themselves in the potential
participant's shoes, and try and encourage them that way" (SOM1).

"I suppose given the nature of the men we work with it might have felt that they could communicate better you know. People might have more empathy with their lives which are often pretty chaotic and everything" (SOM3).

However, one offender manager also highlighted the risk of the peer researcher crossing the line between empathy and sympathy as they engaged participants. They could potentially be drawn back to a life of criminal behaviour or re enforcement of those ideas and lifestyles if they were unable to manage the boundaries between themselves and the MOAM participant. "Boundaries, because you know they kind of sit between the research people and the offender, and it can be really easily again, can be really easy for them to be drawn back towards it. Even if you're not drawn back into offending, it can be drawn back in to that life" (SOM4).

To reduce this risk, the offender manager highlighted the importance of a degree of separation between the peer researchers' old and new life for their own protection as the draw of the perceived benefits of criminal activity can be very powerful.

"They need to be that kind of a couple of steps further away, then perhaps sometimes other people do. Mainly because it is, you know it's a powerful life, that kind of status. You know easy disposable income, and the thrill can be a big draw for someone. So I do think they really need that degree of separation for their own safety" (SOM4).

7.3.2   Theme: "Challenging the stereotype"

The second theme described by the specialist offender managers (n=5) highlighted the ability of the peer researchers' to challenge the negative stereotypes associated with being an ex-offender and having a criminal record. The offender managers describe how they could not always tell if the individual was a peer researcher or a research assistant because they conducted themselves so professionally. In most of the research sites, the peer researchers were trusted and treated like any other professional. However, the offender managers did

share examples of when the peer researchers were treated with suspicion. Despite these concerns, the peer researchers were described as a real example that change was possible for the MOAM participants and the probation service as a whole. The three identified sub themes are describe in more detail below and include: "You just couldn't tell", "Trusted professionals" and "Proving change is possible".

7.3.2.1   Sub theme: "You just couldn't tell"

Some of the offender managers (n=3) commented on the peer researchers' enthusiasm and how helpful they were, challenging the stereotype of an ex-offender.

"I really like the attitude of the one we've got here. I like the enthusiasm and I like the energy for what they do" (SOM4).

"The peer researcher was sort of so professional and kind of, and not stereotypical or someone might have a stereotypical view of someone who's been in prison or whatever. They are just not like that. I think it is just helpful to sort of challenge your own stereotypes" (SOM1).

The peer researchers' professionalism was highlighted through their awareness of the importance of maintaining boundaries and confidentiality. One specialist offender manager explained because of the peers lived experience they were more aware of the importance of maintaining professional boundaries, and understood how to conduct themselves in the work place.

"I think I get more sense that, you know, within that atmosphere people [the peer researchers] are more aware of not crossing the boundaries. They've been badly affected by, throughout their lives, people not respecting boundaries, harming them in care homes or harming them in other sorts of ways, as well as professionals in the criminal justice system" (SOM1).

The offender manager described how they did not realise the peer researcher had personal lived experience of the criminal justice system until it was explained to them.

"It was never highlighted by anyone to me that he was. So I think that was a positive experience. I think at the time, for someone in that role. We just did not know the difference. I just couldn't tell!" (SOM1).

Despite the offender managers describing the peer researchers as professional, they explained some of the service users had a different understanding of what a professional was. One offender manager described how one participant rejected someone with lived experience because they wanted to see a "professional".

"This guy was talking to him about his drugs. This guy, said 'Oh I've been there, you know, I've done this that and the other' and this fella flipped. He said 'I want a professional, you know, to do my report.' You know, and he kicked off good style" (SOM3).

7.3.2.2   Sub theme: "Trusted professionals"

Several offender managers (n=4) explained peer researchers were mostly viewed by probation staff as different from service users because they had been given responsibilities in their role as a peer researcher.

"Handling money and all this sort of things, and having an email address, I think for them [the participants] that is real. That's probably, even if it doesn't say something explicitly, there's something very implicit about the fact that these people [the peer researchers] are different and they're to be trusted" (SOM1).

"When it's explained to them what the purpose is, most people are co-operative with that I imagine" (SOM5).

One probation office highlighted how much of a change of attitude there had been towards professionals with lived experience since they started working in the probation system over 15 years ago.

"I mean within probation, you know, it used to be, when I first started working as a probation office a long time, like for 15 years. I remember they weren't allowed in the office, and some of the service users are given a little talk at the team meeting. Oh my god, they are not allowed in the office, and I thought bloody hell, you know!" (SOM1).

Another offender manager suggested that the peer researchers were trusted because they worked for User Voice.

"One thing that has been really helpful is when people say oh 'where have they come from?' If you say 'oh they have come from User Voice', they know yeah what you mean. So they understand kind of the implications that comes with that" (SOM4).

The response the peer researchers' received also has an impact on how the MOAM participants saw the peer researchers as well.

"Having a peer there seems to make a huge difference, because it's also a real sort of symbolic thing of the outside world coming in. That person being allowed to come in must mean they've really made it, because they really have. They've crossed that divide" (SOM1).

However, one offender manager explained that although the peer researcher had been given this trust, sometimes they struggled to see themselves as an equal to other professionals and they would often take on more a subsidiary role in joint meetings.

"I think when you're in the room with them a bit more; I feel perhaps they think they have to take a subsidiary role to you as the professional. I don't know why they do that. I suppose it's just they're used to doing that" (SOM1).

7.3.2.3   Sub theme: Proving change is possible

All of the specialist offender managers (n=5) described how the peer researchers were a positive symbol and an example of someone who had changed their behaviour and moved on in their lives.

"For our organisation [probation service] I think it's a huge bonus for probation as well. You've got it from somebody who's come out the other end, and has stayed out" (SOM2).

"I think it's the fact that they exist. The fact that there are people who have been rehabilitated and are now working in the system" (SOM4).

The example of the peer researcher as a positive symbol was described as validating for the MOAM participants they met with as part of the research trial.

"I mean to have our [peer] researcher there, they see visibly that this person has been there, can contribute, has come out the other side and is being employed to do this job. So I think it's hugely validating and prosocial" (SOM2).

"I would say that it's very validating, and I think it's helpful for the service users" (SOM1).

The offender managers (n=2) also described how for them as a professional working in the probation service the peer researchers were an example of someone who had made positive changes in their lives.

"It's quite nice to see people, that you know have lived experiences can come in and to do a role like that" (SOM5).

"I find that the more people that have had direct experience and can contribute, that are relevant and are there to discuss can be a positive source. I'd say again hugely positive in my experience, and I welcome it" (SOM2).

The offender managers (n=3) suggested the MOAM participants might see the peer researchers as role models and someone to aspire to be like.

"I think that person is also a symbol of someone who's rehabilitated and done very well, and is a role model. Someone to aspire too. So I think it's very helpful" (SOM1).

"So I think that's a huge, huge. They'll often say 'well can I be one?', 'can I, can I, would I be able to do that?' So they see the prosocial" (SOM2).

Some of the offender managers (n=2) went on to explain that for some MOAM participants the experience of interacting with the peer researcher might have supported them to move away from criminal activity, which aided their rehabilitation.

"They're meeting somebody who is in a role where they're you know, sort of busy and they're being paid and they're getting out and about doing something a bit more positive perhaps. That may influence some people into thinking they could get on with something themselves" (SOM5).

"I think this is a really, and even if they don't end up doing something like permanently, I think it feels really, just really sort of like a push to start the possibility of other things happening for them" (SOM1).

However, one offender manager felt that this was not the peer researcher's role, and they did not have this effect on the participants.

"Probably not. I cannot imagine how they would because that is not their job. It is not the job of the peer researcher, is not about rehabilitation" (SOM3).

7.3.3   Theme: The therapeutic effect

The final theme described by the specialist offender managers (n=5) explored the therapeutic effect of the research process for the MOAM participants and the peer researchers. They highlighted how a regular meeting with a researcher who had lived experience of the challenges they were facing in their lives made the participant feel valued and gave them hope. The peer researchers benefited from the interaction as they also felt valued and rewarded by the experience. However, the specialist offender managers who shared their experiences raised some concerns about the potential negative impact of the approach on the peer researcher themselves as it may bring up trauma from their past, particularly when meeting with a participant in custody. The three identified sub themes are

describe in more detail below and include: "You haven't been forgotten, you are not lost",

"They are not an ex-offender when they come in" and "It can take you back to where you

don't want to be".

7.3.3.1   Sub theme: "You haven't been forgotten, you are not lost"

Some of the offender managers (n=4) described how the experience of being followed

up at regular intervals over a two-year period could have a positive impact on the participants

because they felt valued and not forgotten.

"I think it's just really, really important. I think it plants the idea in their mind, and I think it

plants the idea that they haven't been forgotten, and they're not lost" (SOM1).

"One thing they were talking about was how much they value just somebody getting in touch

every so often and having a chat with them. You know they feel like they've not been forgotten

about" (SOM4).

This impact was described as particularly important for those participants who had been

recalled or had reoffended and been returned to custody. The offender managers (n=2) had

explained how one could easily be forgotten when in prison making it harder to maintain

relationships.

"There much more sort of rule-bound and hierarchical, you know, in that structure, and that

divide is much bigger. So I think that makes a huge difference them going inside, and making

an effort to come and see them and follow them up" (SOM1).

"As I say a lot of the men we deal with are very lonely men, they won't admit it but they are.

You know, because of you know often because of their traumatic childhood, because in and

out of prison you cannot maintain relationships, things like this. Having somebody just talking

to you, who's not judging you" (SOM3).

One offender manager described how the impact of not feeling forgotten meant the participants felt valued, but it also gave them a feeling of hope, continuity and positivity.

"I think it's that feeling they've not been forgotten, because people, often they're just forgotten and no one does anything, and they haven't got to do anything. So yeah, I think that's a real symbol of hope I think" (SOM1).

It was suggested this approach could potentially lead to the development of a more trusting relationship and the participant could feel more empowered.

"I think they felt they were able to be more open. They found it empowering that someone was in that position interviewing him, and it wasn't sort of quite stereotypical views of what a psychologist might be like, or what a probation might be like" (SOM1).

Although the offender managers consistently described the positive impact of the peer researchers meeting with the participants regularly, it was also highlighted by one offender manger there may also have been other contributing factors which led to the participants feeling valued. For example, the vouchers which were given to each participant at the end of the research meeting, or, if the meeting took place in a prison, sent to a friend or relative in the community, encouraged engagement.

"I mean don't get me wrong I imagine a big part of that [engagement] is because they know they get vouchers for doing it, I'm not so naive as to think that's not a factor. But you know somebody just you know ringing up 'hi how are you, can we have a little chat about how you're doing'" (SOM4).

7.3.3.2   Sub theme: "They are not an ex-offender when they come in"

All of the offender managers (n=5) described how they believed the role of a peer researcher had a positive, therapeutic effect on the peers themselves, as they felt valued and rewarded by the experience.

"Well I, you know I would imagine that, you know, I would imagine it's a rewarding job and I just imagine it would improve their self-esteem" (SOM3).

"So I think it's about your role isn't it, and having that appreciated by those around you so that you have done something that's turned your life around. So maybe acknowledging that as well" (SOM2).

This sense of value and reward was driven by an awareness of contributing to a project that was worthwhile; provided an opportunity for people to share their views and made a difference to people's lives by giving back to society.

"I should think perhaps they feel they're taking part in something that's worthwhile. I would imagine that for most people who are involved in it, it's the sort of motivating part of being involved in that" (SOM5).

"I think they recognise that they've been through a lot, and I think they think that they want to help people have a better journey than they did, and help other people" (SOM1).

One offender manager compared the impact on the peer researcher to the feeling they experienced following a successfully meeting with a service user whom they would supervise as part of their role in the national probation service.

"I imagine when they are, when they have a person who's attended and completed all the work I imagine that's slightly rewarding. So they're sort of contributing and getting somewhere with the task. So I should think it is not dissimilar to how offender managers feel when they turn up or they do and you have a better session you know" (SOM5).

The offender managers (n=2) suggested how the experience of being valued could provide someone with a feeling of status. The peer researcher no longer felt like an offender but saw themselves as "prosocial", and rehabilitated

"Yeah I think maybe that they don't want to be seen either as being perceived as being, what's the word, an offender. They want to see themselves as being prosocial, as having come out the other end. So I think that's huge for them, that's rewarding for them" (SOM2).

"Basically I think it is a big boost to self-esteem, big boost to self-respect and you know how they see themselves. They are not an ex-offender when they come in" (SOM4).

One offender manager highlighted that the peer researcher approach was a move away from "once an offender, always an offender" mentality.

"I mean I think it is much better, but I think in probation it just feels like once an offender, always an offender kind of thing. The fact we do not call them service users, not allowed to. So I really felt, because they were obviously, they were treated like a normal, you know, a normal employee, and I honestly didn't know the difference" (SOM1).

Another offender manager went on to explain how this process could be particularly rewarding for an individual with a criminal record who could often find it difficult to secure employment.

"You know that they felt they got a bit of status from it, because it's hard for you know somebody with criminal convictions to get a job which makes them feel as if there's a bit of status to it. They'll get you they'll get you know a sense of reward from it" (SOM3).

For the first time for some of the peer researchers, a part of their lives they felt they had to hide away was given real value and they could use their experiences to help others.

"I feel a sense that their experience, their lived experience is really valuable, and there's only so much you can sort of learn from books or study" (SOM1).

"You know, you've done this you've done that and it's always seen negatively, your criminal past rather than useful in any way. So you know suddenly, you know it's seen, your criminal past is seen as having some value if you like" (SOM3).

7.3.3.3   Sub theme: "It can takes you back to where you don't want to be"

In contrast, several of the specialist offender managers (n=4) highlighted the potential negative impact of the work on the peer researchers. It was suggested meeting with a participant in custody or at a probation office might force them to relieve a difficult time in their lives.

"Well I think again it's something they said and it takes you back, it takes you back to where you don't want to be, and how to deal with those feelings and emotions if you like" (SOM2).

No reference was made to the impact of a peer researcher entering a probation office, but the experience of visiting a prison was described as potentially traumatising

"It might be traumatising for them to go back into prison, hearing [about] people's violence or depending, you know" (SOM1).

"I know once he said you know you hear information that takes you back to where you were yourself in prison, and sometimes that's tough too and triggers all sorts of behaviours and feelings" (SOM2).

One of the offender managers also described the impact of a negative interaction with a staff member could have on a peer researcher if they were treated unfairly by a criminal justice professional.

"So I think the more risk to them is not so much, I think as being really traumatised by anything that the service user might say in terms of when they're doing peer research, but more in terms of if they weren't treated in a fair and equal way by other staff members" (SOM1).

One offender managers highlighted the importance of the peer researchers receiving adequate support with managing the emotions that may be triggered by meeting with participants to collect the research data.

"You know they will be hearing horrible things from people you know our client group have gone through some really horrible times to get where they are, they've not had a great run to

get in to their current situation. I think peer researchers need to be hearing about this, hearing about this all day every day. I think that's where they need support for it not to start impacting on them" (SOM4).

7.4   Qualitative summary

The specialist offender mangers who worked alongside the peer researchers in each of the 13 sites described the peers as positive role models for the MOAM participants and were real examples of rehabilitation. Their involvement in the trial provided the opportunity to break down the barriers between "us and them" and challenged the negative stereotypes associated with being an "offender" or "ex-offender". The peer researchers developed trusting relationships with the majority of the offender managers they interacted with. Their role was described as "prosocial" and a reminder for the participants and offender managers that change was possible. These findings suggest the ability to trust an individual with a criminal record was a significant part of the rehabilitative process. The specialist offender managers who shared their experiences suggested how therapeutic the process of meeting with a peer researcher every 3 months could be for the MOAM participants, as they felt valued and not forgotten. The peer researchers also benefited from the experience as they felt respected within their role, and were making a significant contribution to a large government funded research study. These findings were strengthened by the range of examples shared by the specialist offender managers about the changes they observed. However, the offender managers also raised some concerns about the peer researchers' ability to maintain boundaries between themselves and a participant currently under the supervision of the national probation service.

