

**"They've been there, they know". How mental health service users think about mental health staff with lived experience.**

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## **Abstract**

Many practitioners with lived experience of mental health problems themselves work in NHS mental health services, and recovery oriented policy encourages such practitioners to use their lived experience to support service users. Research, mostly from the perspective of practitioners with lived experience (as opposed to the perspectives of service users), suggests there are benefits to service users in using lived experience, such as increased hope, along with disadvantages such as practitioners over-identifying. Professional guidance for such practitioners however is ambiguous and mainly focuses upon preventing risk to service users from impaired practice. This leaves practitioners without support in using their lived experience in a way that is helpful to service users.

This Grounded Theory study aimed to develop theory explaining the factors service users took into account when thinking about practitioners with lived experience, and if and how practitioners should disclose this. Eight people who had used NHS mental health services in the last five years were interviewed about their views and experiences of practitioners with lived experience.

Analysis resulted in a theoretical model which showed that disclosure can lead to hope and worry, both of which are mitigated by five theoretical codes about: competence, recovery, relevant lived experience, NHS context, and stigma. Guidance about the use of lived experience in the clinical setting is offered. Further research with different populations to test the assumptions of the model is recommended.

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## Chapter 1 – Introduction

### Overview of chapter

This chapter will begin by examining evidence for the prevalence of mental health practitioners with lived experience of mental health difficulties in the NHS. This will be followed by a discussion of key policy and theoretical contexts for the study. Using the “wounded healer” concept as a theoretical framework, the chapter then discusses recent evidence that demonstrates the benefits and risks of having practitioners with lived experience working in the NHS. Service user-focused assessments of peer workers will be discussed, and this will be followed by an overview of the relevant aspects of the literature around therapist self-disclosure, including a review of recent studies of practitioners disclosing lived experience to service users. Existing professional codes of conduct relevant to such practitioners will then be discussed.

It will be argued that current guidelines for practitioners with lived experience do not reflect research to date as they focus too narrowly on risk, and do not acknowledge possible benefits of disclosure. It will also be highlighted that there is a lack of evidence to inform decisions about when and how to disclose lived experience of mental health problems. Furthermore, it will be argued that there is some evidence of differences in how practitioners with lived experience, and service users experience their work together. This suggests that a service user perspective is necessary to gain a full understanding of the implications of disclosure for practitioners with lived experience. This will lead into a statement of the current study’s rationale and aims.

### **Prevalence of mental health staff with lived experience**

It is likely that NHS mental health service users will be receiving care at some point from practitioners with lived experience. The latest NHS staff survey (National NHS staff survey, 2015) shows that 41% of all staff working in UK Mental Health Trusts had suffered work-related stress in the last 12 months, compared with 36% of all staff across the NHS; the figures were particularly high for mental health nurses, of whom 50% reported work-related stress. In an influential review of NHS staff health and wellbeing, (Boorman, 2009) it was found that 37% of NHS staff reported stress, depression or anxiety that was caused or exacerbated by their work, compared to 30% of non NHS staff. A recent internet survey of 1106 NHS psychological practitioners (Rao et al., 2016), found that 46% reported feeling depressed for at least some of the past week, and 70% reported finding their job stressful some or all of the time. Similarly, 60% of mental health social workers in a postal survey reported scores above the clinical cut off in the GHQ-12 (Evans et al, 2006). These large-scale studies of the NHS focus upon practitioners who are currently experiencing difficulties in their mental health. Data from these sources does not give information about practitioners who have previously experienced mental health issues, or practitioners who are currently experiencing mental health issues other than depression, anxiety or stress related issues.

Data relating to people who have had, at any point, lived experience of a mental health issue, rather than those who are currently feeling depressed,

stressed or anxious, is patchy. The BBC reported in 2015 that around 3% of NHS staff were on leave at any time with a mental health problem (following their request of NHS data under the Freedom of Information act (BBC 2015)). The report also suggested this was an underreported figure as people with physical and mental health co-morbidities were likely to only report the physical health issue.

Turning to staff who have had experience of mental health issues at any point, rather than those who are currently experiencing symptoms, one study examined equal opportunities monitoring data for new staff at a Mental Health Trust. This study (Perkins, Renaldi & Hardisty, 2010) found that 31% of those recruited to management level positions (and 23% recruited overall) had reported having had a mental health problem at some point; it was implied in the paper, but not stated, that the monitoring data included specific mental health diagnoses but these were not reported. The authors suggested that there was also a possibility of underreporting of mental health issues due to fears of discrimination.

A survey of staff in a Dorset NHS Mental Health Trust, (Morgan, Leahy, Gale & Lawson, 2013), revealed that 53% of all survey respondents (survey total n=436) reported “personal experience of mental health issues” and 37% reported having “used mental health services or treatments”. A survey in Devon (Roberts, Good, Woolridge, & Baker, 2011) using the same questionnaire, found that personal experience of mental health issues was

reported by 43% of staff, and 22% reported using mental health services or treatments (survey response rate 23%).

These two surveys both use self-reported definitions of lived experience. They differentiate between staff reporting lived experience of mental health issues, and staff who received treatment for their mental health issues. It is not possible to be sure that differentiating between those who did and didn't receive treatment is a failsafe way of indicating greater or lesser severity of the problems experienced, as accessing health services and treatments also indicates the respondents' willingness to engage with services, not just the severity of the problem. It is not easy to make comparisons between these and other surveys. Extrapolating from these to the NHS as a whole is also problematic. The survey could be over-reporting prevalence, if the survey attracted more practitioners with lived experience because it was relevant to them, or under-reporting because practitioners feared stigma and did not disclose in the survey. Secondly these two rural, West Country NHS trusts may not be particularly representative of the NHS as a whole.

It is possible to say with confidence though, that in Dorset, where the response rate was 30%, at least 16% of all of the staff in the trust (53% of respondents x 30% of all staff) had personal experience of mental health issues, and in Devon (Roberts et al, 2011), at least 9% of all staff (43% of respondents x 23% of all staff) had some kind of lived experience.

The existing research about practitioners with lived experience in the NHS shows a complex picture, where it appears that a high percentage

experience mental health issues and continue to work, and reasonably high percentages self-identify as having had lived experience at some point. The degree to which those populations overlap is not clear, but it may be suggested that support and guidance for those with lived experience may help prevent relapse and therefore decrease the number of people with current difficulties. The data from Dorset (Morgan et al., 2013) and Devon (Richards et al., 2011) suggests that upwards of around one in eleven staff would benefit from support in using their lived experience with service users, and the NHS has stated (Shepherd, Boardman and Burns, 2010) that offering such support is a key priority, however currently little guidance exists for such practitioners.

### **Policy and theoretical contexts of the study**

#### ***Lived experience from the biomedical and recovery perspective***

Mental health services in the NHS have adopted ideas from a recovery perspective (e.g. Department of Health, 2009). Within a recovery approach, the view of mental health lived experience is thought to differ from that held in the dominant bio-medical model of healthcare within the NHS. The biomedical approach conceptualizes lived experiences of mental health as being symptoms of “mental illness” which in themselves are meaningless, in the way that a sneeze merely indicates the presence of a cold (Stickley 2006), and as such, clinical recovery is seen in terms of eradication of these symptoms. Clinical recovery has often been contrasted with personal recovery, which focuses on strengths, hope, healing, value, and inclusion

(Roberts and Boardman, 2013, 2014; Shepherd, Boardman, and Slade, 2008). In this conception, lived experiences of mental health issues are not thought of as meaningless symptoms, but rather an aspect of a person's life which can be reflected upon and used in the process of developing personal recovery. This means, as will be discussed below, that people with lived experience could also draw upon these experiences to help clients in their recovery.