The offender managers highlighted the importance of a degree of separation between the peer researchers' old and new life for their own protection as the draw of the perceived

benefits of criminal activity could be very powerful. The specialist offender managers described this process as the difference between being empathetic but not sympathetic to the needs of the participants they met with. Concerns were raised about the possible trauma a peer researcher may have experienced from hearing the personal accounts from the participants about their experiences, and revisiting a prison where they had served their sentence or a probation office they had previously reported to. The importance of the peer researchers receiving adequate support with managing the emotions that maybe have been triggered by the role was highlighted by the specialist offender managers. These findings were similar to those raised by the research assistants in the first half of this chapter, and should be considered when evaluating the impact of involving researchers with lived experience. In the next and final chapter, the themes from the interviews with the research assistants and offender managers described in this chapter, and those outlined by the participants and peer researchers in chapters 6 and 7 are discussed together.

CHAPTER 8 Discussion and conclusion

This chapter discusses the findings described in chapters 5, 6 and 7 of this thesis to explore the impact of the involvement of researchers with lived experience on a randomised control trial (RCT) in the National Probation Service (NPS). The chapter evaluates to what degree the adoption of the approach enhanced the validity of the data collected, and created opportunities for the transfer of knowledge between the peer researchers and the traditional researchers involved in the study. The limitations of this thesis are reviewed as well as recommendations for further research. The last section of the chapter sets out the key findings and conclusions of the study.

Overview of findings

This is the first mixed methods study exploring the impact of the involvement of researchers with lived experience as data collectors on a RCT in the NPS in England and Wales. The trial participants' experiences were captured through semi-structured interviews and a self-report scale. The research assistants, specialist offender managers and the peer researchers themselves were also interviewed about their experiences of working as part of study team which involved researchers with lived experience as data collectors. The qualitative findings of this thesis suggest the inclusion of the peer researchers may have enhanced the validity of the data collected by eliciting more honest answers and provided the opportunity for researchers with lived experience and without to share knowledge across a range of areas. However, the inclusion of lived experience did not guarantee participant engagement, and there were a number of other factors which should be considered when assessing the impact of patient and public involvement (PPI) on clinical trials in the criminal justice system. The qualitative results of this thesis also found the impact of the involvement of the peer researchers went beyond the study team, as the adoption of the approach challenged stereotypes associated with being an "ex-offender" held within our society; raised

the issue of how clinical trials should be conducted and how different types of knowledge are valued. In contrast, the quantitative findings reported no significant difference between the experiences of the two groups of participants regardless of the type of researcher they met with. It is important to remember, the MOAM participants who shared their experiences did not exclusively meet with a either a peer researcher or research assistant during the following up period and therefore their answers may have been shaped by their previous experiences of meeting with a different type of researcher. This limitation in the design of the study should be considered when interpreting the results described in this chapter. It is also important to note that the rating scales used were showing ceiling effects, in other words the scale may not have been suitable for measuring the more subtle differences that existed in the reaction of participants to peer researchers versus research assistants. The sub sections below discuss these findings in more detail and explore the impact of involving data collectors with lived experience on the trial participants, the peer researchers who collected the data and the wider structures of the criminal justice and academic institutions involved in the study.

8.1   Breaking down barriers to engagement

Overall, the findings suggest the involvement of researchers with lived experience as data collectors may have had a positive impact on the quality of the data collected for the MOAM trial. It was suggested through shared lived experience, the peer researchers were able to break down barriers to engagement by developing trusting relationships with the MOAM trial participants. These findings largely fit with the work of Rise who found in their qualitative study of patients with severe mental health diagnosis that "user participation during the research process strengthens the authenticity of the results" (Rise et al., 2014). Across the five groups of participants who shared their experiences of the peer researcher approach, three themes emerged describing this process of engagement.

Firstly, due to their shared lived experience, before the participant met with the peer researcher they reported feeling relaxed because they knew what to expect from the interaction. The MOAM participants who met with the peer researchers described this process as "automatic common ground" (MOAM/PR 6), whilst the User Voice operational staff members used the expression "creation of a safe space" (UVOS2) to described the interaction. The quantitative findings from this thesis also reported that the participants felt relaxed and able to ask the peer researcher questions. These findings contrast with the qualitative reports from the participants who met with a research assistant who described their first meeting with a researcher without lived experience as "daunting" (MOAM/RA24). These accounts suggest lived experience may have increased levels of engagement in the early stages of the research process enabling study teams to access participants who may struggle to engage in a clinical trial. These findings are largely consistent with the work of Barnes who found some participants did not feel able to participate in their qualitative study, of patient's experiences of compulsion under the mental health act of 1983, because the interviewer they met with did not have similar lived experience to themselves (Barnes et al., 2000).

Secondly, the findings from this thesis suggest that as a result of shared lived experience, the peers may have been able to reduce the power differentials between the participant and the researcher, which critical theorists argue can occur as a result of the bio-medical model traditionally adopted in health care research. Through their shared lived experience with the peer researchers, the participants reported feeling more able to speak openly and honestly about their experiences potentially enhancing the accuracy and depth of the data collected. This process was described by one specialist offender manger as "bridging the gap" between professionals and service users (SOM2). The reduction in power differentials enabled the participant to feel more "comfortable" (MOAM/PR1) because they

were not being "judged" by the researcher whom they met with (MOAM/PR4). These qualitative reports are supported by the findings from the self-report data, which suggested the participants who met with the peer researchers felt able to trust the researcher and share honest answers. In these scenarios it may have been the case that the dynamic between the participant and researcher started to shift from the authoritative structures of power described by Foucault as the Modern Experience (Foucault, 1965), to a more equal interaction between two individuals. The outcome of this process may have enabled participants to feel more able to share open and honest answers with the peer researchers, potentially improving the validity of the data collected. The qualitative accounts from the participants and specialist offender managers are supported by the feedback from the research assistants who described examples of the participants sharing more detailed answers with the peer researchers during the baseline and follow up assessments. These findings are largely consistent with the conclusions reached by Milton, who reported the use of peer interviewers in their study of peer supported self-management interventions for people following a mental health crisis, helped participants to feel more comfortable and therefore able to speak frankly about their experiences (Milton et al., 2017).

Thirdly, through their shared lived experience the findings suggest the participants were able to relate to the peer researchers they met with describing how they "felt relaxed knowing that they'd been in my shoes" (MOAM/PR1). The peer researchers expanded on the qualitative accounts from the participants suggesting how in some cases their ability to relate to a research participant went beyond the practical aspects of the criminal justice system, and they were able to engage participants on an "emotional level" as well (UVPR1). The quantitative findings from this thesis support these qualitative reports and found the participants who met with a peer research felt understood. The impact of being able to relate to the researcher may have removed some of the stigma associated with the label "offender" or "ex-offender" possibly

enabling participants to feel more able to open up about their experiences during the research meeting. These findings support previous studies that reported shared lived experience can "normalize stigmatized experiences" (Siantz et al., 2019; Strudwick et al., 2017). In addition to the participants feeling relaxed and able to relate to the peer researchers, the findings from this thesis also suggest the peer researchers' lived experience enhanced the design of the randomized control trial.

The merits of randomly allocating participants to different treatment arms to reduce bias are well documented as the gold standard of how to evaluate the effectiveness of an intervention as well as the importance of measuring change over time (Evans, 2003). However, findings from this thesis also suggest the design of the randomised control trial could have been further enhanced by the involvement of researchers with lived experience as data collectors. The qualitative reports from the participants who shared their experiences suggested the impact of regular contact with the peer researchers made the trial participant feel valued and facilitated a trusting relationship because the participant did not feel "forgotten" (SOM1). The research assistants expanded on this concept and shared examples of how the peer researchers' informal engagement techniques enabled them to build rapport overtime. These findings support the value of the inclusion of experimental knowledge in RCTs highlighted in previous research (Campbell et al., 2011; INVOLVE, 2012b, 2013; Rise et al., 2014; Staley, 2009b). However, the findings from this thesis are not consistent with a recent systematic review completed by Crocker who found no significant improvement in retention rates of participants over time due to the involvement of researchers with lived experience (Crocker et al., 2018). Although Croker's systematic review did identify 10 studies that involved patients in recruiting or retaining participants, none involved PPI in data collection which may account for the differences in the reported impact between the two studies.

The findings from this thesis suggest the involvement of researchers with lived experience may have enabled the study team to access participants and topic areas that may not have been accessible to traditional researchers, improving the accuracy of the data collected. These findings have significant implications for further research, particularly for clinical trials conducted in the criminal justice system which target hard to reach populations. However, although all five groups of participants who shared their experiences highlighted the value of PPI, the qualitative reports also described how lived experience alone was not enough to guarantee engagement, and there are a number of other factors that should be considered when evaluating the impact of researchers with lived experience on the validity of the data collected.

Not all of the MOAM participants felt able to relate to the peer researcher they met with. Some participants suggested how they struggled to trust other people because of their own lived experience of the criminal justice system; "I just did not trust the process because of my experience" (MOAM/PR4). These qualitative reports were supported by the accounts from the specialist offender managers who described how "I think they are very suspicious and very mindful of people in authority, because of the kind of experience they've had" (SOM1). This pattern of mistrust by some participants fits with personality traits of an individual with anti-social personality disorder (Kaylor, 1999) and those who have experienced imprisonment (Western, Braga, Hureau, & Sirois, 2016) which should be considered when interpreting these results. For other participants they felt unable to trust the peer researcher because of their lived experience, and queried if the peer was still "mixed up in a criminal lifestyle" (MOAM/PR10), or in some cases questioned whether the peer was now part of the probation system. These findings are largely consistent with Livingston's qualitative study, of treatment planning in a forensic mental health hospital, which found, that some participants were reluctant to participate in the study because they did not feel

comfortable with disclosing information to a researcher with lived experience similar to their own (Livingston, Nijdam-Jones, & Team, 2013). The qualitative accounts reported in this thesis also described a number of other factors which could have affected a participant's ability to engage in the research process which were independent from the type of researcher the participant met with.

The User Voice operational staff members highlighted the importance of soft skills to enable the peer researcher to engage participants in the research process. "Communication" (UVOS1), "patience" (UVPR4) and "leadership" (UVPR4) skills were all required to be an effective peer researcher. The trial participants also valued these skills and a "normal" communication style (MOAM/PR 10) was described as particularly important to encourage them to engage in the research process. The qualitative accounts from the trial participants who met with a research assistant to complete the outcome measures also described the value of clear communication and therefore the importance of these skills were not related to the individual researcher's lived experience. The findings from this thesis also indicated the personal circumstances for the participant at the time of the assessment could affect their ability to engage in the research process.

How the participant was feeling on the day of the meeting was described as particularly important and could affect how they engaged. The qualitative accounts from the User Voice staff members explained "because a particular thing has happened that week or that day or whatever, that a person doesn't want to touch that subject" (UVOS2). This event could be entirely independent from the research trial and not related to the type of researcher they met with. For example, the participant may have just had an argument with their partner or family member, or been in a particularly difficult meeting with their probation officer prior to meeting with the researcher. Environmental factors were reported to have also affected the participant's ability to engage in the trial.

There was consensus amongst the peer researchers that for everyone's safety, research meetings should take place in prison or probation, and it would not have been appropriate to meet with participants in a public place; "There was no way you could meet in the community" (UVPR1). However, the findings suggest that for some participants meeting in this space did affect their ability to engage in the research process regardless of the type of researcher they met with because they did not feel able to trust the system. One User Voice operational staff member described how "that's nothing to do with their emotions or their disorder maybe; it's an environment that's causing this person to behave in this way" (UVOS1). For example, one of the peer researchers described how the participants "thought they were being listened to" during the assessment (UVPR5). In addition to the environment, for some the high street vouchers offered to all participants at the end of each assessment regardless of the type of researcher they met with encouraged them to engage; "it definitely worked when you are giving out free vouchers" (MOAM/RA20). Interestingly, these findings do not support previous research that found financial incentives have little impact on recruitment and retention rates in clinical trials (Brueton et al., 2014). However, as this thesis did not aim to evaluate if participant incentives did increase rates of engagement it is not possible to report if this was the case for the MOAM trial.

8.2   Learning from each other

The findings from this thesis suggest there was a transfer of knowledge between the peer researchers, research assistants and specialist offender managers who worked together to implement the MOAM trial. All three groups reported how the experience of working on the trial provided the opportunity to develop their knowledge about research and the criminal justice system, leading to personal skill development for each group of individuals involved. In addition, this transfer of knowledge also had a positive impact on the trial as expertise about research, engagement and the criminal justice system were shared between different

groups of individuals involved in the study. These findings are largely consistent with Strudwick's work who reported involving interviewers with lived experience in their study of mental health patients' perspectives of barcode medication administration was of "mutual benefit, with both the peers and the workers learning and growing together" (Strudwick et al., 2017). The type of knowledge and the reported impact of the transfer of information between the peer researchers, research assistants and specialist offender managers are discussed in more detail below.

Through their experience of working alongside the research assistants, the peer researchers reported how their "time management" (UVPR5), "multi-agency working" (UVPR3) and "communication" (UVPR2) skills developed. In addition, the peers described how the experience developed their understanding of research, in particular the complexities of implementing a RCT and the structure of clinical services. The descriptions shared by the peer researchers were supported by the qualitative reports from the research assistants who suggested working on the trial was an opportunity for the peer researchers to develop "new skills that they just wouldn't get from another job" (RA4). These findings are consistent with the work of Livingston who reported how the peer researchers involved in their qualitative study of perceptions of treatment planning in a forensic mental health hospital gained skills and knowledge as a result of the role (Livingston, Nijdam-Jones, & Team, 2013). The peer researchers, research assistants and offender managers all described how the impact of this transfer of knowledge from the research assistants to the peer researchers increased the peers confidence in themselves and it was a rewarding experience.

The peer researchers reported feeling "valued" (UVPR5) and the role improved their "self-worth" (UVPR4). The qualitative reports from the research assistants supported these findings, describing how the peers felt "empowered" (RA4) and the specialist offender managers suggested the role "improved their self-esteem" (SOM3). These findings are

consistent with Stevensson's work who also found in their qualitative study, about the use of psychotropic medication during pregnancy, the peer researchers found their work "rewarding and positive" (Stevenson et al., 2016). The implication of these findings are significant for a group in society who are normally negatively labelled and stigmatized because of their previous offending behaviour. Despite the positive impact of the role on the peer researchers, the research assistants, offender managers and the peers themselves also explained how the work could have an adverse emotional impact on researchers with lived experience, especially if their experiences were recent.

The qualitative reports from the peer researchers described the experience of going back into a prison or a probation office could be "traumatic" (UVPR5). The research assistants and special offender managers supported the accounts from the peers, and described how the role "can take you back to where you don't want to be" (SOM2) and "it's still quite painful for them" (RA1). These findings are largely consistent with the Svensson's study who reported some of the peers who collected data as part of their evaluation of mental health services felt "burdened" by the case histories of the service users they met with (Stevenson et al., 2016). The MOAM study protocol described how the peer researchers would be supported by their line manager, and able to access an independent employee assistance scheme if they needed additional support. However, the qualitative reports from both the peer researchers and research assistants indicated the support that was available was not sufficient. Adequate clinical supervision should be available for researchers with lived experience in future studies to enable them to manage the emotional demands of the role, and to reduce the risk of further trauma. The findings from this thesis also indicate there was a transfer of knowledge from the peer researchers to the research assistants who worked alongside them in each of the 13 sites.

The research assistants explained how the peer researchers taught them about the criminal justice system, and developed their understanding of how to "maintain engagement" with participants over time (RA2). The accounts of the transfer of knowledge from the peer researchers to the research assistants were supported by the qualitative reports from the specialist offender managers who suggested the peers were able to explain to the UCL research team "how the system works" (SOM4). The peer researchers themselves supported this idea by describing how "I was like an insight [about] how it would work from the other side" (UVPR3). The knowledge the peer researchers were able to share created more opportunities for the research assistants to collect data and therefore increased follow up rates for the trial. These findings build on the work from Barnes' study, of patients' experiences of compulsion under the mental health act 1983, who found the involvement of researchers with lived experience as data collectors developed the skills and knowledge of the traditional researchers they worked alongside (Barnes et al., 2000). In addition to the impact on the trial, the research assistants explained in their qualitative reports the positive impact of the experience of working alongside the peer researchers had on them personally.

There was a strong sense from the qualitative reports from the research assistants how much they valued the opportunity to work with a team of researchers with lived experience of the criminal justice system; "it was really exciting that we were able to do this" (RA5). These views were mostly supported by the qualitative reports from the peer researchers who also described the experience of working with the research assistants positively; "I always felt welcome, well respected" (UVPR3). The research assistants reported the experience enabled them to develop their skills with maintaining "boundaries" (RA2) and working with people who had "different life experiences" from themselves (RA2). The specialist offender managers also described how they developed their skills and knowledge from working alongside the peer researchers, especially during the recruitment phase of the trial.

The qualitative accounts from some of the specialist offender managers explained how there was a transfer of knowledge from the peer researchers, particularly around the use of "terminology" (SOM4) and "resilience" (SOM3). The specialist offender managers described this process as "bridging the gap" between the service user and the professional (SOM2). Through this transfer of knowledge from the peer researchers, the specialist offender managers were able to develop their language and engagement skills to engage participants in the trial and increase recruitment rates. These findings are important to consider when conducting research in the criminal justice system, as the socially constructed relationship between the service users and the offender manager, or patient and clinician is structured around control and power, described by Foucault as the "Modern Experience" (Foucault, 1965). The involvement of researchers with lived experience therefore provided the opportunity to breakdown these socially constructed power imbalances between the two individuals. The qualitative reports from some of the specialist offender managers also suggested the experience of working alongside researchers with lived experience had a personal impact on them, and reminded them of the importance of being "curious" in order to be more effective in their role to not only supervise but also support service users (SOM1).

In addition to the transfer of knowledge from the peer researchers to the specialist offender managers, the qualitative reports from the peers described how working alongside the offender managers provided the opportunity for them to develop a different type of relationship with criminal justice professionals. These accounts were supported by the qualitative reports from the research assistants which suggested how the role gave the peers a "different experience of probation services" (RA3). The process of starting to develop a more positive relationship, and more confidence when interacting with authority figures was reported to improve the peer researchers' "own self-image" leading to improved confidence and self-worth (UVPR4). These findings are particularly important for a group of individuals

who are stigmatised by society because of their previous offending behaviour, and challenges the stereotypes associated with being an "ex-offender".

The findings from this thesis found the involvement of researchers with lived experience did lead to the transfer of knowledge between the peer researchers, research assistants and specialist offender managers who worked alongside each other to recruit and follow up participants for the MOAM trial. The qualitative accounts reported in this thesis describe how due to this transfer of information there was a positive impact on the trial and individuals themselves. However, although several positive examples were reported, the peer researchers explained they did not always feel included in all aspects of the research process, and highlighted how this was a missed opportunity by the study team to share knowledge between different organisations and individuals. From a review of the grant application and study protocol, the peer researchers' role is consistently described as data collectors. As the MOAM trial was the first multisite RCT conducted in the NPS, the decision to involve researchers with lived experience was an innovative approach to adopt. However, the reasons for why the peer researchers were not involved beyond data collection were not reported in study documentation, or in the qualitative or quantitative data collected for this thesis and therefore it is not possible to explain the reasons for this decision. One possible explanation may be because the research team at UCL had limited experience of PPI in this area and they may have felt unable to include researchers with lived experience beyond the data collection role because of their own lack of expertise. These challenges are similar to those which were faced by Tew in their qualitative study of mental health patients who reported bringing "experience and expertise together was not necessarily a straight forward process as the situation in which we had gained experience was located in very different standpoints" (Tew, 2008). Despite the mostly positive qualitative accounts shared by the peer researchers, there is a risk that PPI in the MOAM trial could be considered tokenistic because

their involvement was restricted to one aspect of the study, and the peers were given limited opportunity to shape the direction of the research. Future research teams who choose to involve researchers with lived experience as data collectors should considered working with service user organization to develop ideas about how to expand the involvement of peer researchers beyond data collection to provide more opportunities to share knowledge across the study team. However, due the scope of their role, the team of research assistants the peer researchers worked alongside were also unable to influence the direction of the trial and therefore these findings should be interpreted within the hierarchal structure of a clinical trial as well as Arnstein ladder and Boote's level of participation models (Arnstein, 1969; Boote et al., 2002).

8.3   Challenging the stereotype

In addition to the positive impact on the validity of the data and the opportunity to facilitate the transfer of knowledge between peer and traditional researchers, the findings from this thesis also found the involvement of researchers with lived experience as data collectors had a wider impact beyond the clinical trial they were involved in. The qualitative accounts from the research assistants, offender managers and User Voice staff members highlighted the adoption of the approach challenged stereotypes associated with being an "ex-offender" and how health care research should be conducted. Through the involvement of experiential knowledge the barriers created by the "us and them" culture (RA5) were broken down by the peer researchers who were able to "bridge the gap" between service users and professionals (SOM2). How stereotypes were challenged, and the impact of this process are discussed in the context of the criminal justice system, higher education institutions and wider society in more detail below.

There was a strong sense amongst the specialist offender managers who shared their experiences of working alongside the peer researchers of the importance of PPI in the

MOAM trial. The qualitative accounts from the specialist offender managers highlighted the involvement of the peers was "hugely validating and prosocial" (SOM2) as their role challenged the negative stereotypes associated with being an "ex-offender". The offender managers explained for the service users the peer researchers were "someone to aspire to" (SOM1), and for probation staff a symbol of "rehabilitation" (SOM1). The qualitative accounts from the research assistants supported the reports from the specialist offender managers describing the peers as "someone they [the participants] can identify with" (RA1). These findings have significant implication for our understanding of the role of lived experience in the rehabilitation process of service users in the criminal justice system. Involving peer researchers as data collectors in a randomised control trial also challenges assumptions as to how health care research should be conducted.

The established academic system is structured around the bio-medical model. Traditionally in health care research one group of individuals who are academically educated study another groups of individuals who are labelled to be patients or service users. However, through the adoption of the peer researcher approach, findings from this thesis present a different perspective by challenging the belief that "rigorous, independent and scientifically based research is best placed to discover the objective truth" (Crotty & Crotty, 1998). The MOAM trial was the first multi-site RCT that had been conducted in the NPS in the England and Wales, and it was the first time the UCL study team had involved peer researchers as data collectors in a clinical trial of this size. Despite the unknown territory, the research team successfully followed up enough participants to the primary end-point to be adequately powered. The MOAM example and the findings from this thesis demonstrate it is possible to involve researchers with lived experience as data collectors in a multisite RCT, and the involvement of experiential knowledge can enhance the quality of the data collected and benefit the individuals involved. The findings from this thesis therefore support previous

studies which highlighted the value of involving forensic mental health patients in research because of their ability to breakdown power differentials with participants facilitating the disclosure of sensitive information (Livingston, Nijdam-Jones, & Team, 2013). The implications of these results are important for the MOAM research team; members of the trial oversight committees and for future academic teams to consider when designing a clinical trial. In addition to challenging our assumptions of how research should be conducted, the involvement of the peer researchers as data collectors in the MOAM trial also challenges our assumptions of how knowledge is defined and therefore valued.

Critical theorists argue traditionally, knowledge is defined as the skills and expertise learnt in the classroom and these ideas are mirrored in the implementation of health care research. Aacademics submit grant applications to bid for funding to carry out research. Grants are then awarded based on levels of experience, and experience is judged by the researchers' qualifications and publication record. Critical theorists suggest knowledge learnt in the classroom is therefore prioritised, and it is assumed researchers with this type of expertise should have the power to decide what is studied and how. However, the findings from this thesis challenge these assumptions, suggesting that knowledge learnt through experience can have an important role to play in clinical trials and may not be able to be replicated by expertise obtained through academic study. Through valuing experiential knowledge and therefore citizen participation, the findings from this study suggest the validity of the data improved as well as the peer researchers' self-worth. The experience highlighted the value of the peer researchers' knowledge developed through their own experiences and their unique ability to be able to "bridge the gap" (SOM2) between service users and professionals to contribute to the generation of knowledge. Standpoint theory can be used to explain this process by suggesting how the knowledge of those who are traditionally excluded is validated through PPI, as patients are able to contribute thoughts and

ideas not accessible to traditional researchers (Kokushkin, 2014). The qualitative accounts

describe how the peer researchers' felt empowered by the role because their knowledge was

valued supporting the work of Arnstein and Boote who argue in their models, the higher the

level or rung of participation the greater the redistribution of power (Arnstein, 1969; Boote et

al., 2002). These finding challenge assumptions about how knowledge is defined and are

important to consider when deciding who is best placed to study whom.

The MOAM trial case study demonstrates how involving researchers with lived

experience as data collectors in a clinical trial can enable different types of knowledge to be

brought together creating the opportunity to bridge the gap between service users and

professionals and readdress broader structural imbalances of power for the benefit of

individuals, science and society as a whole.

8.4   Limitations and recommendations for further research

The findings from this study must be considered in light of the following limitations.

Firstly, although the study adopted a mixed methods approach and included a large

qualitative sample, the focus of this thesis was one case study that involved five peer

researchers. Therefore, the reported PPI impact could have been due to the approach adopted

by the individuals involved. The study should be replicated to explore if the results can be

generalised to a larger population.. Secondly, although all five groups of participants were

asked to reflect on their experiences during the lifetime of the study, data were only collected

at one time point. Therefore, it was not possible to measure change over time and the results

may have been limited by recall. Thirdly, the MOAM participants who were interviewed had

not exclusively met with a either a peer researcher or research assistant during the following

up period. Although the participants were asked to only share their experiences of their last

meeting, it may have been the case that their descriptions of meeting with a peer research or

research assistant were shaped by their previous experience of meeting a different member of

the research team. Fourthly, although the researcher's position is declared in the methods section of the thesis, there is still a possibility that the data collected may be unreliable. It is not possible to know for certain, but participants may have made certain statements for impact or under reported information they did not want to disclose due to embarrassment or felt unable to trust the researcher. Fifthly, the mixed method approach of this thesis is limited by the lack of significant results from the quantitative data. These findings may have been limited by the sample or the outcome measure used. It may also be the case that there was no significant differences between the two groups, but without further work in this area, it is not possible to draw meaningful conclusions from this dataset. Finally, a group of researchers who were independent from the RCT, but had no personal lived experience of the criminal justice system conducted the interviews and collected the self-report data. Drawing on the findings from this thesis, the use of traditional researchers may have affected the reliability of data collected because the participants could have felt less able to share their feedback with someone whose lived experience was different from their own. This approach may have limited the quality of the data collected and therefore the findings of this thesis.

This thesis has brought to light the impact of involving data collectors with lived experience on a RCT in the NPS. However, in order to address some of the limitations outlined above, there is a need for further research in this area to understand the impact in more depth of involving researchers with lived experience on clinical trials. Future evaluations of the approach should consider exploring the impact of PPI across multiple case studies as part of one evaluation to ensure results can be generalised. Creating a control group should be considered when evaluating the impact of PPI for studies where peers work alongside traditional researchers to reduce the risk of leakage. A control group could be created through randomising participants to either meet exclusively with a research assistant or peer researcher to complete the outcomes measures, which was not the case for the

MOAM trial. In addition, as is often the case with an intervention study, the data collectors and the members of the team completing the analysis should remain blind to allocation to reduce the risk of conscious or unconscious bias strengthening the results of the study. However, due to the complex nature of measuring the impact of PPI some authors have argued an RCT methodology may not be an appropriate approach to adopt suggesting how PPI is a very different intervention than a clinical service for example (Staley, 2015), and further work is needed in this area to develop an appropriate methodology. Drawing on the findings from this thesis, studies exploring the impact of PPI on clinical trials should involve researchers with lived experience as data collectors. This approach would reduce the risk of under reporting by participants who may feel unable to be open about their experiences because they felt unable to trust the researcher. However, if peer researchers are involved as data collectors, future study team should also consider involving data collectors with lived experience who are independent from their immediate organisation or team to minimise the risk of the creation of bias in their evaluation.

8.5 Conclusion

This study examined for the first time the impact of the involvement of peer researchers with lived experience of the criminal justice system as data collectors on a RCT in the NPS in England and Wales. The study found the involvement of User Voice peer researchers in some cases did increase the validity of the data collected through the creation of automatic common ground leading to the disclosure of more honest answers. However, the inclusion of lived experience did not remove all the barriers to engagement, and for some participants created additional barriers. Findings from this thesis highlight the importance of future study teams ensuring adequate clinical supervision is available for researchers with lived experience to enable them to manage the emotional demands of the role, and to reduce the risk of further trauma. The transfer of knowledge between individuals strengthened the trial and provided

opportunities for personal development for the peers and traditional researchers Through the inclusion of researchers with lived experience as data collectors, stereotypes associated with being an "ex-offender" and how knowledge is valued were challenged and redefined.

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APPENDIX

Appendix A: Systematic review PRISMA diagram
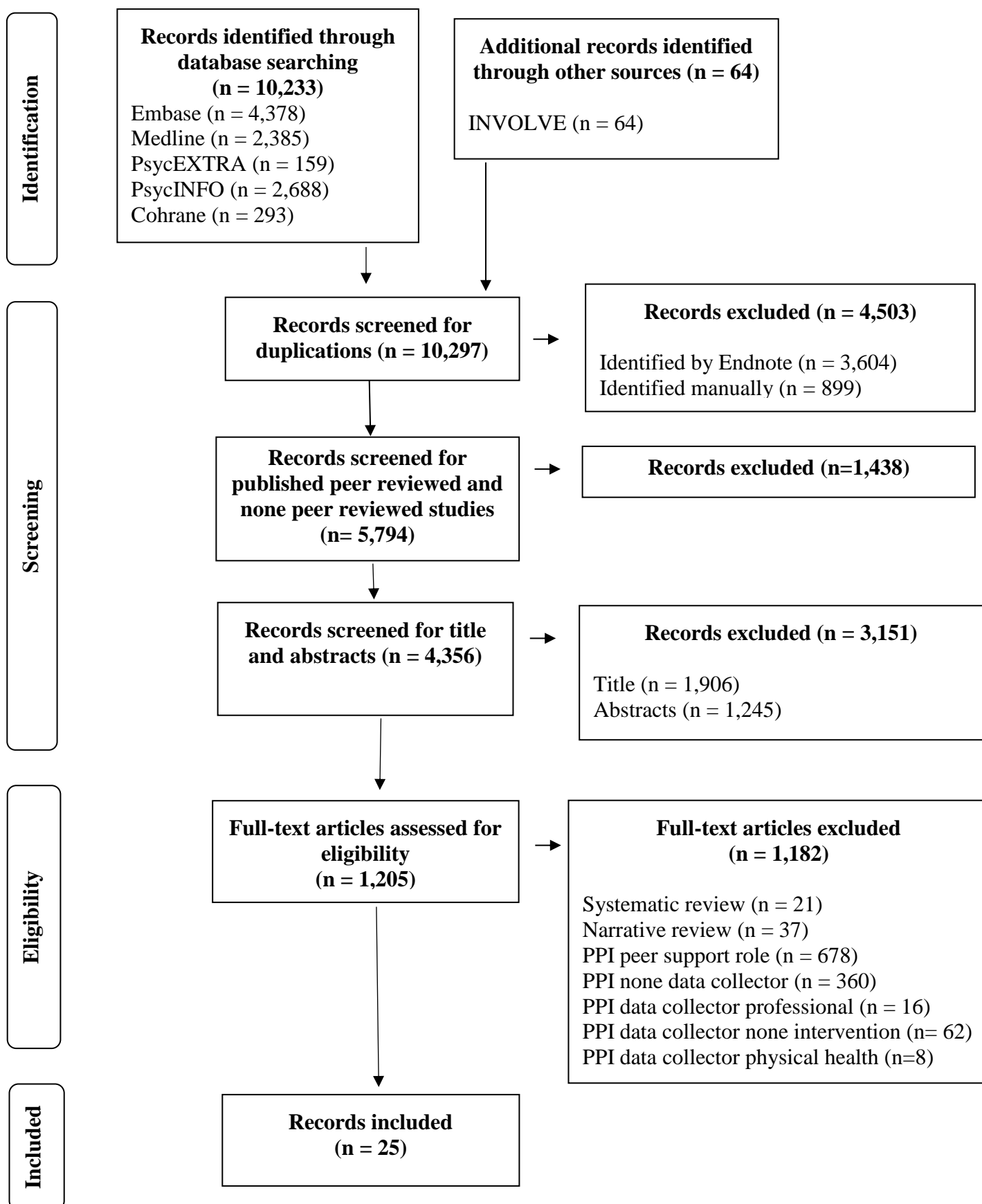
Appendix B: Systematic review _ Study characteristics