### ***NHS utilization of lived experience in mental health***

The adoption of a recovery perspective, which values lived experience as a form of expertise that can support recovery has led to the increased employment, since 2010, of peer workers in NHS settings, who are employed with the intention of utilizing their lived experience to support clients in their recovery (Repper, Aldridge, Gilfoyle, Gillard, Perkins & Rennison, 2013). However, as Richards, Holttum and Springham (2016) point out, these types of expertise are usually held within clearly defined roles: peer workers as experts by experience, and other practitioners as experts as a consequence of training.

Less attention has been paid to utilizing the experience of mental health practitioners who themselves have lived experience of mental health issues. NHS policy around implementing recovery gives "supporting staff with their recovery journey" as a key organizational priority (Shepherd et al, 2010), and a recent NHS trust funded conference (Beyond "Them and Us", Leeds, 2015) discussed how practitioners' lived experience should be used in NHS

mental health services. However awareness across the NHS, rather than in particular groups of trusts, is still growing rather than established.

Thus, while an increased recovery perspective in NHS mental health services has meant that lived experiences are more likely to be seen as potentially useful tools for supporting clients in their recovery, this has been mostly translated into the creation of peer worker roles, rather than into the development of structures around practitioners with lived experience. Recently, research into practitioners with lived experience has been growing, although the idea itself is not new in the field of psychotherapy and mental health.

### **Literature pertaining to practitioners with lived experience**

#### ***Wounded Healers***

Ancient Greek and Shamanistic traditions suggest that those who have themselves been wounded and recovered have an enhanced ability to heal others (Kirmayer, 2003). In the psychological literature, mental health difficulties were conceptualized as 'wounds', and Jung (1963) suggested that psychotherapists' introversion into their own 'wounds' would give them insight into how to bring about 'healing' in their clients. 'Wounded healer' theory suggests that those who have experienced and recovered from their 'wounds' are motivated to become 'healers' as a consequence. A key assumption of the 'wounded healer' concept is that the 'healer' has



recovered from their initial 'wound': they are not currently impaired by their difficulties, and have also learned from overcoming them.

Jung (1963) also asserts that there is a false dichotomy between the idea of 'healer' and that of 'wounded person', which unhelpfully leads to people who are 'wounded' feeling they are unable to recover, and therefore failing to access their own resources to 'heal' themselves. This leads to his explanation of the mechanism by which a 'wounded healer' helps a client. Firstly, they can draw upon their experiences of overcoming 'woundedness' to directly help their clients. Secondly, their position as both a 'healer' and 'wounded' challenges service user and staff perceptions of these roles as mutually exclusive. This challenge potentially allows a person with 'wounds' (i.e. a service user) to see themselves and others with 'wounds' as having the potential to 'heal' themselves. For both kinds of helping to occur, it is necessary for the client to know that the healer is 'wounded', implying disclosure would be needed.

### ***Review of studies into 'wounded healers'***

A recent review (Zerubavel & Wright, 2012) examined the empirical literature around 'wounded healers' working in psychotherapy in the USA. They report on studies of therapists with lived experience, which show improvements in the therapy process, such as greater therapist empathy, understanding, patience and hope for their clients' positive outcomes. The review also finds that such therapists are more vulnerable to being traumatized by their work, and that they may be less emotionally present

with clients, may over-identify and be less able to maintain professional neutrality, risking damage to the therapy process.

Zerubavel and Wright (2012) also argue that 'wounded healers' are at risk of being pathologised by other staff members, whose roles as 'gatekeepers' mean they are responsible for assessing the mental health status of other practitioners. These staff may fear relapse, and lack confidence in the confidence of 'wounded healers'. This gatekeeping role is argued to promote stigmatizing social beliefs. The authors suggest that 'wounded healers' diagnosis affects the intensity of their fears of stigmatization, as certain conditions are more strongly associated with stigmatized notions of mental illness such as irrationality and violence.

### ***Stigma in NHS mental health services***

The clinical biomedical model of recovery is widely used in the NHS for physical health issues. If mental health practitioners also hold the view that lived experiences are simply meaningless symptoms, this may facilitate the development of stigmatizing beliefs. This is because behaviour resulting from "meaningless symptoms" is defined mostly as unproductive, unpredictable and lacking responsibility (Vatne & Holmes 2006). Research shows that such a construal of lived experience can facilitate stigmatizing views in mental health professionals (Angermeyer & Matchinger, 2005; Read, 2007; Walker & Read, 2002). This being so, one might expect settings, such as the NHS, with an overarching medical ethos, to also foster such stigmatizing views.

This is borne out by a quantitative longitudinal study of 3579 mental health clients between 2008 and 2011 in 15 NHS mental health trusts across the UK (Corker et al., 2013), using the Discrimination and Stigma Scale (Brohan, Clement, Rose, Satorius, Slade & Thornicroft, 2013), which showed that 34% of participants reported being “treated differently, and less well” by mental health staff. While the low response rate (<10%) makes generalizing difficult, and those with more interest in the topic as a result of experiencing discrimination may have taken part, the study supports the notion that mental health staff in the NHS can behave in a stigmatizing way.

Over half of the participants in a survey of an NHS mental health trust in Dorset (Morgan et al. 2013) reported that they felt there was an “us and them” culture at the trust, relating to the stigmatizing view that there are qualitative differences between people who provide, and people who receive, mental health services. This is a particularly conflicting message for practitioners who have lived experience themselves, suggesting as it does that they themselves do not fit in with other practitioners, or indeed, other service users, as they are members of two groups which, on a conceptual level, are exclusive of each other.

### ***Existing studies of practitioners with lived experience***

There is a small but growing literature examining the experience of mental health professionals with lived experience of mental health issues. Some focus upon the experience of those who developed mental health difficulties while they were working in their professional roles, such as clinical

psychologists (Charlemagne-Odle, Harmon & Maltby, 2014), psychotherapists (Telepak, 2010), counselling psychologists (Gilroy, Carroll & Murra, 2001) and social workers (Stanley, Manthorpe & White, 2007). Of the eleven clinical psychologists interviewed by Charlemagne-Odle et al. (2014), six had been given diagnoses of mental health issues, and the others had experienced significant levels of psychological distress. Telepak interviewed eight psychotherapists, all of whom had diagnoses of mental health issues, whereas Gilroy and colleagues (2001) reported on a self-report postal questionnaire, filled out by 425 counseling psychologists. Stanley and colleagues (2007) reported on telephone interviews from 50 social workers with lived experiences of depression. These studies suggest that becoming symptomatic while practicing is not an entirely negative experience. Practitioners report, on the one hand, that in some cases they were less able to concentrate upon their clients and less able to offer helpful interventions (Charlemagne-Odle et al., 2014), but on the other, they reported an increase in practitioner's empathy towards their clients and a lessening of the perceived power difference between them.

In all of the above studies, practitioners felt isolated as a result of keeping their difficulties secret from their colleagues, and feared being stigmatized by them. Telepak (2010), reported that many practitioners found it easier to disclose their lived experience to service users rather than colleagues, and conceptualized this as a result of fearing stigma. Nearly half of the 50 UK based social workers interviewed for the study conducted by Stanley and colleagues (2007), reported delaying seeking treatment because of

concerns about stigma. In all three studies cited above, the most commonly experienced difficulty was depression, in keeping with both the relative frequency of the issue in the general population, and perhaps reflecting the strong relationship between workplace stress and depression (Bhui, Dinos, Stansfeld & White, 2012). It is interesting that practitioners reported a high degree of fear of stigmatization, as depression is thought to be the least stigmatised of all mental health issues (Jorm, Korten, Jacomb, Christensen, Rogers and Pollitt, 1997). High levels of stigma about depression might suggest that practitioners with mental health issues are more stigmatized in the caring professions than elsewhere.