Table 1: Study aims and setting

Author	Primary or secondary paper	Title of paper	Aim	Intervention	Setting	Location	Date
Barber	Primary	Monitoring the Dissemination of Peer Support in VA Healthcare System	Monitoring system for peer support programs for veterans with chronic psychiatric disorders	Vet-to-Vet peer support program for patients with chronic psychiatric disorders	Health	USA	2008
Bocking	Primary	Here if you need me: Exploring peer support to enhance access to physical health care	To articulate the views of consumers in regards to the use of peer workers to further the physical health of people with mental illness	Peer support	Health	Australia	2018
Biringer	Primary	Service users' expectations of treatment and support at the Community Mental Health Centre in their recovery	Explore service users' expectations at the start of treatment at a Community Mental Health Centre	Treatment and support at the Community Mental Health Centre	Health	Norway	2016
Campbell	Primary	A mental health promotion approach to reducing discrimination about	Examine the effectiveness of a psychosocial mental health promotion workshop	Psychosocial mental health promotion workshop	Education	UK	2011

		psychosis in teenagers				
Fletcher	Primary	Working towards least restrictive environments in acute mental health wards in the context of locked door policy and practice	Understand and develop evidence-based recommendations for the impact of a policy requiring all acute mental health wards in the State to be locked.	All acute mental health wards in the State to be locked	Health	Australia	2019
Korsbek	Primary	Momentum: A smart phone application to support shared decision making for people using mental health services	Examine the use of a smartphone application as a modern decision aid to support shared decision making in mental health	Smartphone application to support shared decision making in mental health	Health	Denmark	2016
Livingston	Primary	Supporting Recovery by improving Patient Engagement in a Forensic Mental health hospital results from a demonstration project	To explore the effectiveness of an intervention to increase patient engagement by establishing a peer support program, strengthening a patient advisory committee, and creating a patient led research team	The patient engagement intervention	Forensic	Canada	2013
Livingston	Secondary	Perceptions of Treatment Planning in a Forensic Mental Health Hospital: A Qualitative,	To examine treatment planning from the perspectives of inpatients and service providers at a forensic mental health hospital	Treatment planning	Forensic	Canada	2013

		Participatory Action Research Study					
Milton	Primary	Development of a peer-supported, self-management intervention for people following mental health crisis	Development of a peer-provided self-management intervention for mental health service users following discharge from crisis resolution teams	Peer-provided self-management intervention for mental health service users following discharge from crisis resolution teams	Health	UK	2017
Rise	Primary	How do patients with severe mental diagnosis cope in everyday life - a qualitative study comparing patients' experiences of self-referral inpatient treatment with treatment as usual	Explore how patients with severe mental diagnosis coped for months after signing a contract for self-referral, as compared to patients receiving treatment as usual	Self-referral admission contract	Health	Norway	2014
Olso	Secondary	More than just a bed: mental health service users' experiences of self-referral admission	To explore service users' experiences of having the opportunity to refer themselves for a short inpatient stay	Self-referral admission contract	Health	Norway	2016
Hart	Primary	Attuned Practice a service user study of specialist child and adolescent mental health, UK	To address the views of teenage clients and their parents on service delivery in a specialist	Child and Adolescent Mental Health Services	Health	UK	2005

			Child and Adolescent Mental Health Service				
Gillard	Primary	Open access support groups for people experiencing personality disorders: do group members experiences reflect the theoretical foundations of the SUN project	Critically explore where and how the theoretically informed model underpinning the SUN Project is reflected in the view and experiences of people attending the project	Open access support group	Health	UK	2015
Gillard	Secondary	Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study	To describe a process of qualitative data analysis in a mental health research project with a high level of mental service user and carer involvement; reflect critically on how we produced our findings and consider the implications of research coproduction for study findings		Health	UK	2012
Crain	Primary	The contribution of IPS to recovery from serious mental illness: a case study	To explore the experiences of those patients receiving Individual placement and support and their support networks	Individual Placement and Support programme	Health	Canada	2009

Ridley	Primary	Subjective experience of compulsory treatment from a qualitative study of early implementation of the Mental Health (care and treatment) (Scotland) Act 2003	Explore the experience of compulsory psychiatric treatment under new legislation during 2007–2008	Compulsory psychiatric treatment	Health	UK	2013
Stevenson	Primary	Decisions about the use of psychotropic medication during pregnancy: a qualitative study	To understand the perspectives of women with severe mental illness concerning the use of psychotropic medicines while pregnant	Psychotropic medicines while pregnant	Health	UK	2016
Pinfold	Secondary	Anti-psychotic medication decision making during pregnancy: a co-produced research study	Understand how women with a diagnosis of schizophrenia or Bipolar disorder approach medication decision making in pregnancy	Psychotropic medicines while pregnant	Health	UK	2019
Sampogna	Primary	Experience of the Time to change programme in England as predictor of mental health	Test the extent to which experience of Time to Change programme is a positive predictor of selected coping strategies	Time to Change anti-stigma programme	Health	UK	2017

		service users' stigma coping strategies				
Stevensson	Primary	Satisfaction with mental health services a user participation approach	Investigate user satisfaction with mental health services in a county in southern Sweden	Mental health services	Health	Sweden	2006
Siantz	Primary	Peer respites: a qualitative assessment of consumer experience	Explore the experiences of persons staying at two peer respites	Mental health peer supported respite care	Health	USA	2019
Strudwick	Primary	Thank you for asking: Exploring patient perceptions of barcode medication administration identification practices in inpatient mental health settings	Elicit patient perceptions of barcode medication administration identification practices in inpatient mental health settings	Barcode medication administration identification practices	Health	Canada	2017
Barnes	Primary	Valuing Experience: Users' Experiences of Compulsion under the Mental Health Act 1983	To explore the impact of compulsion on people's 'careers' within mental health services and how the use of compulsion affects relationships with mental health worker	Compulsion under the Mental Health Act 1983	Health	UK	2000

| Tew | Secondary | Researching in partnership reflecting on a collaborative study with mental health service users into the impact of compulsion | Impact upon mental health service users of having been compulsorily admitted to hospital | Compulsory hospital admission | Health | UK | 2008 |
| Leung | Primary | Patient and family member readiness, needs, and perceptions of a mental health patient portal a mixed methods study | Identify patient and family readiness, needs, and perceptions of a mental health patient portal | Mental Health Patient Portal | Health | Canada | 2019 |

Table 2: Study methods

Author	Primary or secondary paper	Title of paper	Study type	Data collection	RCT	Study population	Sample size
Barber	Primary	Monitoring the Dissemination of Peer Support in VA Healthcare System	Quant	Questionnaires	No	War Veterans with chronic psychiatric disorders	1,847 war veterans
Bocking	Primary	Here if you need me exploring peer support to enhance access to physical health care	Qual	Focus group	No	Patients diagnosed with mental illness	4 focus groups with a total of 31 mental health patients
Biringer	Primary	Service users' expectations of treatment and support at the Community Mental Health Centre in their recovery	Qual	Interviews	No	Mental health patients	10 mental health patients
Campbell	Primary	A mental health promotion approach to reducing discrimination about psychosis in teenagers	Quant	Questionnaires	Cluster RCT	Secondary school pupils in the North West of England	92 secondary school pupils
Fletcher	Primary	Working towards least restrictive environments in	Qual	Facilitated forums	No	Participants who identified as mental health service	35 mental health service

		acute mental health wards in the context of locked door policy and practice				consumers, carers, or staff of acute mental health hospital wards	consumers, carers or staff
Korsbek	Primary	Momentum: A smart phone application to support shared decision making for people using mental health services	Qual	Focus groups and interviews	No	Multidisciplinary staff members, doctors, mental health service consumers	13 focus groups with health multidisciplinary staff members 7 interviews with health multidisciplinary staff members
Livingston	Primary	Supporting Recovery by improving Patient Engagement in a Forensic Mental health hospital results from a demonstration project	Mixed methods	Quantitative and qualitative data	No	At least 19 years of age; English-speaking; receiving treatment services for at least 1 month at the forensic hospital; deemed by their psychiatrist as capable for study participation	25 mental health patients
Livingston	Secondary	Perceptions of Treatment Planning in a Forensic Mental Health Hospital: A Qualitative, Participatory Action Research Study	Qual	Interviews	No	Adjudicated Not Criminally Responsible on Account of Mental Disorder; currently receiving treatment services at the forensic hospital;	29 inpatients 16 service providers

						attended at least one review board hearing and approved by their psychiatrist as capable to participate in the study.	
Milton	Primary	Development of a peer-supported, self - management intervention for people following mental health crisis	Mixed methods	Stage 1 Evidence review Stage 2 Focus group Stage 3 Qualitative interviews Stage 4 Pilot trial Stage 5 focus group	No	Crisis resolution team service users NHS	Stage 1 = 0 Stage 2 = 41 Stage 3 = 12 Stage 4 = 27 Stage 5 = 4
Rise	Primary	How do patients with severe mental diagnosis cope in everyday life - a qualitative study comparing patients' experiences of self-referral inpatient treatment with treatment as usual	Qual	Interviews	Yes	Patients with a diagnosis of severe mental illness	25 adult mental health patients
Olso	Secondary	More than just a bed: mental health service users' experiences of self-referral admission	Qual	Interviews	No	Patients with a diagnosis of severe mental illness	42 mental health patients
Hart	Primary	Attuned Practice a service user study of specialist child and	Qual	Focus groups	No	Teenage clients from specialist CAMHS and their parents	27 young people

30 parents |

		adolescent mental health, UK					
Gillard	Primary	Open access support groups for people experiencing personality disorders: do group members experiences reflect the theoretical foundations of the SUN project	Qual	Interviews	No	Mental health patients with severe, long-term mental health problems.	38 adult mental health patients
Gillard	Secondary	Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study	Mixed methods	Interviews Questionnaires	No	Adult users of a range of adult mental health services supporting self-care	120 adult mental health patients
Crain	Primary	The contribution of IPS to recovery from serious mental illness: a case study	Qual	Interviews	No	Case study of a 42 year old man who had schizophrenia and who attends a community mental health team and the experiences of his mother, employer, and clinical supports.	1 mental health patient 3 stakeholders
Ridley	Primary	Subjective experience of compulsory	Qual	Interviews	No	Service users who had experienced compulsory	49 mental health patients

		treatment from a qualitative study of early implementation of the Mental Health (care and treatment) (Scotland) Act 2003				psychiatric treatment under new legislation during 2007–2008	
Stevenson	Primary	Decisions about the use of psychotropic medication during pregnancy: a qualitative study	Qual	Interviews	No	Women who had had a baby in the past 5 years and had taken antipsychotics or moodstabilisers for severe mental illness within the 12- month period immediately prior to that pregnancy	12 mothers
Pinfold	Secondary	Anti-psychotic medication decision making during pregnancy: a co-produced research study	Qual	Interviews	No	Women who had had a baby in the past 5 years and had taken antipsychotics or moodstabilisers for severe mental illness within the 12- month period immediately prior to that pregnancy	12 mothers
Sampogna	Primary	Experience of the Time to change programme in England as predictor of mental health	Qual	Telephone interview surveys	No	Aged between 18 and 65 years; having a diagnosis of any mental disorder; being in contact with	3909 mental health patients

		service users' stigma coping strategies				the specialist mental health services in the previous 6 months	
Stevensson	Primary	Satisfaction with mental health services a user participation approach	Mixed methods	Interviews Questionnaires Focus group	No	Patients attending a mental health service or admitted to inpatient care on 14 or 15 February or 16 17 March in 2005	227 mental health patients
Siantz	Primary	Peer respites: a qualitative assessment of consumer experience	Qual	Interviews	No	Mental health respite service users	27 mental health patients
Strudwick	Primary	Thank you for asking: Exploring patient perceptions of barcode medication administration identification practices in inpatient mental health settings	Qual	Interviews	No	Inpatient mental health patients in forensic, youth, geriatric, acute and rehabilitation services	52 mental health patients
Barnes	Primary	Valuing Experience: Users' Experiences of Compulsion under the Mental Health Act 1983	Qual	Interviews	No	Mental health patients	11 mental health patients
Tew	Secondary	Researching in partnership reflecting on a collaborative study with mental			No	N/A	N/A

		health service users into the impact of compulsion					
Leung	Primary	Patient and family member readiness, needs, and perceptions of a mental health patient portal a mixed methods study	Mixed methods	Survey	No	Patients and family members affiliated with Canada's largest mental health hospital	110 patients and family members

Table 3: Patient and Public Involvement

Author	Primary or secondary paper	Title of paper	PPI term	Demographics of PPI data collectors	Other PPI activities in addition to data collection
Barber	Primary	Monitoring the Dissemination of Peer Support in VA Healthcare System	Peer facilitator	Veteran peer facilitators	Non reported
Bocking	Primary	Here if you need me exploring peer support to enhance access to physical health care	Consumer researcher	Mental health consumer with extensive experience in focus group studies with consumer participants	Data analysis
Biringer	Primary	Service users' expectations of treatment and support at the Community Mental Health Centre in their recovery	Co researcher	Persons with service user experience in mental health	Data analysis Report writing Author
Campbell	Primary	A mental health promotion approach to reducing discrimination about psychosis in teenagers	Service user researcher	Ex- mental health service-user	Non reported
Fletcher	Primary	Working towards least restrictive environments in acute mental health wards in the context of locked door policy and practice	Lived experience co - facilitators	Lived experience of acute mental health wards	Data analysis
Korsbek	Primary	Momentum: A smart phone application to support shared	People with lived experience of	Lived experience of mental health issues	Data analysis

		decision making for people using mental health services		mental health issues	
Livingston	Primary	Supporting Recovery by improving Patient Engagement in a Forensic Mental health hospital results from a demonstration project	Peer researchers	Lived with mental illness	Study design
Livingston	Secondary	Perceptions of Treatment Planning in a Forensic Mental Health Hospital: A Qualitative, Participatory Action Research Study	Peer researchers	People with mental illness who had been adjudicated 'Not Criminally Responsible on account of Mental Disorder (NCRMD) and were detained in a forensic hospital	Study design Recruitment of participants Data analysis Dissemination
Milton	Primary	Development of a peer-supported, self - management intervention for people following mental health crisis	peer researchers	Service user-researchers	Data analysis
Rise	Primary	How do patients with severe mental diagnosis cope in everyday life - a qualitative study comparing patients' experiences of self-referral inpatient treatment with treatment as usual	A research associate	Service user experience	Data analysis Report writing
Olso	Secondary	More than just a bed: mental health service users' experiences of self-referral admission	A research associate	A research associate with user experience participated in some of the interviews	Data analysis

Hart	Primary	Attuned Practice a service user study of specialist child and adolescent mental health, UK	Service user researcher	Lived experience of CAMHS	Leadership role
Gillard	Primary	Open access support groups for people experiencing personality disorders: do group members experiences reflect the theoretical foundations of the SUN project	Service user researcher		Development of data collection tool
Gillard	Secondary	Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study	Health service researcher	Personal experience of mental health issues or of caring for someone with personal experience of mental health issues and some prior research experience.	Data analysis
Crain	Primary	The contribution of IPS to recovery from serious mental illness: a case study	Peer researcher	Participated in Individual Placement and Support (IPS) programme	Data analysis Report writing Author
Ridley	Primary	Subjective experience of compulsory treatment from a qualitative study of early implementation of the Mental Health (care and treatment) (Scotland) Act 2003	Peer researchers	Mental health service users	Development of data collection tools
Stevenson	Primary	Decisions about the use of psychotropic medication	Peer researchers	Women with personal experience of using antipsychotic	Designed of the study

		during pregnancy: a qualitative study		medications and making or considering decisions about medicines and pregnancy	Development of data collection tool Advisory panel Data analysis Report writing
Pinfold	Secondary	Anti-psychotic medication decision making during pregnancy: a co-produced research study	Peer researchers	Women with personal experience of using antipsychotic medications and making or considering decisions about medicines and pregnancy	Data analysis
Sampogna	Primary	Experience of the Time to change programme in England as predictor of mental health service users' stigma coping strategies	Peer interviewers	Lived experience of mental health problems	Non reported
Stevensson	Primary	Satisfaction with mental health services a user participation approach	User interviewer	Experience of being a mental patient or a close relative to a patient	Non reported
Siantz	Primary	Peer respites: a qualitative assessment of consumer experience	Peer interviewers	Recent experience working as a Peer Advocate, a Peer Specialist, and/or a Health Navigator with	Data analysis

				lived experience of mental health	
Strudwick	Primary	Thank you for asking: Exploring patient perceptions of barcode medication administration identification practices in inpatient mental health settings	Peer support worker	Shared experiences of emotional and psychological pain	Design of the study Data analysis Dissemination
Barnes	Primary	Valuing Experience: Users' Experiences of Compulsion under the Mental Health Act 1983	User member	Mental health service users	Design of the study Development of data collection tool
Tew	Secondary	Researching in partnership reflecting on a collaborative study with mental health service users into the impact of compulsion	Service user researchers	Mental health service users	Design of the study Development of data collection tool
Leung	Primary	Patient and family member readiness, needs, and perceptions of a mental health patient portal a mixed methods study	Peer support worker	Peer support worker	Recruitment of participants

Appendix C: Systematic review_ Themes and sub themes

Theme		Sub theme		Prevalence (n=25)
4.3.2.1	Adopting the peer researcher approach	4.3.2.1.1	Expectations	8
		4.3.2.1.2	Impact	11
4.3.2.2	Coproduction in action	4.3.2.2.1	Learning together	19
		4.3.2.2.2	Shared decision making	8

Appendix D: User Voice peer researcher job description and person specification

DUTIES AND RESPONSIBILITIES

User Voice's regional Engagement Teams are responsible for engaging with a diverse range of service users with different experiences in order to improve services and promote active citizenship. As balanced Teams they will have a range of complementary skills in order to achieve these aims, including service user engagement, service provider engagement, project management, research and administration.

Research

- Arranging and undertaking research and evaluation activities, supported by the Research and Evaluation Team, including interviews, focus groups, surveys and report writing
- Keeping accurate and up to date records of service user's personal development through User Voice projects
- Working with external partners (such as universities) on specific research projects

Engagement

- Service user engagement and recruitment, including through presentations, surveys, focus groups and workshops
- Staff engagement, including through presentations, staff meetings and individual meetings
- Stakeholder engagement, including other statutory and voluntary sector partner agencies

Retainment

- Providing training to an accredited standard
- Group facilitation, including meetings, focus groups, workshops and large events
- Recruiting and managing service users and volunteers, including providing clear activities, support and signposting them to further opportunities

Co-ordination

- Contributing to the development of project planning documents and producing regular project reports
- Keeping accurate and up to date records, including project participants contact details, levels of engagement and diversity and equality monitoring data

- Assessing risk, working within safeguarding best practice and reporting incidents

In addition to the above duties, the post holder will be required to perform other duties, which are assigned from time to time. However, such other duties will be reasonable in relation to the individual's skills, abilities and grade.

PERSON SPECIFICATION

Essential:

1. Experience of the criminal justice system and/or other associated systems as a service user with the ability and motivation to harness this experience positively in working with service users
2. Ability to organise and facilitate research activities, including interviews, focus groups and wide scale surveys
3. Ability to act as an effective, authentic and credible advocate for User Voice's values, methods and programmes with the ability to inspire and motivate service users
4. Ability to communicate confidently with clarity and enthusiasm around User Voice aims and objectives with partner agency staff
5. Well organised with the ability to prioritise tasks effectively and meet deadlines amid a range of competing demands
6. Competent in IT, especially the use of spreadsheets, with a willingness to learn how to use new software
7. A strong and demonstrable commitment to the aims and values of User Voice
8. A strong and demonstrable commitment to and understanding of the promotion of equality and diversity
9. A strong and demonstrable commitment to and understanding of the promotion of safeguarding
10. Ability to offer peer support and be a role model for other User Voice staff and volunteers

Desirable:

1. Group facilitation and/or counselling skills
2. A background in, or experience of, engaging with adult and young people with convictions
3. Preparing to Teach in the Lifelong Learning Sector (PTTLS) trained

4. Good written and IT skills to support the co-ordination and management of projects

5. Ability to write in a clear and concise way, for both communication and reporting purposes

6. Experience in applied social research and a qualification in research methods and/or social science

Appendix E: Research assistant job description and person specification

Overview of the post

Large scale randomised control trial (RCT) comparing Mentalization Based Therapy (MBT) with other services currently offered, by probation, to adult male offenders with a diagnosis of antisocial personality disorder (ASPD) living in the community.

MBT is a psychological treatment that focuses on improving understanding of our own and others' mental states, an ability that forms the basis for the everyday judgement we all make about the meaning of other peoples' behaviour and how to respond to it. The intervention process lasts for 12 months and consists of one weekly group session and one monthly individual session. The service is being delivered by the National Probation Service and forms part of the National Offenders Personality Disorder Pathway Strategy. The service will be robustly evaluated against key outcomes criteria including reduction in aggressive acts and antisocial behaviours, reoffending, increased health and quality of life and cost of efficiency of service.

Duties and responsibilities

- Plan and undertake data collection across 13 study sites by preparing, setting up, conducting and recording interviews with participants in the community and in custody;

- Support Peer Researchers with data collection;

- Conduct small scale literature searches;

- Travel to and from sites across England and Wales working alone and in pairs;

- Maintain study spreadsheets in order to provide the Trial Coordinator with regular updates;

- Promote the trial with potential referrers in the probation service through presentations and written material;

- Liaise with other professionals to collect data as well as to track participants;

- Use own initiative to deal with day to day problems which might affect the achievement of research objectives and deadlines;

- Coordinate own work with that of others to avoid duplication of effort, working closely with colleagues to deliver research objectives;

- Data entry and maintenance of trial database;

- Maintain regular communication and contact with other members of the research team and collaboration with the study sites involved in the project;

- Maintain the highest standard of professional conduct and record keeping in accordance with UCL policies and procedures;

- Attend training events as appropriate in order to update knowledge and develop skills;

- Assist with any other duties commensurate with the scope and purpose of this post that are delegated by senior staff members of the project.

Person specification:

Training and qualifications:
Essential • Good first degree (2.i or higher) in Psychology or relevant discipline, e.g. Health   sciences, sociology etc.
Desirable • Postgraduate qualification in Research Methods, Clinical or Health   Psychology.
Knowledge and experience:
Essential • Experience of conducting assessments/interviewing participants; • An understanding of participants' confidentiality requirements; • Working knowledge of safeguarding procedures for those working with vulnerable   population;

- The ability to manage the input of a range of individuals and groups, including

  clinicians, probation staff, research assistants and various academic staff as well as

  service users;

- Proven ability to design and conduct presentations to a wide range of audiences;

- Sound knowledge of research principles and procedures for clinical research;

- Experience of common software packages used in research and data entry (e.g. MS

  Excel Access) and in the analysis of quantitative data (SPSS);

- Sound knowledge of randomised control trials.

Desirable
- Experience of working with male offenders in custody or the community;

- Experience of being involved in a substantive national research trial;

Appendix F: Ethical approval

NHS
Health Research Authority

London - South East Research Ethics Committee

Barlow House

3rd Floor 4 Minshull Street Manchester

M1 3DZ

Tel: 0207 104 8002

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented

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10 April 2019

Ms Liz Simes, Research Manager

Department for Clinical, Educational and Health Psychology

Dear Ms Simes

Study title:	**Mentalization Based Therapy (MBT) for Antisocial Personality Disorder: A Pilot Randomised Controlled Trial.**
REC reference:	**14/LO/1696**
Amendment number:	**Substantial Amendment 5**
Amendment date:	**02 December 2018**
IRAS project ID:	**158559**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The purpose of the amendment was to notify the Committee of the intention to explore the impact ofinvolving researchers with lived experience of criminal justice system in data collection for a randomised control trial.

There were no ethical issues raised.

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 [MOAM Participants Interview Schedule]	1.0	02 December 2018
Interview schedules or topic guides for participants [Offender Manager Interview Schedule]	1.0	02 December 2018
Interview schedules or topic guides for participants [Peer Researcher Interview Schedule]	1.0	02 December 2018
Interview schedules or topic guides for participants [Research Assistant Interview Schedule]	1.0	02 December 2018
Interview schedules or topic guides for participants [User Voice Operational Staff Interview Schedule]	1.0	02 December 2018
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 5	02 December 2018
Other [Patient Questionnaire]	1.0	02 December 2018
Participant consent form [User Voice Peer Led Research]	1	02 December 2018
Participant consent form [User Voice Peer Led Research - Peer Researcher]	1	02 December 2018

Participant consent form [User Voice Peer led Research - Offender Manager]	1	02 December 2018
Participant consent form [User Voice Peer led Research - Participants]	1	02 December 2018
Participant consent form [User Voice Peer led Research - Research Assistant]	1	02 December 2018
Participant information sheet (PIS) [User Voice Peer led Research - UV Staff]	1	02 December 2018
Participant information sheet (PIS) [User Voice Peer led Research - Offender Manager]	1	02 December 2018
Participant information sheet (PIS) [User Voice Peer led Research - Participant]	1	02 December 2018
Participant information sheet (PIS) [User Voice Peer led Research - Peer Researcher]	1	02 December 2018
Participant information sheet (PIS) [User Voice Peer led Research - Research Assistant]	1	02 December 2018
Research protocol or project proposal	6	02 December 2018

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 thestudy.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research EthicsCommittees 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 onlinelearning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

14/LO/1696:	**Please quote this number on all correspondence**

Yours sincerely

On behalf of

Ms Stephanie ChairChair

E-mail:nrescommittee.london-southeast@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Professor Peter Fonagy, University College London

        Ms Suzanne Emerton

London - South East Research Ethics Committee Attendance at Sub-Committee of the REC meeting

Committee Members:

Name	Profession	Present	Notes
Mr Ron Driver **in the Chair**	Retired University Lecturer/Statistician	Yes	
Professor Zahur Zaman	Retired Clinical Pathologist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Ewa Grzegorska	Approvals Administrator

Appendix G: Summary of the development of the data collection tools

All five interview schedules and the self-report scaled used in the study were developed in line with the protocol outlined below.

Stage	Description
1	Systematic literature review completed to understand current knowledge and practice
2	Initial discussion with User Voice to generate topics and structure of data collection tools
3	Data collection tools drafted
4	Initial versions reviewed by supervisors and tools amended in line with feedback
5	Pilot interviews completed with non-clinical population and amended in line with observations and feedback
7	Revised tools reviewed by User Voice and amended in line with feedback
8	Revised tools reviewed by supervisors and amended in line with feedback
9	Final versions submitted to NHS REC as part of the ethics application for the study. Ethical approval granted. Data collection tools finalised.

Appendix H: Interview schedule_ MOAM participants

Thank you for agreeing to take part in the interview. This interview is about your experience of meeting with a researcher to complete the questionnaires. The interview will take between 30 and 60 minutes and you will be free to take a break at any time. You do not have to answer every question during the interview, and you only have to share the information you would like to share.

Do you have any questions before I turn on the Dictaphone to record the interview?

    [answer any questions raised]

I am now going to turn on the Dictaphone to record the interview

    [Turn on the Dictaphone]

    [State date of the interview and participant ID number]

We are now going to start the interview

Engagement / Data collection:

The first couple of questions are about meeting with the researcher.

Q1. How was your appointment arranged?

    PROMPT: How did the researcher contact you?

    PROMPT: Was your offender manager involved?

    PROMPT: Who decided what time and when you were going to meet?

Q2. How would you describe the experience of meeting with the researcher to complete the questionnaires?

    PROMPT: [Only to be asked to the participants who met with a peer researcher] Did the peer researcher tell you they had personal experience of being in prison or on probation, and how did you feel about this?

    PROMPT: Did you feel listened too?

    PROMPT: Did you feel understood?

    PROMPT: Did the researcher make you feel comfortable?

PROMPT: What was it like meeting with a researcher in a probation office/prison to complete the questionnaires?

PROMPT: Was there anything about the interaction that made you feel uncomfortable or you didn't like?

Q3. How did you feel about answering the questions?

PROMPT: Did you feel you were able to be honest?

PROMPT: Did you feel you were able to trust the researcher?

Q4. Did you answer every question or were there questions you didn't want to answer?

PROMPT: How did you feel about this?

PROMPT: How did the researcher respond?

Q5. How would you feel about meeting the researcher again in the future to complete the research questionnaires?

<u>**Boundaries:**</u>

Some of the researchers collecting data for the project have lived experience and have either been in prison, on probation or both. These researchers are called peer researchers. Some of the researchers don't have lived experience and are called research assistants.

Q6. What do you think are the advantages of someone with lived experience meeting with participants to complete the questionnaires?

PROMPT: Would you prefer to meet with a researcher who did have a shared experience? If so why?

PROMPT: Would you feel more comfortable?

PROMPT: Does it make a difference?

Q7. What do you think are the disadvantages of someone with lived experience meeting with participants to complete questionnaires?

PROMPT: Would you prefer to meet with a researcher who didn't have a shared experience? If so why?

PROMPT: Would you feel more comfortable?

PROMPT: Does it make a difference?

Empowerment/personal skills and development:

Q8. In what ways do you think meeting with the researcher to complete the questionnaires has had a positive impact on you?

PROMPT: Has the experience effected the way you see the future?

PROMPT: Following this experience, do you think you would like to be part of another research project in the future?

Q9. Can you tell me a bit about the more difficult aspects of meeting with a researcher to complete the questionnaires?

PROMPT: Is there anything you didn't enjoy?

Q10. Before we bring interview to an end, is there any other feedback you would like to share with me about your experiences of meeting with the researcher to complete the questionnaires?

Thank you for participating in the interview. We have now reached the end of the interview and I am now going to turn off the Dictaphone.

[Turn off Dictaphone]

Appendix I: Interview schedule_ User Voice Peer researchers

Thank you for agreeing to take part in this interview. As outlined in the participant information sheet this interview is about your experiences of the MOAM trial. The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of meeting with a researcher to complete questionnaires for the MOAM trial. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

Do you have any questions before I turn on the Dictaphone to record the interview?