Other studies examine the experience of practitioners who had experienced mental health difficulties prior to becoming practitioners. Cain (2000) found, in a qualitative interview study of social workers, psychologists and a psychiatrist in the USA, that all felt that their experiences enhanced their capability as practitioners. They identified more easily with clients' feelings and thoughts, and also had a better understanding of practical issues faced by service users. They felt that they experienced a better therapeutic alliance, feeling increased empathy towards them, and thought that they modelled a genuine trust in therapy and hope for the service user's outcome in a way that related to their own experiences and recovery. They also reported instances of over-identifying with their clients, but suggested that this decreased as they became more experienced. They also reported fear of stigma from colleagues. Similar findings have been found recently in two further qualitative interview studies of mental health practitioners with a

range of professional backgrounds (Adame, 2011, 2013; Richards et al., 2016).

The findings in the aforementioned studies underpin those anticipated by the 'wounded healer' literature: that therapists' skills may be enhanced in the areas of hope, empathy and identification with the client; that there are risks of over-identification with the client, and that therapists may be less trusted by and may trust less, their colleagues, who may see them as more risky because of their lived experience. These studies suggest that practitioners who work while unwell, at least when they are experiencing depression, may be at risk of being less effective in their role, for example, experiencing decreases in their ability to concentrate on and intervene helpfully with clients (Charlemagne-Odle et al., 2014), and being less able to speak out when they felt their clients were being referred to disrespectfully by colleagues (Cohen, 2000). They do not appear to, (or do not report), putting their clients at risk by having experiences of depression while working. However, these studies do not provide any insight into service users' experiences of practitioners with lived experience. While the practitioners in the studies above report empathetic identification with service users, it is not possible to know, without hearing the service user's side of the story, whether this translates into their experiencing more empathy from the practitioner.

### ***Peer workers***

Peer workers in the UK have parallels with practitioners with lived experience, as they are also employed by NHS trusts to support service users. Unlike such practitioners, peer workers are expected to disclose and use their lived experience to support service users. Their expertise is understood as coming from their own lived experience of mental health issues, whereas other mental health staff's expertise is thought to come from training (Repper & Carter, 2011).

Two recent reviews of the peer worker literature (Repper & Carter, 2011, and Miyamoto & Sono, 2012) have indicated that, in common with ideas about 'wounded healers', peer workers are theorized to be able to help clients because of their shared experience of difficulties and their experience of recovery. Where research takes into account client perspectives, the evidence gives a mixture of negative as well as positive findings. Interestingly, one quantitative study using structured interviews of 628 service users who offered or received (and sometimes offered and received) peer support (Bracke, Christiaens & Verhagehe, 2008), showed that service users who mostly offered peer support had greater increases in self-esteem (Rosenberg, 1965) and self-efficacy (Sherer et al., 1982) than those who mostly received it. This could underline the importance of garnering the viewpoints of clients as well as those providing their support, as experiences of supporting, and being supported may differ, as is also suggested by research into social support (Brown, Nesse, Vinokur & Smith, 2003). However, as Bracke and colleagues' (2008) study was cross-

sectional in nature, it may simply reflect that those who mostly received peer support did so because they had more difficulties at that point in time, which would have then played a part in their lower self-esteem and self-efficacy. It may be that those who mostly offered peer support were able to do so because they had better levels of functioning in the first place and therefore already had higher self-esteem and self-efficacy.

### ***Advantages and disadvantages of peer working***

Repper and Carter (2011), and Miyamoto and Sono (2012) found that service users felt more accepted, understood, empathized with and seen as individuals by peer workers than by other staff. This is in line with the research discussed above in the 'wounded healer' literature. It also reflects findings that service users value being treated as individuals (Bonney & Stickley, 2008), and with the assertion by May (2000) that people with lived experience are more able to empathize with service users. Service users also valued mutual responsibility and interdependence with the peer worker (Miyamoto & Sono, 2012). One study, however, found that service users reported less satisfaction overall with peer worker case managers, (Solomon & Draine, 1994). The authors of this randomized controlled trial (RCT) of case management by peer workers compared to case management by non-peer workers argued that wide differences between individual case managers were more responsible for the overall lower satisfaction levels than whether or not the manager was a service user. However, there may be other explanations for the lower satisfaction levels, for example stigmatizing beliefs held by the service users or other professionals, or simply, differences in the experience of care.



### ***Effect of power on the helping relationship in peer working***

Both Repper and Carter (2011) and Miyamoto and Sono (2012) reported that it was not clear whether service user satisfaction with peer workers related to the shared lived experience, or the nature of the relationship with the peer worker. If the shared lived experience increases service user approval, it suggests that there may be a benefit for mental health staff to let service users know about their lived experience, just as the peer workers let service users know about theirs. With regard to the relationship, research into the key characteristics of a helping relationship, from a service user perspective (Borg and Kristiansen, 2004), showed that hope, flexibility with professional boundaries and sharing of power, as well as being proficient in their role, and personality factors were all important. It may be that peer workers had more flexibility with professional boundaries and sharing of power because the role has less status in the NHS than other practitioners' roles (Repper & Carter, 2011), and that this caused the increased satisfaction, rather than the shared lived experience per se.

Repper and Carter (2011) suggested that the lower difference in power and status between the peer workers and the service users, which was partially as a consequence of peer worker expertise coming from experience rather than from training, was key factor in the helpfulness of the peer workers. They made the tentative suggestion that professional practitioners with lived experience would not be as helpful as peer workers, because of the greater asymmetry of power between fully trained practitioners, and service users.

However, one interview study (Mowbray, Moxley & Collins, 1998) of eleven peer workers supporting service users on a work-finding program in the USA, concluded that some clinical training was required. The authors found that some peer workers took on too much responsibility, had difficulty understanding what they needed to do, reported difficulties around boundaries with service users, and were shocked by their clients levels of distress and were not holding hope for service user recovery. Repper and Carter (2011) have discussed the tension between peer workers being able to utilize training, which may result in them becoming more like professional practitioners, and being able to maintain their position as experts by experience which is thought to underpin their helpfulness.

Turning to the wider context, research from a service user perspective shows that factors such as i) clarity around roles and boundaries (Miyamoto & Sono, 2012), and ii) the peer worker being situated in a team with an established recovery focus (McLean, Biggs, Whitehead, Pratt & Maxwell, 2009), are valued. The need for clarity around roles and boundaries may reflect difficulties for service users (as well as mental health staff), in adjusting to the unusual or novel concept of being supported by someone offering lived experience rather than knowledge garnered from training. In teams where a recovery focus is present, there may be less of a conceptual leap required to make sense of support from peer workers, both for service users and staff.

### **Evidence from the psychotherapist self-disclosure literature**

If, as suggested in the 'wounded healer' literature, lived experience is useful therapeutically when service users are aware of it; and if, as suggested in the peer worker literature, it is helpful in providing positive role models and hope for service users, then it would be useful for service users to be aware of practitioners' lived experience, allowing these benefits to take place. A reasonably large literature exists about psychotherapists who disclose personal information about themselves, although less is written about other mental health practitioners, or the disclosure of lived experience in particular. This psychotherapist self-disclosure literature advises caution in almost all kinds of personal disclosure, and specifies avoiding disclosing lived experience of mental health related difficulties.

Some of this caution relates to therapeutic orientation: psychodynamically influenced theory suggests that any disclosures harm the countertransference (Peterson, 2002). Another reason given is to prevent boundary violations, as Epstein (1994) suggests that increased self-disclosure precedes sexual involvement with service users. One difficulty with avoiding all self-disclosure is pointed out by Gibson (2012), who suggests that practitioners do not necessarily know exactly what they are conveying to service users through their non-verbal communications, nor what has been conveyed by others or by other means (e.g. social media). Thus, there is a question around the degree to which a practitioner has the ability to completely keep their own lived experience a private matter, and

whether or not disclosure, in some circumstances, is preferable to assumed or guessed 'information' about the practitioner.

### ***Reviews of psychotherapist self-disclosure research***

A review of evidence of the outcomes of psychotherapist self-disclosure (Hill & Knox 2001) emphasizes the importance of keeping attention focused upon the service user. This is in contrast to findings discussed above that service users valued interdependence with peer workers (Miyamoto & Sono, 2012). Hill and Knox (2001) and Knox and Hill (2003), examined service user and psychotherapist views of all kinds of self-disclosures and found that service users believed psychotherapists disclosed in order to normalize the service users' experiences and help them bring about desired change. Similarly, psychotherapists also aimed to normalize service users' experiences, and to give information. Hill and Knox (2001) argue that the main mechanism underpinning any benefits of therapist self-disclosure is the improvement in the client-therapist relationship, and suggest that disclosures should focus mainly upon observations of the relationship as they occur, rather than upon therapist's lived experiences, as these are most clearly beneficial to the relationship.

Hill, Helms, Tichenor, Spiegel, O'Grady and Perry (1988), in a rare quantitative observational study of psychotherapists (n=8) in therapeutic sessions with service users (n=13), found, using a variety of validated measures following video-assisted recall of sessions, that service users rated the psychotherapists use of self-disclosure as significantly more

helpful than other therapeutic techniques, such as offering information, interpreting or showing approval. Service users also reported significantly higher levels of involvement in sessions where psychotherapists disclosed. However, there were mixed views amongst therapists, with five reporting self-disclosure as the least helpful technique, and three reporting it as most helpful. This suggests that client views of the helpfulness of disclosure may differ from those of some practitioners. However, the conclusions that can be drawn regarding disclosure of lived experience from this study are limited as the self-disclosure in the study was of any personal information relating to the practitioner, rather than specifically to lived experience of mental health issues. In the experiment, self-disclosure was also very rare, meaning that service user views may have also been influenced by the unusual nature of the disclosure, rather than its usefulness alone.

In a large review of research into practitioner (not just psychotherapist) self-disclosure, (Henretty and Levitt, 2010), the clinical importance of the topic was underlined by the finding that 90% of practitioners reported using personal disclosure at some point in their work. Regarding self-disclosures in general, they report that service users prefer it, increasing their own levels of disclosure in response, and that the two main effects of clinician self-disclosures are a decrease in perceived 'expertness' and an increase in perceived 'therapist warmth'. They suggest that it is important to consider to whom, when, why, how and what, in making personal disclosures. They suggest that the disclosure of similarities between the practitioner and service user; and that disclosure of a stigmatized identity, such as being

LGBT, in particular is appropriate and helpful, however they are cautious about disclosures of lived experience of mental health issues. They reviewed research which had concluded that disclosure of 'past struggles that have been successfully resolved' was helpful and appropriate for service users (Cabaj, 1996; Knox and Hill, 2003; Mathy, 2006, Mulchahy, 1998), but the authors none the less cautioned against such disclosures. Their caution was based on the conclusions of two studies: Dilts, Clark and Harmon (1997), and Mallow (1998).

The first study (Dilts, et al., 1997) reported that the authors had been intending to interview psychiatrists with substance abuse issues, but had been unable to find any, so instead carried out a case discussion of seven vignettes, obtained by asking other psychiatrists to reflect upon their and other colleagues' practice. It is not possible to verify details of these cases, and they may be imaginary or an amalgam of multiple cases. In two of the seven vignettes, psychiatrists do not disclose to service users. Two further vignettes deal with service users, who, while unconcerned by the disclosure per se, do not keep the psychiatrists disclosure private. One of the remaining three vignettes describes a situation where a service user, following a disclosure described as helpful, alternated between attending, and refusing to attend the same AA meetings as the practitioner, although the therapy was unaffected. The final two vignettes describe service users who left therapy following a disclosure, one who remained for several weeks before relapsing into substance abuse and then dropping out of therapy, and the other who never returned following disclosure.

The discussion concludes that in three of the five cases disclosure “appears to be beneficial to the recovery of the patient and seems to promote an increased sense of self-esteem in patients” (p70, Dilts et al., 1997) but that it also may result in service users projecting their own feelings of shame onto the disclosing therapist. They conclude that the service user who left immediately following a disclosure and never returned had been negatively affected by the disclosure. The authors suggest that any disclosure should be preceded by a consideration of the effects upon the client, practitioner and the relationship between them.

The second paper (Mallow, 1998), is theoretical, drawing on the author’s clinical experience of working psychoanalytically with clients who have addictions, and who frequently request disclosures of the author’s lived experience, based upon their prior experiences of peer support in addiction treatment. As might be expected for a psychoanalytic therapist, the author discusses the possibility of practitioner disclosure leading to interruptions to the transference process, and the possible loss of focus on the client’s concerns. The author concludes that self-disclosure should be carefully considered by the practitioner, taking into account “both the harm and the benefit to the patient” (p497, Mallow, 1998).

Both studies put forward the view of the authors that disclosures may result in both benefit and harm to clients, as is the case in most studies of self-disclosure reported in the rest of Henretty and Levitt’s (2010) review. However, these two particular studies do not constitute robust evidence, as

they do not employ research paradigms, but rather act as suggestions for further research into the effects of practitioner disclosures of lived experience. Recently, two studies of practitioners disclosing lived experience have been carried out, one of which explored service users' reactions; these may shed further light upon the benefits and drawbacks of such disclosures.

***Recent studies of reactions to practitioners who disclose lived experience***

Somers, Pomerantz, Meeks and Pawlow (2014), carried out an experimental analogue study of practitioner self-disclosure of lived experience of mental health issues. They used vignettes of practitioners treating student clients for depression, PTSD or alcohol abuse, with an added sentence describing how the practitioner disclosed their own experience of the mental health issue in question, in the experimental condition. They found that the participants (155 undergraduates) rated the disclosing practitioners as significantly more likeable, sincere and warm, and more likely to form good working relationships, than those in the non-disclosing condition. However, the disclosing therapist was not rated as significantly more likely to be understanding of clients, nor any more likely to be chosen as a therapist by the participants themselves. Thus it could be argued that the study suggests that in a non-clinical population, the disclosure of similar lived experience results in the practitioner being seen as personally more likable, but not necessarily any more competent in their role. There was no opportunity for participants to voice any concerns that



they potentially had about practitioners who disclosed their lived experience. It is unclear how well these findings would translate to a clinical population.

One mixed methods study (de Vos, Netten & Noordenbos, 2015) reported survey responses from 205 service users and 26 practitioners in a Dutch eating disorders (ED) clinic. This clinic followed a protocol where practitioners recounted their lived experiences of ED at the outset of therapy and drew on them in therapy. The researchers distributed a questionnaire with a mixture of closed and open ended questions to practitioners (response rate 75%) and service users (response rate 57%), and carried out a form of content analysis upon the open ended question responses. Descriptive statistics indicated that nearly all (97%) of service users reported satisfaction with the use of lived experience in therapy, with high levels (82%) reporting experiencing increased empathy. Other advantages stated by a third or fewer of the service users were feeling accepted, feeling hopeful, and the perception that the practitioner had high levels of insight and understanding of their difficulties and was more accessible and open. A minority (11%) reported disadvantages. These were categorized as being caused by negative comparisons of themselves to the practitioner and the practitioner not keeping enough distance from them.