   [Answer any questions raised]

I am now going to turn on the Dictaphone to record the interview

   [Turn on the Dictaphone]

We are now going to start the interview.

Motivation:

Q1. Before you started working as a peer researcher what did you think it would be like?

Q2. Can you tell me about why you wanted to be a peer researcher?

Defining terms:

Q3. What is a peer researcher to you?

   PROMPT: Who can be a peer researcher?
   PROMPT: What skills do you think you need?

Q4. How would you describe the peer researchers' job in the trial?

Training and support:

We are now going to move on to talk a bit about the training you were given for the project.

Q5. What did you find most useful and the training you were given and why?

Q6. What aspects of the training were not so useful and why?

Q7. Can you tell me a bit about any topics that weren't covered in the training and you think should have been?

Involvement:

Q8. What areas of the trial have the peer researchers been involved in?

Q9. Are there areas of the trial you have not been involved in, and how do you feel about this?

Q10. How do the peer researchers share their views and ideas about how the project is run?

Data collection:

I understand as part of your role you are meeting with participants to collect follow up data.

Q11. Can you tell me about what it is like when you go into a probation office to collect data?

> *PROMPT: How do you experience collecting data in this type of space?*
> *PROMPT: How do you think the participants experience this type of situation?*

Q12. And what happens when you go into a prison to meet with a participant to collect data?

> *PROMPT: How do you experience collecting data in this type of space?*

> *PROMPT: How do you think the participants experience this type of situation?*

Q13. If you were designing a similar study in the future, where would you choose to interview participants?

Engagement:

For the trial I understand you are meeting with participants in different parts of the country.

Q14. Can you tell me about how you approach engaging participants?

> *PROMPT: What do you think it is important to think about?*

Q15. Can you tell me about a time when you have found it difficult to engage with a participant?

> *PROMPT: why do you think you found it difficult to engage with the participant?*

Q16. How do you feel about the honesty of the information disclosed to you by participants?

Q17. For those participants you have met with more than once, how would you describe their engagement over time?

Boundaries:

Q18. What do you think are the advantages of someone with lived experience collecting data for the trial?

Q19. What do you think are the disadvantages of someone with lived experience collecting data for the trial?

Collaborative working:

For this project I understand you are working with lots of different groups of people, who work for different types of organisations.

Q20. What is it like working on a research project with a university?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q21. How does it work when you need to communicate with clinical staff who are part of the MBT team?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q22. And how does it work when you need to communicate with the offender managers in each of the sites?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Personal skills and development:

Q23. Has being a peer researcher equipped you with any new skills that you might not have otherwise had, and if so what are they?

Q24. Do you think the experience of being a peer researcher has taught you anything new about research that you did not know before?

Q25. What do you think the peer researchers and User Voice have taught UCL about conducting research in the criminal justice system?

<u>**Empowerment:**</u>

Q26. Can you tell me in what ways the experience of being a peer researcher has had an impact on the way you feel about yourself in a positive way?

Q27. Can you tell me a bit about the more challenging and difficult aspects of the role?

Q28. How would you describe the impact of the peer research approach on the participants?

Q29. What have you enjoyed most about the experience?

Q30. Before we bring the interview to an end, is there any other feedback you would like to share with me about your experiences of working on the project?

Thank you for participating in the interview. We have now reached the end of the interview and I am going to turn off the Dictaphone.

[Turn off Dictaphone]

Appendix J: Interview schedule_ User Voicer operational staff members

Thank you for agreeing to take part in this interview. As outlined in the participant information sheet this interview is about your experiences of working on the MOAM trial. The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of developing the User Voice peer researcher approach and managing staff involved in the project. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

Do you have any questions before I turn on the Dictaphone to record the interview?
  [Answer any questions raised]

I am now going to turn on the Dictaphone to record the interview
  [Turn on the Dictaphone]
  [State date of the interview and participant ID number]

We are now going to start the interview.

Motivation:
Q1. Can you tell me about why you think the peer researcher approach was adopted for the trial?

Q2. Why do you think someone with lived experience of the criminal justice system might be motivated to apply for the role of a peer researcher?

Defining terms:
Q3. What is a peer researcher to you?

  PROMPT: Who can be a peer researcher?

  PROMPT: What skills do you think you need?

Q4. How would you describe the peer researchers' job in the trial?

<u>Training and support:</u>

We are now going to move on to talk about the training and support offered to the peer researchers.

Q5. From your observations what type of support and training do you think the peer researchers need in their role?

Q6. Can you tell me about any additional training or support you think the peer researchers would benefit from for this project, and why?

<u>Involvement:</u>

Q7. How would you describe the peer researchers' role in the trial?

Q8. Are there areas of the trial the peer researchers have not been involved in, and how do you feel about this?

<u>Data collection:</u>

Part of the peer researcher role involves meeting with participants to collect follow up data.

Q9. Can you tell me about how you think the peer researchers experience collecting data in a probation office?

Q10. How do you think the participant experiences meeting with the peer researcher in this type of space?

Q11. And how do you think the peer researchers experiences collecting data in a prison?

Q12. How do you think the participant experiences meeting with the peer researcher in this type of space?

Engagement:

For the trial the peer researchers are meeting with participants in different parts of the country

Q13. Can you tell me about how the peer researchers are able to engage participants?

> *PROMPT: What do you think it is important to think about?*

Q14. Can you tell me about a time when it has been difficult for a peer researcher to engage with a participant?

> *PROMPT: why do you think it might have been difficult to engage them?*

Q15. How do you feel about the honesty of the information disclosed to the peers by the participants?

Q16. For those participants who have met with the peer researchers more than once, how would you describe their engagement over time?

Boundaries:

Q17. What do you think are the advantages of someone with lived experience collecting data for the trial?

Q18. What do you think are the disadvantages of someone with lived experience collecting data for the trial?

Collaborative working:

For this project User Voice are working with lots of different groups of people, who work for different types of organisations.

Q19. What is it like working on a research project with a university?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q20. How does it go when the peer researchers need to communicate with clinical staff who are part of the MBT team?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q21. And how does it work when the peer researchers need to communicate with the offender managers in each of the sites?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Personal skills and development:

Q22. What new skills do you think the peer researchers have learnt since working on the project that they didn't have before?

Q23. What do you think the peer researchers and User voice have taught UCL about conducting research in the criminal justice system?

Empowerment:

Q24. In what way do you think the trial has had an impact on the how the peer researchers feel about themselves in a positive way?

Q25. Can you tell me a bit about the more challenging and difficult aspects of the peer research role?

Q26. How would you describe the impact of the peer research approach on the participants?

Q27. What do you think you as an individual, and User Voice as an organisation have enjoyed most about the experience of collaborating with UCL on this project?

Q28. Before we bring the interview to an end, is there any other feedback you would like to share with me about the impact of the peer researcher approach on the trial?

Thank you for participating in the interview. We have now reached the end of the interview and I am going to turn off the Dictaphone.

[Turn off Dictaphone

Appendix K: Interview schedule_ research assistants

Thank you for agreeing to take part in this interview. As outlined in the participant information sheet this interview is about your experiences of working alongside the User Voice peer researchers on the MOAM trial. The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of interacting with User Voice peer researchers during the MOAM trial. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

Do you have any questions before I turn on the Dictaphone to record the interview?

      [Answer any questions raised]

I am now going to turn on the Dictaphone to record the interview

      [Turn on the Dictaphone]

We are now going to start the interview.

Motivation:

Q1. Can you tell me about why you think the peer researcher approach was adopted for the trial?

Q2. Why do you think someone with lived experience of the criminal justice system might be motivated to apply for the role of a peer researcher?

Defining terms:

Q3. What is a peer researcher to you?

                  PROMPT: Who can be a peer researcher?

                  PROMPT: What skills do you think you need?

Q4. How would you describe the peer researchers' job in the trial?

Training and support:

We are now going to move on to talk about the training and support offered to the peer researchers.

Q5. From your observations what type of support and training do you think the peer researchers need in their role?

Q6. Can you tell me about any additional training or support you think the peer researchers would benefit from for this project, and why?

Involvement:

Q7. What areas of the trial have the peer researchers been involved in?

Q8. What do you think it is like for the peer researchers to work on the trial?

Q9. What are your thoughts about the level of involvement that the peer researchers have through the research process?

> *PROMPT: Are there areas of the trial the peer researchers have not been involved in, and how do you feel about this?*

Q10. How do the peer researchers share their views and ideas about how the project is run?

Data collection:

Part of the peer researcher role involves meeting with participants to collect follow up data.

Q11. Can you tell me about how you think the peer researchers experience collecting data in a probation office?

Q12. How do you think the participant experiences meeting with the peer researcher in this type of space?

Q13. And how do you think the peer researchers experiences collecting data in a prison?

Q14. How do you think the participant experiences meeting with the peer researcher in this type of space?

Engagement:

For the trial the peer researchers are meeting with participants in different parts of the country.

Q15. From your experience of working alongside the peer researchers can you tell me about how they approach engaging participants?

Q16. Can you tell me about a time when you think the peer researchers might have found it difficult to engage a participant?

> *PROMPT: Why do you think the peer researchers might find it difficult to engage with some participants?*

Q17. From your observations how do you feel about the honesty of the information disclosed to the peer researchers by participants?

Q18. For those participants who have met with a peer researcher more than once how would you describe their engagement over time?

Boundaries:

Q19. What do you think are the advantages of someone with lived experience collecting data for the trial?

Q20. What do you think are the disadvantages of someone with lived experience collecting data for the trial?

Collaborative working:

For this project I understand you are working with lots of different groups of people, who work for different types of organisations.

Q21. What is it like and how do you feel about working on a research project with a user led organisation?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q22. How does it go when the peer researchers need to communicate with clinical staff who are part of the MBT team?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q23. And how does it work when the peer researchers need to communicate with the offender managers in each of the sites?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Personal skills and development:

Q24. Does the peer research element mean that your work on this trial is different to other research projects you may have been involved with before?

Q25. What new skills have you developed sine you have been working alongside the peer researchers?

Q26. What new skills do you think the peer researchers have learnt since working on the project that they didn't have before?

Q27. What do you think the peer researchers and User Voice have taught UCL about conducting research in the criminal justice system?

Empowerment
Q28. In what way do you think the trial has had an impact on the how the peer researchers feel about themselves in a positive way?

Q29. Can you tell me a bit about the more challenging and difficult aspects of the peer research role?

Q30. How would you describe the impact of the peer research approach on the participants?

Q31. What have you enjoyed most about the experience of working alongside the peer researchers?

Q32. Before we bring the interview to an end, is there any other feedback you would like to share with me about the impact of the peer researcher approach on the trial?

Thank you for participating in the interview. We have now reached the end of the interview and I am going to turn off the Dictaphone.

[Turn off Dictaphone]

Appendix L: Interview schedule_ specialist offender managers

Thank you for agreeing to take part in this interview. As outlined in the participant information sheet this interview is about your experiences of working alongside the User Voice peer researchers on the MOAM trial. The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of interacting with User Voice peer researchers and UCL research assistants during the MOAM trial. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

Do you have any questions before I turn on the Dictaphone to record the interview?

      [Answer any questions raised]

I am now going to turn on the Dictaphone to record the interview

      [Turn on the Dictaphone]

We are now going to start the interview.

Background:

Q1. My first question is can you confirm roughly how long you have been a Specialist and Offender Manager and working on the MBT project?

Motivation:

Q2. Can you tell me about why you think the peer researcher approach was adopted for the trial?

Q3. Why do you think someone with lived experience of the criminal justice system might be motivated to apply for the role of a peer researcher?

Defining terms:

Q4. What is a peer researcher to you?

        PROMPT: Who can be a peer researcher?

PROMPT: What skills do you think you need?

Q5. How would you describe the peer researchers' job in the trial?

<u>Training and support:</u>

We are now going to move on to talk about the training and support offered to the peer researchers.

Q6. From your observations what type of support and training do you think the peer researchers need in their role?

Q7. Can you tell me about any additional training or support you think the peer researchers would benefit from for this project, and why?

<u>Involvement:</u>

Q8. How would you describe the peer researchers' role in the trial?

Q9. Are there areas of the trial the peer researchers have not been involved in, and how do you feel about this?

<u>Data collection:</u>

Part of the peer researchers' role involves meeting with participants to collect follow up data.

Q10. Can you tell me about how you think the peer researchers experience collecting data in a probation office?

Q11. How do you think the participant experiences meeting with the peer researcher in this type of space?

Q12. And how do you think the peer researchers experiences collecting data in a prison?

Q13. How do you think the participant experiences meeting with the peer researcher in this type of space?

Engagement:

For the trial the peer researchers are meeting with participants in different parts of the country.

Q14. From your experience of working alongside the peer researchers can you tell me about how they approach engaging participants?

Q15. Can you tell me about a time when you think the peer researchers might have found it difficult to engage a participant?

> *PROMPT: Why do you think the peer researchers might find it difficult to engage with some participants?*

Q16. From your observations how do you feel about the honesty of the information disclosed to the peer researchers by participants?

Q17. For those participants who have met with a peer researcher more than once how would you describe their engagement over time?

Boundaries:

Q18. What do you think are the advantages of someone with lived experience collecting data for the trial?

Q19. What do you think are the disadvantages of someone with lived experience collecting data for the trial?

Collaborative working:

For this project I understand you are working with lots of different groups of people, who work for different types of organisations.

Q20. What is it like working on a research project with a user led organisation?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q21. How does it go when the peer researchers need to communicate with clinical staff who are part of the MBT team?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Q22. And how does it work when the peer researchers need to communicate with the offender managers in each of the sites?

> *PROMPT: Can you describe a situation when you think it has worked particularly well?*
>
> *PROMPT: Are there times when it has been more challenging, and can you give me an example?*

Personal skills and development:

Q23. What new skills do you think the peer researchers have learnt since working on the project that they didn't have before?

Q24. From your experience what influence do you think interactions with the peer researcher has had on the participants? (MBT group members, the men that are involved in the trial)

> *PROMPT: Do you think the experience of meeting with a peer researcher might support the participant to rehabilitate?*

Q25. What do you think the peer researchers and User voice have taught UCL about conducting research in the criminal justice system?

Empowerment:

Q26. In what way do you think the trial has had an impact on the how the peer researchers feel about themselves in a positive way?

Q27. Can you tell me a bit about the more challenging and difficult aspects of the peer research role?

Q28. How would you describe the impact of the peer research approach on the participants?

Q29. What have you enjoyed most about the experience of working alongside the peer researchers?

Q30. Before we bring the interview to an end, is there any other feedback you would like to share with me about the impact of the peer researcher approach on the trial?

Thank you for participating in the interview. We have now reached the end of the interview and I am going to turn off the Dictaphone.

[Turn off Dictaphone]

Appendix M: Participant Information Sheet_ MOAM participants

Additional Interview: Exploring the User Voice peer researcher approach

Information Sheet for participants

What this information sheet tells you

You have been invited to participate in an interview to share your experiences of being part of the MOAM trial which is exploring how effective Mentalizaition based therapy (MBT) is at supporting people.

This information sheet tells you about the research we are doing and explains why we would like you to get involved.

It also tells you what will happen if you agree to take part in our study.

Why we would like your help

University College London (UCL) is collaborating with User Voice to collect data for the MOAM trial. User Voice is a user-led charity founded by Mark Johnson, an ex-offender and former drug user. The charity works to transform the criminal just system by placing service users at the heart of all they do. By running peer-led service user councils, research and consultation projects, User Voice strives to transform individuals, institutions and the conversation around criminal justice. Eighty-five per cent of User Voice staff have lived experience of the youth or criminal justice system, and many have experience of the care system and substance misuse.

User Voice peer researchers with lived experienced of the criminal justice system are meeting with participants to complete questionnaires to understand how effective MBT is at supporting people. UCL research assistants are also meeting with participants to collect the same questionnaire data. We would like to talk to participants about their experiences of meeting with both type of researchers so we can understand the most effective way to conduct this type of research in the future.