Higher percentages of practitioners than service users espoused the advantages of using lived experience in therapy, suggesting that practitioners may be over-estimating the helpfulness of their disclosures to service users. On the other hand, practitioners were more forthcoming about

possible difficulties, with two fifths reporting disadvantages of disclosing, however these were focused upon difficulties for the practitioner rather than the service user such as experiencing painful feelings themselves. Neither type of participant reported concerns around stigma. This may be explained by the fact that the study reported from a clinic where practitioners are recruited on the basis of their lived experience and who receive training in the use of it, quite a different scenario to the NHS setting, where levels of acceptance of lived experience in mental health practitioners are not so high, and where stigma may play a role.

While interesting, the study only reports on the views of just over half of service users. It may be that those who are less interested in, or less enthusiastic about, the use of lived experience, were less motivated to respond, resulting in a bias towards positive results. There appeared to be small differences between service users and practitioners, regarding how helpful disclosure was perceived to be. However, no inferential statistics were presented so it is difficult to draw any firm conclusions. Overall, though, it appears that these two studies findings are quite heavily weighted towards service user and practitioners benefiting from practitioner disclosure, but it is also clear that there are possible negative consequences to be addressed.

### ***Summary of theory about practitioners with lived experience***

In a recovery focused approach, it is theorized that practitioners with lived experience will be able to draw upon these experiences to help others; peer workers are hypothesized to also be helpful to service users because they

are more equal in terms of power and status than other practitioners. The 'wounded healer' literature suggests that a practitioner with lived experience will be able to demonstrate that healing is possible, although they themselves are vulnerable to stigma both from service users and from other practitioners. In the disclosure literature, Hill and Knox (2001) theorize that disclosure, especially of factors relating to the current thoughts and feelings of the practitioner in the room, can be helpful because it leads to an enhanced client-therapist relationship. The specifics of disclosure are thought by Henretty & Levitt (2010) to play a role, and they highlight the importance of considering who, what, why, when and how to disclose, and suggest that a shared identity may also influence the helpfulness, or not, of disclosure.

#### ***Summary of research findings about practitioners with lived experience***

Research into practitioners with lived experience suggest such practitioners in hypothetical situations are seen favourably, (Somers et al., 2014) and that service users are highly satisfied with them in settings where such disclosures are an accepted part of the treatment protocol (de Vos et al., 2015). Qualitative interview studies of practitioners with lived experience (e.g. Cain, 2000; Charlemagne-Odle et al., 2013; Stanley et al, 2007; Adame, 2011, 2013; Richards et al., 2016 ) reveal that they experience higher levels of empathy for service users but also may experience impairment in their ability to work therapeutically when they experience symptoms (Charlemagne-Odle et al., 2013). Even when they are well, such practitioners risk over-identifying with service users and experiencing emotional pain when painful memories are activated in the session (Cain,

2000). Research from service user perspectives finds service users feel treated as individuals and empathized with more by peer workers; however one large scale study from the 1990s found less satisfaction with peer workers than other practitioners (Solomon et al., 1994) , and another suggested that peer workers needed more training (Mowbray et al., 1998). More recent studies suggested contextual factors such as being in a team with a recovery focus enhanced service users experiences of peer workers (McLean et al., 2009).

The mixture of positive and potentially negative effects of disclosure in theory and research, and the potential for high numbers of practitioners with lived experience to be working in the NHS, suggests that practitioners would benefit from professional guidance around how best to use their lived experience with service users.

## **Guidance for practitioners with lived experience**

### ***Professional practice guidelines***

Mental health staff in the NHS come from a variety of professional disciplines, all of which provide their practitioners with ethical codes or guidelines to be followed. See Table 1 below for the guidelines which were examined for this study.

Table 1. Professional guidelines for mental health professions

<b>Profession</b>	<b>Relevant Guideline (s)</b>
Psychologists	<i>Health and Care Professions Council Standards of Conduct, Performance and Ethics</i> (Health Professions Council, 2016) <i>British Psychological Society Code of Ethics and Conduct</i> (British Psychological Society, 2006)
Psychotherapists	<i>UK Council for Psychotherapy Ethical Principles and Code of Professional Conduct</i> (UK Council for Psychotherapy, 2009) <i>British Association of Behavioural and Cognitive Psychotherapies Standards of Conduct, Performance and Ethics</i> (British Association of Behavioural and Cognitive Psychotherapies, 2010).
Psychiatrists	<i>Royal College of Psychiatrists Good Psychiatric Practice - Code of Ethics</i> (Royal College of Psychiatrists, 2014) <i>General Medical Council - Good Medical Practice</i> (General Medical Council, 2013) <i>Vulnerable patients, safe doctors – Good practice in our clinical relationships</i> (Royal College of Psychiatrists, 2013)
Mental Health Nurses	<i>Nursing and Midwifery Council Code for Nurses and Midwives</i> (Nursing and Midwifery Council, 2015)
Support workers	<i>Nursing and Midwifery Council Code for Nurses and Midwives</i> (Nursing and Midwifery Council, 2015) <i>Health and Care Professions Council Standards of Conduct, Performance and Ethics</i> (Health Professions Council, 2016)
Occupational therapists	<i>Health and Care Professions Council Standards of Conduct, Performance and Ethics</i> (Health Professions Council, 2016)
Social Workers	<i>Health and Care Professions Council Standards of Conduct , Performance and Ethics</i> (Health Professions Council, 2016)

### ***Guidelines around fitness to practice***

While only one guideline directly referred to the disclosure of lived experience, all guidelines referred directly or obliquely to practitioners who experienced difficulties with their mental health while in practice. This was in reference to the responsibility to maintain one's own fitness to practice, and the responsibility to notice if other practitioners were unfit to practice, with the aim of preventing risk to service users from incompetent practice. This of course is relevant to all practitioners, not just those with lived experience, and does not speak to the issue of how to make use of knowledge gained by previous experiences of mental health difficulties. It also frames practitioners' mental health difficulties in the context of risk, without any reference to positive uses of lived experience.

### ***Contradictions in the guidelines***

Most of the guidelines discussed the importance of professional boundaries between practitioner and client, but, apart from the clear definitions of sexual contact and exploitative relationships, did not define the boundaries of professional behavior. While this allows for flexibility regarding individual differences, it does not guide practitioners with lived experience in their practice.

One guideline, unlike all the others, referred directly to the disclosures of lived experience (RCPsych, 2013), and was unequivocal in its

condemnation of such disclosures, stating that “Disclosure of personal information is always unnecessary and introduces a false mutuality into the doctor-patient relationship” (p20, RCPsych, 2013). It was implied that the personal information related to lived experience as it came as part of a discussion of a vignette describing a psychiatrist who tells a patient about his divorce “and the depression that followed” (p19, RCPsych, 2013). These examples are defined as boundary violations and the first step towards further, more serious violations. Motivation for such disclosures is described as coming from the practitioner’s need for help with unresolved difficulties. While the guideline is perfectly clear that any disclosures of any kind are unacceptable, this is not in keeping with an approach where a practitioner might be considering drawing on their lived experience with the aim of helping their client, and rather it frames the disclosure of lived experience as being something that occurs when a practitioner is impaired.

Another theme across the guidelines is the importance of avoiding actions which ‘decrease confidence in the profession’. As mental health issues are still stigmatized in most cultures, discovering that a professional has lived experience may decrease some clients or carers’ ‘confidence in the profession’. On the other hand, it has been shown that stigma decreases when people in positions of responsibility openly discuss their stigmatized condition (Corrigan, 2002). Psychiatrists have a duty to decrease and “promote a positive image of mental illness in the media” (RCPsych 2014, p19); disclosure of lived experience by trusted professionals may do just

that. The absence of a duty to promote a positive image of mental illness in their own profession is also notable.

Overall, there is little in existing professional codes to guide practitioners with lived experience, and that which there is, is categorically negative, framed in a context of practitioners being impaired by the experience of mental health issues, which may cause harm to clients.

### **Guidelines in the literature**

Turning to the academic literature, and focusing upon work which included client viewpoints, searches of PubMed, Web of Knowledge, British Nursing Index, the Health Technology Assessment (HTA) Programme Database, PsycINFO, NHS Evidence, and the grey literature, found one research paper containing guidelines for using and sharing lived experience within health and social care (Morgan & Lawson, 2015). This reports on the findings of three focus groups: i) service users; ii) mental health staff with lived experience, and iii) representatives of professional groups such as social workers, psychiatrists, psychologists, and an NHS trust. The representatives themselves did not have lived experience.

The findings are expressed in two sections. The first area is a justification for the guidance. It conceptualizes lived experiences of mental health difficulties as being directly comparable to other difficult lived life experiences, such as bereavement. It suggests that guidance is necessary for all staff on how to share such 'difficult experiences', not just staff with lived experience of mental health issues. However, it could be argued that service users come into contact with mental health staff, when they are



experiencing mental health difficulties, precisely because the nature of their difficulties are conceptualized by our culture and in a biomedical model of illness, as qualitatively different to other 'normal' experiences (Vatne & Holmes 2006). When mental health related experiences (e.g. hearing voices) are shared the person sharing may experience or anticipate stigma in a way that they may not when they share other difficult life experiences (e.g. bereavement).

The second section of the findings gave guidance for sharing lived experience, with 'tips' on the factors to consider, e.g. 'be aware of the impact of what you say and how it might affect the other person'. The generalized nature of such tips, which seemed to have originated from practitioners with lived experience, rather than from service users, may be helpful but are limited. For example, the quoted tip requires an awareness of the effect of disclosure of lived experience on service users. Research into this is currently limited, and so awareness would rely upon the assumptions, personal experiences or guesswork of the practitioner.

It is not clear to what extent service users' views are represented in these guidelines, as the findings do not represent the views of the different groups separately. The majority of quotations appear to represent the perspective of mental health staff with lived experience, such as "I couldn't nurse people who'd experienced the same as me". It is also possible that the stated purposive nature of the study (to provide guidelines for mental health staff with lived experience), meant that unstated assumptions, for example that disclosures of lived experience will be beneficial to service users, may have influenced what service user participants felt was acceptable to say or not

say. Thus service users who had misgivings about mental health staff with lived experience may not have contributed, or taken part in the study due to its stated purpose. Another drawback of the guidance in general is the focus upon the act of telling a service user about lived experience. There are other ways in which lived experience might be helpfully used, both without disclosing (e.g. how to personally reflect upon their lived experiences with relation to their current clients) and following disclosure (e.g. how to manage the changed relationship with the service user).

Professional guidance focuses upon managing risks that may be posed by practitioners who are not fit to practice because of issues with their mental health. Sharing lived experience with service users is conceptualised in guidelines to psychiatrists as a boundary violation which is likely to be an outcome of a practitioner not being fit to practice. This means that current professional guidelines are not in keeping with the theory and research which suggests practitioners sharing their lived experience may have some benefits for service users, and does not help practitioners make decisions about how or when to use it. One research paper (Morgan and Lawson, 2015) attempted to make suggestions for practitioners on how to use their lived experience, and included service users in their focus groups, but it is not possible to discern the degree to which service user views were incorporated into the guidelines developed.

### **Rationale for the current study**

Many mental health practitioners in the NHS have lived experiences of mental health issues, and NHS recovery oriented policy encourages them to

draw upon their lived experience to help service users. This is backed up by evidence and theory which suggests that practitioners with lived experience can show increased empathy; and that following disclosure they can offer hope, model recovery, normalize stigmatized identities and improve the practitioner-client relationship. There is evidence for the view that practitioners who disclose are seen as warmer and more approachable by both by clinical and non-clinical populations.

However, evidence also suggests there may be disadvantages for practitioners in disclosing, in that they may be exposed to stigma and discrimination, and disadvantages for the service user from impaired practitioners who may be less effective therapeutically, or from a change of focus in therapy from the service user to the practitioner. The evidence also suggests that there may be differences between the perspectives of practitioners with lived experience, and service users in receipt of their care. There are few studies from the latter group; further studies exploring the service user perspective are warranted in order to develop a clearer understanding of the advantages and disadvantages of the use of lived experience from a service user perspective.

As the evidence suggests that there are both advantages and disadvantages to the use of lived experience with service users, it would not seem in the best interests of service users for practitioners to avoid using lived experience altogether. Rather, it would follow that professional guidance is warranted so that practitioners can work effectively and safely. This is especially important given the high prevalence of practitioners with lived experience, the finding that 90% of practitioners use self-disclosure,

and the move in the NHS towards practitioners with lived experience using it to help service users. However, current guidelines focus mainly on the avoidance of risk and lack clarity around how to use lived experience in a positive way.

This study aimed to develop understanding of service user perspectives of practitioners with lived experience, in order to address the gap in the literature that exists in this specific, important area. Service user understandings are particularly important because they are the recipients of the care that practitioners with lived experience offer, and there is research to suggest a difference between their experiences of care and the experiences of those providing it. By understanding better how service users think about and experience practitioners with lived experience, it will be possible to develop guidelines that take into account the potential effects of such practitioners, and especially the effects of disclosure, upon service users.

### **Research aims and questions**

The current study aimed to develop theory explaining, firstly, the factors service users take into account when considering staff with lived experience, and secondly the circumstances and other factors service users take into account when considering if and how they would like staff to share this information with them.

## **Chapter 2 – Methods**

### **Design**

This is a qualitative, cross-sectional interview study of eight mental health service users recruited from a range of mental health service user groups in London. Constructivist Grounded Theory (Charmaz, 2006) was used to analyze the interview transcripts.

### **Participants**

#### **Eligibility Criteria**

Participants were adults with recent experience of using NHS mental health services. The following inclusion criteria were used:

1. Participants were aged 18 or over
2. Participants had used NHS mental health services in the last 5 years
3. Participants had the current capacity to consent to be interviewed
4. Participants were able to carry out the interview in English. (No budget was available for translation services so English speaking participants were required).

Both service users who had, and who had not had, first-hand experience of a mental health professional with lived experiences of mental issues were recruited. This was to allow for a development of an understanding of the role of first-hand experiences in forming views about mental health staff with lived experiences, and allowed for a broader range of perspectives to be studied.

### **Participant details**

Demographic details and information about use of mental health services for all participants (n=8) are presented in Table 2 below. Participants' ages ranged from 26 to 65, with a median age of 40. The majority were White, British and university educated. Half were currently receiving NHS mental health care for long term conditions. All but one had a diagnosis of depression alongside other conditions and half reported frequent admissions to mental health inpatient services. Three participants had direct experience of one or more mental health practitioners with lived experience disclosing this to them, and five (including two who also had experienced disclosure) had experienced working with mental health practitioners who they suspected of having lived experience. Two participants had no known experience of working with a mental health practitioner with lived experience.