Do you have to take part?

No. Taking part is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the interview will not affect the care that you receive from services either now or in the future, or your participation in the MOAM research trial.

What is this "research" about?

We are speaking with participants involved in the MOAM trial as well as User Voice peer researchers; User Voice operational staff; UCL research assistants and offender managers about their experience of being involved in a research project where data is collected by User Voice peer researchers. There are no right or wrong answers, we just want to hear from you about your experiences and what you think.

What are the benefits of being part of the research study?

Taking part is an opportunity for you to share your experiences. You will also receive a payment after you have completed the interview to thank you for taking part.

What payment will you receive?

Everyone who agrees to be interviewed will be offered £35.00 in high street vouchers at the end of the interview to thank them for taking part in the research.

What happens if you agree to take part?

You are completely free to decide whether or not you want to take part in the study. If you agree, you will be asked to sign a form giving your consent to be interviewed.

What does signing the form mean?

The form shows that you agree to take part in the study, and that you agree to meet with a member of the research team to be interviewed about your experiences of being involved in the MOAM trial.

If you do give your consent to be interviewed, you are still free to leave the study at any point, without giving a reason. You can continue to meet the research team to complete the standard questionnaires and not take part in the additional interview.

What questions will we be asking you and how long will it take?

The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of meeting with a researcher to complete questionnaires for the MOAM trial. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

What happens to the answers you give during the interview?

The interview will be audio recorded. The information recorded during the interview is private and will not be shared with the User Voice peer researchers or UCL research assistants you have met with; User Voice management or anyone outside of the research team. All of your information will be stored under an ID number. No information will ever be linked to your name.

What will happen to the audio recording after the interview?

The audio-taped recording of the interview will be stored in a secure area at UCL and will only be listened to by the researchers involved in this part of the study. These tapes will be securely disposed of once the study has been written up.

What will happen to the results of the study?

Once the study had been written up if you like we can send you a summary of the findings. You will not be identified in any publications.

Rules that we must follow

There are a few things for you to know before you decide whether or not to take part in this study. We have to follow some important rules to make sure that people who take part in the research are treated well and not harmed in any way. Here are those rules:

(1) Consent or agreeing to take part in the study

You do not have to agree to take part if you do not want to. As we said earlier, you are completely free to decide whether or not you want to take part in the study.

Taking part in the study will not affect the services or support you receive, or you involvement in the wider study.

(2) Confidentiality: keeping what you tell us private

All the information you give us is private. Records are locked up and will not be shown to anyone outside the research team without your signed agreement. Nothing you say will be told to anyone outside the research team, except in three circumstances:

- We would have to tell the police or another relevant agency if we were told that someone was sincerely planning to seriously harm a specific person.

- Or that you were directly at risk of serious harm.

In the event of a serious criminal disclosure where a court were to demand participant case records, these would have to be made available on demand for legal authorities.

(3) Reporting the findings of the study

The third thing you should know is that a report will be written about the results of the study. In that report, the results will be presented in such a way that no one can find out that it is you or know that you took part. In other words, we can guarantee that information about you will be secret and private because we talk about groups not the individual. The reports will be available for all participants taking part.

(4) Making sure the trial is run properly

UCL must make sure that the study is being run properly and that we follow the rules described above. Some documents from the study may be looked at by responsible people appointed by UCL to make sure of this, and we would like your permission to let those people see the documents they need to see.

If you have any concerns and would like to contact someone outside of the team you can do this through your local Primary Care NHS Trust or the Research Governance Sponsor, UCL. You can write to:

Joint UCLH/UCL Biomedical Research Unit,

R&D Directorate (Maple House),

Rosenheim Wing, Ground Floor,

25 Grafton Way,

London

WC1E 5DB

Please quote reference number 14/0604. All communication will be dealt in strict confidence.

Conclusion

Finally, there are no risks associated with you taking part in the study. What we learn in this study will help the research team understand the best way to carry out research in the future.

Your questions or concerns

If you have any questions or concerns about the research study Elizabeth Simes, Research Manager, will be available to discuss these concerns with you. You can contact her at:

      Elizabeth Simes

If you would like to speak to User Voice about this study or if you would like more information about their work, please contact:

      Mala Ram, Impact Manager

Appendix N: Participant Information Sheet_ User Voice Peer researchers

Exploring the User Voice peer researcher approach
Information Sheet for peer researchers

What this information sheet tells you

You have been invited to participate in an interview to share your experiences of being part of the MOAM trial which is exploring how effective Mentalizaition based therapy (MBT) is at supporting people.

This information sheet tells you about the research we are doing and explains why we would like you to get involved.

It also tells you what will happen if you agree to take part in our study.

Why we would like your help

University College London (UCL) is collaborating with User Voice to collect data for the MOAM trial. User Voice is a user-led charity founded by Mark Johnson, an ex-offender and former drug user. The charity works to transform the criminal justice system by placing service users at the heart of all they do. By running peer-led services user councils, research and consultation projects, User Voice strives to transform individuals, institutions and the conversation around criminal justice. . Eighty-five per cent of User Voice staff have lived experience of the youth or criminal justice system, and many have experience of the care system and substance misuse.

User Voice peer researchers with lived experienced of the criminal justice system are meeting with participants to complete questionnaires to understand how effective MBT is at supporting people. UCL research assistants are also meeting with participants to collect the same questionnaire data. We would like to talk to User Voice peer researchers who have collected data for the MOAM trial about their experiences of being involved in this type of research so we can understand the most effective way to conduct this type of research in the future.

Do you have to take part?

No. Taking part is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the interview will not affect your employment or involvement in the MOAM trial now or in the future.

What is this "research" about?

We are speaking with User Voice peer researchers as well as participants involved in the trial; offender managers; User Voice operational staff and UCL research assistants about their experience of being involved in a research project where data is collected by User Voice peer researchers. There are no right or wrong answers, we just want to hear from you about your experiences and what you think.

What are the benefits of being part of the research study?

Taking part is an opportunity for you to share your experiences. You will also receive a payment after you have completed the interview to thank you for taking part.

What payment will you receive?

Everyone who agrees to be interviewed will be offered £35.00 in high street vouchers at the end of the interview to thank them for taking part in the research.

What happens if you agree to take part?

You are completely free to decide whether or not you want to take part in the study. If you agree, you will be asked to sign a form giving your consent to be interviewed.

What does signing the form mean?

The form shows that you agree to take part in the study, and that you agree to meet with a member of the research team to be interviewed about your experiences of being involved in the MOAM trial. If you do give your consent to be interviewed, you are still free to leave the study at any point, without giving a reason.

What questions will we be asking you and how long will it take?

The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of collecting data for the MOAM

trial. You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

What happens to the answers you give during the interview?

The interview will be audio recorded. The information recorded during the interview is private and will not be shared with UCL research assistants; other User Voice peer researchers collecting data for the trial; User Voice management or anyone outside of the research team. All of your information will be stored under an ID number. No information will ever be linked to your name.

What will happen to the audio recording after the interview?

The audio-taped recording of the interview will be stored in a secure area at UCL and will only be listened to by the researchers involved in this part of the study. These tapes will be securely disposed of once the study has been written up.

What will happen to the results of the study?

Once the study had been written up if you like we can send you a summary of the findings. You will not be identified in any publications.

Rules that we must follow

There are a few things for you to know before you decide whether or not to take part in this study. We have to follow some important rules to make sure that people who take part in the research are treated well and not harmed in any way. Here are those rules:

(1) Consent or agreeing to take part in the study

You do not have to agree to take part if you do not want to. As we said earlier, you are completely free to decide whether or not you want to take part in the study.

Taking part in the study will not affect the services or support you receive, or you involvement in the wider study.

(2) Confidentiality: keeping what you tell us private

All the information you give us is private. Records are locked up and will not be shown to anyone outside the research team without your signed agreement.

Nothing you say will be told to anyone outside the research team, except in three circumstances:

- We would have to tell the police or another relevant agency if we were told that someone was sincerely planning to seriously harm a specific person.

- Or that you were directly at risk of serious harm.

In the event of a serious criminal disclosure where a court were to demand participant case records, these would have to be made available on demand for legal authorities.

(3) Reporting the findings of the study

The third thing you should know is that a report will be written about the results of the study. In that report, the results will be presented in such a way that no one can find out that it is you or know that you took part. In other words, we can guarantee that information about you will be secret and private because we talk about groups not the individual. The reports will be available for all participants taking part.

(4) Making sure the trial is run properly

UCL must make sure that the study is being run properly and that we follow the rules described above. Some documents from the study may be looked at by responsible people appointed by UCL to make sure of this, and we would like your permission to let those people see the documents they need to see.

If you have any concerns and would like to contact someone outside of the team you can do this through your local Primary Care NHS Trust or the Research Governance Sponsor, UCL. You can write to:

Joint UCLH/UCL Biomedical Research Unit,

R&D Directorate (Maple House),

Rosenheim Wing, Ground Floor,

25 Grafton Way,

London

WC1E 5DB

Please quote reference number 14/0604. All communication will be dealt in strict confidence.

Conclusion

Finally, there are no risks associated with you taking part in the study. What we learn in this study will help the research team understand the best way to carry out research in the future.

Your questions or concerns

If you have any questions or concerns about the research study Elizabeth Simes, Research Manager, will be available to discuss these concerns with you.

You can contact her at:

Elizabeth Simes, Research Manager

If you would like to speak to User Voice about this study or if you would like more information about their work in general, please contact:

Mala Ram, Impact Manager

Appendix O: Participant Information Sheet_ User Voice operational staff members

Exploring the User Voice peer researcher approach
Information Sheet for User Voice operational staff

What this information sheet tells you

You have been invited to participate in an interview to share your experiences of being part of the MOAM trial which is exploring how effective Mentalizaition based therapy (MBT) is at supporting people.

This information sheet tells you about the research we are doing and explains why we would like you to get involved.

It also tells you what will happen if you agree to take part in our study.

Why we would like your help

University College London (UCL) is collaborating with User Voice to collect data for the MOAM trial. User Voice is a user-led charity founded by Mark Johnson, an ex-offender and former drug user. The charity works to transform the criminal justice system by placing service users at the heart of all they do. By running peer-led service user councils, research and consultation projects, User Voice strives to transform individuals, institutions and the conversation around criminal justice. . Eighty-five per cent of User Voice staff have lived experience of the youth or criminal justice system, and many have experience of the care system and substance misuse.

User Voice peer researchers with lived experienced of the criminal justice system are meeting with participants to complete questionnaires to understand how effective MBT is at supporting people. UCL research assistants are also meeting with participants to collect the same questionnaire data. We would like to talk to User Voice operational staff involved in developing the User Voice peer researcher approach and managing staff involved in the project so we can understand the most effective way to conduct this type of research in the future.

Do you have to take part?

No. Taking part is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the interview will not affect your employment or involvement in the MOAM trial now or in the future

What is this "research" about?

We are speaking with User Voice operational staff as well as participants involved in the trial; User Voice peer researchers; UCL research assistants and offender managers about their experience of being involved in a research project where data is collected by User Voice peer researchers. There are no right or wrong answers, we just want to hear from you about your experiences and what you think.

What are the benefits of being part of the research study?

Taking part is an opportunity for you to share your experiences. You will also receive a payment after you have completed the interview to thank you for taking part.

What payment will you receive?

Everyone who agrees to be interviewed will be offered £35.00 in high street vouchers at the end of the interview to thank them for taking part in the research.

What happens if you agree to take part?

You are completely free to decide whether or not you want to take part in the study. If you agree, you will be asked to sign a form giving your consent to be interviewed.

What does signing the form mean?

The form shows that you agree to take part in the study, and that you agree to meet with a member of the research team to be interviewed about your experiences of being involved in the MOAM trial.

If you do give your consent to be interviewed, you are still free to leave the study at any point, without giving a reason.

What questions will we be asking you and how long will it take?

The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of experiences of developing the User Voice peer researcher approach and managing staff involved in the project

You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

What happens to the answers you give during the interview?

The interview will be audio recorded. The information recorded during the interview is private and will not be shared with UCL research assistants; other User Voice peer researchers collecting data for the trial; User Voice management or anyone else outside of the research team. All of your information will be stored under an ID number. No information will ever be linked to your name.

What will happen to the audio recording after the interview?

The audio-taped recording of the interview will be stored in a secure area at UCL and will only be listened to by the researchers involved in this part of the study. These tapes will be securely disposed of once the study has been written up.

What will happen to the results of the study?

Once the study had been written up if you like we can send you a summary of the findings. You will not be identified in any publications.

Rules that we must follow

There are a few things for you to know before you decide whether or not to take part in this study. We have to follow some important rules to make sure that people who take part in the research are treated well and not harmed in any way. Here are those rules:

(1) Consent or agreeing to take part in the study

You do not have to agree to take part if you do not want to. As we said earlier, you are completely free to decide whether or not you want to take part in the study.

Taking part in the study will not affect the services or support you receive, or you involvement in the wider study.

(2) Confidentiality: keeping what you tell us private

All the information you give us is private. Records are locked up and will not be shown to anyone outside the research team without your signed agreement.

Nothing you say will be told to anyone outside the research team, except in three circumstances:

- We would have to tell the police or another relevant agency if we were told that someone was sincerely planning to seriously harm a specific person.

- Or that you were directly at risk of serious harm.

In the event of a serious criminal disclosure where a court were to demand participant case records, these would have to be made available on demand for legal authorities.

(3) Reporting the findings of the study

The third thing you should know is that a report will be written about the results of the study. In that report, the results will be presented in such a way that no one can find out that it is you or know that you took part. In other words, we can guarantee that information about you will be secret and private because we talk about groups not the individual. The reports will be available for all participants taking part.

(4) Making sure the trial is run properly

UCL must make sure that the study is being run properly and that we follow the rules described above. Some documents from the study may be looked at by responsible people appointed by UCL to make sure of this, and we would like your permission to let those people see the documents they need to see.

If you have any concerns and would like to contact someone outside of the team you can do this through your local Primary Care NHS Trust or the Research Governance Sponsor, UCL. You can write to:

Joint UCLH/UCL Biomedical Research Unit,

R&D Directorate (Maple House),

Rosenheim Wing, Ground Floor,

25 Grafton Way,

London

WC1E 5DB

Please quote reference number 14/0604. All communication will be dealt in strict confidence.

Conclusion

Finally, there are no risks associated with you taking part in the study. What we learn in this study will help the research team understand the best way to carry out research in the future.

Your questions or concerns

If you have any questions or concerns about the research study Elizabeth Simes, Research Manager, will be available to discuss these concerns with you.

You can contact her at:

      Elizabeth Simes, Research Manager

If you would like to speak to User Voice about this study or if you would like more information about their work in general, please contact:

      Mala Ram, Impact Manager

Appendix P: Participant Information Sheet_ research assistants

Exploring the User Voice peer researcher approach
Information Sheet for Research Assistants

What this information sheet tells you

You have been invited to participate in an interview to share your experiences of being part of the MOAM trial which is exploring how effective Mentalizaition based therapy (MBT) is at supporting people.

This information sheet tells you about the research we are doing and explains why we would like you to get involved.

It also tells you what will happen if you agree to take part in our study.

Why we would like your help

University College London (UCL) is collaborating with User Voice to collect data for the MOAM trial. User Voice is a user-led charity founded by Mark Johnson, an ex-offender and former drug user. The charity works to transform the criminal justice system by placing service users at the heart of all they do. By running peer-led service user councils, research and consultation projects, User Voice strives to transform individuals, institutions and the conversation around criminal justice. Eighty-five per cent of User Voice staff have lived experience of the youth or criminal justice system, and many have experience of the care system and substance misuse.