*Table 2. Details of participants*

<i>Consultant / participant number</i>	<i>Age</i>	<i>Service User Group</i>	<i>Recruited</i>	<i>Gender (M /F/Trans)</i>	<i>Ethnicity</i>	<i>Highest Educational Attainment</i>	<i>Current Job Status</i>	<i>Mental health service use</i>	<i>Stated Mental health issue(s)</i>	<i>Used inpatient services?</i>	<i>Experienced MHP with LE? (type of MHP)</i>
Participant 1	65	General 1	Face to face	Male	White British	Undergraduate Degree	Retired	Current, Long Term Secondary Adult MH service	Bipolar Disorder	Yes frequently	Suspected only (psychiatrist)
Participant 2	33	General 2	Face to face	Male	White British	Undergraduate Degree	Working	Previous, Short Term Primary MH Care (Counsellor)	Anxiety & Depression Brain Injury	No	Suspected only (counsellor)
Participant 3	55	General 2	Face to face	Female	White British	Postgraduate Qualification	Volunteer	Previous Long Term Primary and Secondary MH care	Depression OCD – hoarding	No	Not
Participant 4	32	General 2	Email	Male	Mixed White / Afro-Caribbean British	Undergraduate Degree	Working	Previous Short Term Primary and Secondary MH care	ADHD Depression	No	Suspected only (psychiatrist)
Participant 5	40	General 3	Email	Female	White British	Undergraduate Degree	Working	Current Long Terms Secondary Adult MH service	Borderline Personality Disorder Depression	Yes frequently	Suspected (psychiatrist) and experienced (support worker)
Participant 6	40	Voice Hearing 1	Email	Male	White British	Postgraduate Qualification	Volunteer	Current Long Term Secondary Adult MH service	Paranoid Personality Disorder Post-Traumatic Stress Disorder	Yes frequently	Experienced (psychoanalyst)
Participant 7	26	Voice Hearing 2	Face to face	Trans	White European	PhD	Studying	Current Long Terms Secondary Adult MH service	Asperger's Eating Disorders Schizoaffective Personality Disorder/voice hearing	Yes frequently	Suspected (social worker) and experienced (counsellor; support worker)
Participant 8	57	General 2	Email	Female	Black African	A Level Equivalent	Not working	Previous, Short Term Primary MH Care (IAPT)	Depression Chronic Pain	No	Not

## **Methodological Approach**

### ***Qualitative research***

Mental health practitioners with lived experience already exist in the workplace, but there is little research to support them and their institutions in making decisions about disclosure and even less which takes into account service user perspectives. Qualitative methods are thought to be particularly useful for the study of under-researched topics (Barker, Pistrang and Eliot, 2002), as the use of existing, or the development of new, quantitative measures such as attitude scales may artificially constrain the scope of the participants' answers (Lyons and Coyle, 2007).

Qualitative research often is informed by interpretivist assumptions around how people create meaning, namely through their subjective interpretations of reality as opposed to a direct reliance upon 'scientific' facts (Bryant and Charmaz, 2007). Indeed, social constructionists would also argue that the 'reality' that people are interpreting when they create meaning is itself constructed by the people experiencing it and their society (Burr, 2015).

With these assumptions, qualitative methods give a greater scope for the co-construction of understanding by the participant and the researcher, leading to a decrease in the power difference between them (Karnieli-Miller, Strier & Pessach, 2009). This is because the participant is encouraged to describe in rich detail the issues that are important to them, and their understanding of the meanings of what they relate can be elicited by the questioning of the researcher. The researcher can also offer their



interpretation of the data, and discuss this interpretation with the participant, which may result in a new understanding for both parties, rather than the researcher's account and understanding being prioritized. This is in contrast to the hierarchical relationship between a quantitative researcher and participant, especially in an experimental paradigm where the researcher's need to reduce confounding variables means that all aspects of the situation need to remain under their control. Decreasing power differences between researcher and participant is particularly relevant when working with mental health service users, whose views have historically been given little credence even in processes that directly affect them (Rush, 2004). Qualitative research enables understanding of experiences, meanings and processes (Harper & Thompson, 2011), and was thought most suitable for the generation of an explanatory framework for the attitudes and circumstances stated by the participants. Grounded Theory (Charmaz, 2006) was proposed, to facilitate the generation of theory to explain the data.

### ***What is Grounded Theory?***

Grounded theory is a theory and a methodology (Glazer & Strauss, 1967). As a theory, it draws upon the ideas of Symbolist Interactionism, which were developed by Blumer (e.g. Blumer, 1969) in the field of sociology in the 1960s. Symbolist Interactionism suggests that people co-construct the meaning of things (e.g. objects, societies, other people) via their social interactions with others. People individually then have a process of interpretation which modifies their understanding of the meaning of things;

and the unique meanings of things to a person are the reason that the person carries out any action (Blumer,1969). This is in contrast to other theories such as Behaviourism (e.g. Skinner, 1966) at the time, which discounted the role of meaning in people's behaviour. Grounded Theory, then, takes as a given the idea that there are both idiosyncratic and group understandings of phenomena which need to be drawn upon in order to make sense of a phenomenon such as people's behaviour in certain circumstances. This leads to the idea that theory needs to be 'grounded' in the meanings which are co-constructed between the participant, their wider context and the researcher.

As a method, Grounded Theory is concerned with enabling such grounding to take place, via a recursive process where data are collected and analyzed. Attention is paid to the development of theory which explains the data, and emerging theory is tested via selectively collecting and analyzing further data. This continues, with the emphasis being upon the data and its emerging meaning and theory explaining it, rather than the researcher's pre-existing theoretical framework (Charmaz, 2006). Ultimately, the aim of this methodology is to produce a theory which explains the phenomena in question and is also grounded in the data about it, a grounded theory.

Analysis in Grounded Theory involves the coding of data. Coding is the description or labeling of some of the data. Codes can be at the simplest level of description, or can be more conceptual (relating to categories of meanings) or ultimately theoretical. The theoretical codes are combined to

create the Grounded Theory (Charmaz, 2006). Incomplete theory, which begins to emerge from the coding of one piece of data, for example an interview with a participant, is used to guide the selection of the next piece of data, which is then analyzed. This process is called “theoretical sampling” and continues until a point at which it is thought by the researcher that no further new, relevant categorical codes are likely to be added by the collection of further data (Charmaz, 2006).

When analysis takes place, codes (of all kinds) are compared within one piece of data but also between different pieces of data. This is called the ‘constant comparative method’, and is aimed at developing categories and theory that explains all of the existing data, and focusing the researcher upon the data rather than their pre-existing notions (Glazer & Strauss, 1967). Ultimately, the grounded theory that emerges can then be compared with existing theoretical concepts, to establish how the new theory contributes to the existing theories.

The development of theory takes place alongside the analysis of data, and is supported by the use of memo writing, where researchers document their emerging ideas about the data. This supports the development of categories, the relationship between them, and also any gaps in the thinking which leads to theory (Charmaz, 2006).

#### ***Justification for the use of Grounded Theory in this study***

Grounded Theory has been thought to be useful in areas where there is little research and where the research is less defined (Henwood & Pidgeon, 1992). As there are few studies of practitioners with lived experience, and

fewer still looking at service users' experiences, the approach seems well matched to the topic. The development of theoretical understandings of how service users think about practitioners with lived experience was thought to be more useful for the development of guidelines for practitioners, and new avenues for research, than a research paradigm which produces a more descriptive analysis, such as Interpretative Phenomenological Analysis (IPA).

IPA focuses upon the meaning that individual participants make of their world, and emphasizes the researcher's interpretation of the participants' experiences and their intended meanings (Smith, Flowers & Larkin 2009). The focus on the individual's experience means that it is more difficult to develop conceptual understandings of how a group of people, such as service users, make sense of phenomena. The importance of the researcher's interpretation means that there may be a greater power difference between the researcher and participant than in the co-produced meanings produced by using Grounded Theory. The focus is upon describing meaning rather than developing a theory explaining the phenomenon being examined, which is the aim of the current study.

Another approach, Thematic Analysis, seeks for patterns of meaning in the data, either according to pre-conceived frameworks, or as they emerge from the analysis, with less of an emphasis upon the individual than in IPA (Braun & Clarke, 2006). This would be helpful for the current study, however

similarly to IPA, Thematic Analysis does not have a stated aim of developing theory to explain the data, which is an aim of this study.