User Voice peer researchers with lived experienced of the criminal justice system are meeting with participants to complete questionnaires to understand how effective MBT is at supporting people. UCL research assistants are also meeting with participants to collect the same questionnaire data. We would like to talk to research assistants who have collected data for the MOAM trial about their experiences of being involved in this type of research so we can understand the most effective way to conduct this type of research in the future.

Do you have to take part?

No. Taking part is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the interview will not affect your employment or involvement in the MOAM trial now or in the future.

What is this "research" about?

We are speaking with UCL research assistants as well as User Voice peer researchers; participants involved in the trial; offender managers and User Voice operational staff about their experience of being involved in a research project where data is collected by User Voice peer researchers. There are no right or wrong answers, we just want to hear from you about your experiences and what you think.

What are the benefits of being part of the research study?

Taking part is an opportunity for you to share your experiences. You will also receive a payment after you have completed the interview to thank you for taking part.

What payment will you receive?

Everyone who agrees to be interviewed will be offered £35.00 in high street vouchers at the end of the interview to thank them for taking part in the research.

What happens if you agree to take part?

You are completely free to decide whether or not you want to take part in the study. If you agree, you will be asked to sign a form giving your consent to be interviewed.

What does signing the form mean?

The form shows that you agree to take part in the study, and that you agree to meet with a member of the research team to be interviewed about your experiences of being involved in the MOAM trial.

If you do give your consent to be interviewed, you are still free to leave the study at any point, without giving a reason.

What questions will we be asking you and how long will it take?

The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of experiences of working alongside User Voice peer researchers.

You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

What happens to the answers you give during the interview?

The interview will be audio recorded. The information recorded during the interview is private and will not be shared with the User Voice peer researchers, other UCL research assistants collecting data for the trial, User Voice management or anyone else outside of the research team. All of your information will be stored under an ID number. No information will ever be linked to your name.

What will happen to the audio recording after the interview?

The audio-taped recording of the interview will be stored in a secure area at UCL and will only be listened to by the researchers involved in this part of the study. These tapes will be securely disposed of once the study has been written up.

What will happen to the results of the study?

Once the study had been written up if you like we can send you a summary of the findings. You will not be identified in any publications.

Rules that we must follow

There are a few things for you to know before you decide whether or not to take part in this study. We have to follow some important rules to make sure that people who take part in the research are treated well and not harmed in any way. Here are those rules:

(1) Consent or agreeing to take part in the study

You do not have to agree to take part if you do not want to. As we said earlier, you are completely free to decide whether or not you want to take part in the study.

Taking part in the study will not affect the services or support you receive, or you involvement in the wider study.

(2) Confidentiality: keeping what you tell us private

All the information you give us is private. Records are locked up and will not be shown to anyone outside the research team without your signed agreement.

Nothing you say will be told to anyone outside the research team, except in three circumstances:

- We would have to tell the police or another relevant agency if we were told that someone was sincerely planning to seriously harm a specific person.

- Or that you were directly at risk of serious harm.

In the event of a serious criminal disclosure where a court were to demand participant case records, these would have to be made available on demand for legal authorities.

(3) Reporting the findings of the study

The third thing you should know is that a report will be written about the results of the study. In that report, the results will be presented in such a way that no one can find out that it is you or know that you took part. In other words, we can guarantee that information about you will be secret and private because we talk about groups not the individual. The reports will be available for all participants taking part.

(4) Making sure the trial is run properly

UCL must make sure that the study is being run properly and that we follow the rules described above. Some documents from the study may be looked at by responsible people appointed by UCL to make sure of this, and we would like your permission to let those people see the documents they need to see.

If you have any concerns and would like to contact someone outside of the team you can do this through your local Primary Care NHS Trust or the Research Governance Sponsor, UCL. You can write to:

> Joint UCLH/UCL Biomedical Research Unit,
> R&D Directorate (Maple House),
> Rosenheim Wing, Ground Floor,
> 25 Grafton Way,
> London
> WC1E 5DB

Please quote reference number 14/0604. All communication will be dealt in strict confidence.

Conclusion

Finally, there are no risks associated with you taking part in the study. What we learn in this study will help the research team understand the best way to carry out research in the future.

Your questions or concerns

If you have any questions or concerns about the research study Elizabeth Simes, Research Manager, will be available to discuss these concerns with you.

You can contact her at:

      Elizabeth Simes, Research Manager

If you would like to speak to User Voice about this study or if you would like more information about their work in general, please contact:

      Mala Ram, Impact Manager

Appendix Q: Participant Information Sheet_ specialist offender managers

Exploring the User Voice peer researcher approach
Information Sheet for offender managers

What this information sheet tells you

You have been invited to participate in an interview to share your experiences of being part of the MOAM trial which is exploring how effective Mentalizaition based therapy (MBT) is at supporting people.

This information sheet tells you about the research we are doing and explains why we would like you to get involved.

It also tells you what will happen if you agree to take part in our study.

Why we would like your help

University College London (UCL) is collaborating with User Voice to collect data for the MOAM trial. User Voice is a user-led charity founded by Mark Johnson, an ex-offender and former drug user. The charity works to transform the criminal justice system by placing service users at the heart of all they do. By running peer-led service user councils, research and consultation projects, User Voice strives to transform individuals, institutions and the conversation around criminal justice. . Eighty-five per cent of User Voice staff have lived experience of the youth or criminal justice system, and many have experience of the care system and substance misuse.

User Voice peer researchers with lived experienced of the criminal justice system are meeting with participants to complete questionnaires to understand how effective MBT is at supporting people. UCL research assistants are also meeting with participants to collect the same questionnaire data. We would like to talk to offender managers who have supported the User Voice peer researchers and UCL research assistants to collect data for the MOAM trial to capture their experiences, so we can understand the most effective way to conduct this type of research in the future.

Do you have to take part?

No. Taking part is entirely voluntary. It is your choice whether or not you would like to participate. Deciding not to take part in the interview will not affect your employment now or in the future.

What is this "research" about?

We are speaking with offender managers as well as participants involved in the trial; User Voice peer researchers; User Voice operational staff and UCL research assistants about their experience of being involved in a research project where data is collected by User Voice peer researchers. There are no right or wrong answers, we just want to hear from you about your experiences and what you think.

What are the benefits of being part of the research study?

Taking part is an opportunity for you to share your experiences. You will also receive a payment after you have completed the interview to thank you for taking part.

What payment will you receive?

Everyone who agrees to be interviewed will be offered £35.00 in high street vouchers at the end of the interview to thank them for taking part in the research.

What happens if you agree to take part?

You are completely free to decide whether or not you want to take part in the study. If you agree, you will be asked to sign a form giving your consent to be interviewed.

What does signing the form mean?

The form shows that you agree to take part in the study, and that you agree to meet with a member of the research team to be interviewed about your experiences of being involved in the MOAM trial.

If you do give your consent to be interviewed, you are still free to leave the study at any point, without giving a reason.

What questions will we be asking you and how long will it take?

The interview will take up to 1 hour and you will be free to take a break at any time during the session. You will be asked questions about your experiences of interacting with User Voice peer researchers and UCL research assistants during the MOAM trial.

You do not have to answer every question the researcher asks you during the interview, and you only have to share the information you would like to share.

What happens to the answers you give during the interview?

The interview will be audio recorded. The information recorded during the interview is private and will not be shared with the User Voice peer researchers or UCL research assistants you have met with; User Voice management or anyone outside of the research team. All of your information will be stored under an ID number. No information will ever be linked to your name.

What will happen to the audio recording after the interview?

The audio-taped recording of the interview will be stored in a secure area at UCL and will only be listened to by the researchers involved in this part of the study. These tapes will be securely disposed of once the study has been written up.

What will happen to the results of the study?

Once the study had been written up if you like we can send you a summary of the findings. You will not be identified in any publications.

Rules that we must follow

There are a few things for you to know before you decide whether or not to take part in this study. We have to follow some important rules to make sure that people who take part in the research are treated well and not harmed in any way. Here are those rules:

(1) Consent or agreeing to take part in the study

You do not have to agree to take part if you do not want to. As we said earlier, you are completely free to decide whether or not you want to take part in the study.

Taking part in the study will not affect the services or support you receive, or you involvement in the wider study.

(2) Confidentiality: keeping what you tell us private

All the information you give us is private. Records are locked up and will not be shown to anyone outside the research team without your signed agreement.

Nothing you say will be told to anyone outside the research team, except in three circumstances:

- We would have to tell the police or another relevant agency if we were told that someone was sincerely planning to seriously harm a specific person.

- Or that you were directly at risk of serious harm.

In the event of a serious criminal disclosure where a court were to demand participant case records, these would have to be made available on demand for legal authorities.

(3) Reporting the findings of the study

The third thing you should know is that a report will be written about the results of the study. In that report, the results will be presented in such a way that no one can find out that it is you or know that you took part. In other words, we can guarantee that information about you will be secret and private because we talk about groups not the individual. The reports will be available for all participants taking part.

(4) Making sure the trial is run properly

UCL must make sure that the study is being run properly and that we follow the rules described above. Some documents from the study may be looked at by responsible people appointed by UCL to make sure of this, and we would like your permission to let those people see the documents they need to see.

If you have any concerns and would like to contact someone outside of the team you can do this through your local Primary Care NHS Trust or the Research Governance Sponsor, UCL. You can write to:

> Joint UCLH/UCL Biomedical Research Unit,
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> R&D Directorate (Maple House),
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> Rosenheim Wing, Ground Floor,
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> 25 Grafton Way,
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Please quote reference number 14/0604. All communication will be dealt in strict confidence.

Conclusion

Finally, there are no risks associated with you taking part in the study. What we learn in this study will help the research team understand the best way to carry out research in the future.

Your questions or concerns

If you have any questions or concerns about the research study Elizabeth Simes, Research Manager, will be available to discuss these concerns with you.

You can contact her at:

> Elizabeth Simes, Research Manager

If you would like to speak to User Voice about this project or if you would like more information about their work in general, please contact:

> Mala Ram, Research and Evaluation Manager

Appendix R: Consent form

University College London (UCL)

Exploring the User Voice peer researcher approach

Research Manager: Elizabeth Simes

CONSENT FORM

Please complete the following: **Please initial box:**

1   I have read the information sheet (version 1 02/12/2018) that

      describes this study.

2   I have had an opportunity to ask questions and discuss this study.

3   I have received satisfactory answers to all my questions.

4   I have received sufficient information about this study.

5   I understand that I do not have to take part in this study.

6   I understand that I am free to withdraw from the study at any

      time without giving any reason

7   I understand that my interview will be audio-taped and stored

        securely as described in the information sheet

        I understand that some documents from the study may be looked

        at by responsible people appointed by UCL, who must make

8   sure (as Research Governance sponsor) that the study is being

        run properly. I give permission for this group to have access to

        the necessary information.

        I understand that the personal information I provide will only be

        used for the purposes of this project and not transferred to an

9   organisation outside of UCL. The information will be treated as

        strictly confidential and handled in accordance with the

        provisions of the Data Protection Act 1998.

10   Do you agree to take part in the study?

To be completed by the participant:
Signed: ………………………………………………………………………………
Name in Block Letters: ……………………………………………………………….
Date: …………………………………………………………………………………

To be completed by the researcher:
I am satisfied that the person named above had given their informed consent to take
part in this study:
Signed: ………………………………………………………………………………
Name in block letters: …………………………………………………………………...
Date: …………………………………………………………………………………….

Appendix S: Self-report scale

You have been asked to complete this questionnaire to share your personal experience of meeting with a researcher to complete the questionnaires for the MOAM / MBT research trial.

Your answers will not be shared with the researcher you met with.

Please read each statement and tick the box to indicate if you strongly disagree; disagree; are not sure; agree or strongly agree with each statement.
Please return the completed questionnaire in the stamped envelope provided.

		Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Q1	The researcher made me feel relaxed during the meeting					
Q2	I felt able to ask the researcher questions if I didn't understand					
Q3	I felt I was able to trust the researcher					
Q4	I felt I was able to give honest answers to the questions the researcher asked me					
Q5	The researcher listened to me					

Q6	I felt the researcher understood me					
Q7	The researcher talked to me in a way that I understood					
Q8	I would feel comfortable meeting with the researcher again to complete the questionnaires					
Q9	Meeting with the researcher was a positive and empowering experience					

Appendix T: Themes and sub themes_MOAM participants who met with a peer researcher

Theme		Subtheme		Prevalence (n=15)
6.1.1	Automatic common ground	6.1.1.1	They have been where I am	11
		6.1.1.2	It's having a connection with somebody who knows how you feel	15
		6.1.1.3	Well they explained stuff to me really well	8
		6.1.1.4	Everybody's crimes were different	3
6.1.2	Impact of common ground	6.1.2.1	I felt relaxed knowing they'd been in my shoes	9
		6.1.2.2	I felt I could be myself and answer honestly	12
		6.1.2.3	I just didn't trust the process because of my experience	6
6.1.3	The impact of seeing someone who had progressed	6.1.3.1	I held then in high esteem	10
		6.1.3.2	I reflected on my own behaviour	8
		6.1.3.3	It's given me hope for the future	6

Appendix U: Themes and sub themes_MOAM participants who met with a research assistant

Theme		Subtheme		Prevalence (n=15)
6.2.1	Meeting with a research assistant	6.2.1.1	Meeting for the first time	8
		6.2.1.2	In the room	15
		6.2.1.3	Impact of the meeting	14
6.2.2	The peer researcher approach	6.2.2.1	They understand because they have been there	15
		6.2.2.2	It depends on the individual person	15

Appendix V: Themes and sub themes_User Voice peer researchers and operational staff members

Theme		Subtheme		Prevalence (n=7)
7.1.1	The peer researcher approach	7.1.1.1	Motivation	7
		7.1.1.2	Having that shared experience	5
		7.1.1.3	Skills required to be an effective peer researcher	5
7.1.2	Collecting data is prisons and probation offices	7.1.2.1	Getting in	5
		7.1.2.2	Levels of engagement	4
		7.1.2.3	Managing boundaries	7
		7.1.2.4	Being treated like an ex-offender	4
7.1.3	Impact on the participant of meeting with a peer researcher	7.1.3.1	Levels of honesty	7
		7.1.3.2	The peer researchers as role models	6
7.1.4	Impact of the role on the peer researcher	7.1.4.1	Feeling valued and a time to reflect	5
		7.1.4.2	Skill development	7
		7.1.4.3	Not feeling part of the entire process	7
		7.1.4.4	Having that lived experience meant it was more challenging	4

Appendix W: Themes and sub themes_research assistants

Theme	Subtheme	Prevalence (n=5)
8.1.1 Engagement style	8.1.1.1 Someone they can identify with	5
	8.1.1.2 A bit more formal, a bit more lay	3
	8.1.1.3 We are seeing you, end of story	2
8.1.2 Levels of engagement	8.1.2.1 I think it's more authentic	4
	8.1.2.2 Developing a relationship over time	4
	8.1.2.3 It's going to vary	4
8.1.3 Shared learning	8.1.3.1 Learning experience for the peer researchers	5
	8.1.3.2 We learnt so much	5
	8.1.3.3 Working together	5
8.1.4 Supervision and support	8.1.4.1 It was too close to home for some of the peer researchers	4
	8.1.4.2 Clinical supervision	5

Appendix X: Themes and sub themes_specialist offender managers

Theme		Subtheme		Prevalence (n=5)
8.2.1	Bridging the gap	8.2.1.1	It feels like us and them if not	3
		8.2.1.2	Any study is just so enriched by the involving service users	3
		8.2.1.3	Being empathetic not sympathetic	4
8.2.2	Challenging the stereotype	8.2.2.1	You just couldn't tell	3
		8.2.2.2	Trusted professionals	4
		8.2.2.3	Proving change is possible	5
8.2.3	Therapeutic effect	8.2.3.1	You haven't been forgotten you are not lost	4
		8.2.3.2	He' not an ex-offender when he comes in	5
		8.2.3.3	It can take you back to where you don't want to be	4