***Rationale for using Charmaz's constructionist version of Grounded Theory***

Charmaz (2000) describes how the originators of Grounded Theory, Glaser and Strauss (e.g. Glaser & Strauss, 1967) diverged in their conception of the method. Glaser's conception remained focused upon the emergence of theory from the data, but Strauss developed the method to include more ways of verifying the developed theory and to become more systematic. Grounded Theory drew upon Symbolist Interactionism, as described above. As understood by Glaser and Strauss (1967), the role of a researcher using Grounded Theory was to discover the meanings that participants had constructed, with others, about the world, which led to their behaviour. The notion was essentially positivist, assuming that there were facts (namely the participants' understandings of the world that they had created) that could be discovered by the researcher. More recently, post-modern theories such as social constructionism challenge the neutrality of the researcher, suggesting instead that both the researcher and the participant are constructing together an understanding of reality that did not fully exist before the researcher began to enquire about it, and therefore is not discovered but constructed (Charmaz 2006). It is therefore possible that using a research paradigm which posits the participant as a co-creator of understanding, rather than the subject of enquiry, could reduce the power difference which has historically existed between researchers or practitioners, and service users. Using this form of Grounded Theory allows the consideration of how the researcher's professional and personal identity

impacts upon the study, which was particularly relevant in this study in which the researcher herself was a trainee practitioner with lived experience of depression.

### ***Sensitizing concepts and the literature review***

Another, practical issue leading to the adoption of a social constructionist version of Grounded Theory for this subject, is the literature review. One contested issue within Grounded Theory has been the role of prior knowledge of the subject of enquiry. Early versions of Grounded Theory, (e.g. Glaser & Strauss, 1967) make it clear that, in order to minimize the imposition of ideas which are not grounded in the data, the analysis and development of a grounded theory should take place before a literature review of the topic under study takes place. This is a difficulty for researchers constrained by regulatory requirements to show a literature review has taken place. Charmaz (2006, p166) has a flexible approach, suggesting that in this case the researcher should allow the review to 'lie fallow' in their mind until the theory has developed. Others such as Ramalho, Adams, Huggard and Hoare (2015), suggest that the literature review, used reflexively can feed into the development of sensitizing concepts which researchers use to initially order their data. In this study the researcher documented her sensitizing concepts, discussed in the Research Quality section below, and also attempted to allow the review to 'lie fallow' by not referring to it, between its initial completion in September 2015, and the completion of the analysis section in May 2016.

## **Materials**

### ***The interview schedule***

In keeping with a qualitative approach, the aim of the research interview was to draw out participants' experiences of and beliefs about the topic in question, rather than to compare the responses of participants to identical questions (Barker et al., 2002). Thus, an interview schedule, rather than a semi-structured questionnaire was developed. It is thought (Willig, 2008) that matching questions to the participant's language and interests will increase rapport and enhance participant confidence. However, full questions were written out rather than just relying on a topic list. This acted as an anchor, giving the researcher something to read from, if the interview did not naturally give opportunities to fit the participant's language and interests to the topics (Charmaz, 2006). In order to promote full and rich answers, open ended questions were developed.

According to Wilkinson, Joffe and Yardley (2004), social desirability bias in answers is increased when participants access 'rational pathways of thought' (p43, Wilkinson et al., 2004), which are typically triggered by questions starting with 'why'. In order to decrease this, participants were encouraged to experience the feelings and mental images they held about the topic with prompts such as "What would go through your head, what images would you have". The interview started with easy to answer demographic questions before moving onto more sensitive topics such as the participants' most recent experiences with NHS mental health staff in order to allow a rapport to be built.

The interview schedule was developed and critiqued by an interested service user consultant. They suggested changes to the language, making the questions more accessible, and also suggested decreasing the number and length of questions. Table 3 below shows details of changes that were made.

*Table 3. Changes made to interview schedule following critique by service user consultant*

Initial interview schedule	Changed Version	Rationale
Q5 Please tell me about how you would feel about knowing that one of the previously discussed mental health practitioners who worked with you, had themselves had difficulties or other issues with their mental health?	Q5. What would you feel if you knew that one of these mental health staff had at some point experienced mental health difficulties themselves?	Made shorter and easier to understand
Q6a Have any of the previously discussed mental health practitioners you have told me about experienced difficulties with their own mental health (at any point)?  Q6b If no - Can you tell me about how you came to the conclusion that [the mental health staff member previously mentioned] had not had any difficulties with their own mental health	Removed Q6b	Felt question to be a direct challenge to the participant's conclusions which may have led them to feel uncomfortable.

### ***Piloting the interview schedule***

The interview schedule was piloted with a male adult volunteer who had used NHS mental health services in the last 5 years, in line with the study's



inclusion criteria. The pilot interview was carried out to see whether it was possible to ask all of the chosen questions within the time available, and to gather feedback on the comprehensibility of the questions. Following the pilot, some questions which did not relate directly to the topic of NHS mental health staff with lived experience were removed. These were:

*Q2. Were there any staff who you felt did a particularly good job?*

*If yes- I'd be interested to hear what you noticed about them*

*Q3. What about staff who you didn't feel were so good - were there any?*

*If yes - What did you notice about them?*

*Q4. Is there anything else that we haven't talked about, that you value in mental health staff?*

Changes were made to the wording to add clarity, for example, the phrase 'mental health staff who had themselves experienced difficulties with their mental health' was replaced with 'mental health staff with lived experience of mental health difficulties'.

#### ***Changes to the interview schedule as the study progressed***

As the researcher developed ideas about the key study topics, new topics were introduced into the interview schedule, in keeping with Grounded

Theory ideas of testing tentative hypotheses by gathering new data (Charmaz 2006).

Interview questions were introduced regarding:

- Participants' motivations for their membership of the service user group.
- Whether the practitioners' specific type of mental health difficulty made a difference to the participant's conclusions, and why.
- Whether the similarity of the participant's and the mental health staff member's lived experience was important to the participant, and why.

The final interview schedule is available in Appendix 1.

## **Procedure**

### ***Sampling and recruitment***

Participants were sampled in line with the Grounded Theory approach, which facilitates the exploration of hypotheses which emerge from the initial interviews by theoretically sampling interviewees and developing and changing the questions asked of them. Participants and potential participants who had not been interviewed were offered the opportunity to give feedback on an initial draft of the results.

One phase of recruitment, was followed by three phases of interviewing. This led to a second, purposive phase of recruitment, which was followed by another three phases of interviewing.

### ***Recruitment procedures***

Participants were recruited from mental health service user groups, rather than directly from NHS trusts. This allowed for service users who have recently received services from NHS trusts, but did not do so at the time of the study, to take part, which meant a wider population could be reached. Because the researcher had limited resources, recruitment from an NHS trust would have resulted in only one or two NHS trusts being recruited from; but as people from a range of different trusts access service user groups, recruiting this way meant that participants from a range of different mental health trusts could be accessed, with the aim of increasing the generalisability of the findings. To further widen the population approached, a snowballing method was also attempted and is described below. Recruiting from service user groups was also thought to minimise the possibility that service users will feel that taking part in the study is linked in some way to the care they receive.

In the initial phase, six mental health service user groups were approached and three agreed to be involved in the study; in the second phase of recruitment four service user groups aimed at voice-hearers were approached and two agreed to be involved.

#### *Face to face recruitment*

In four out of the total of five service user groups, recruitment consisted of the researcher attending and giving a short talk about the research at a service user group meeting (Appendix 5.2). Following the talk the researcher discussed the study with any interested individuals and distributed flyers with brief study information and the researcher's contact

details (Appendix 5.3) One of the two service user groups aimed at voice-hearers did not consent to a talk being given, and recruitment was only via the emailed newsletter.

#### *Recruitment via email*

In all five service user groups, recruitment also took place via a brief article in the group's weekly emailed newsletter (Appendix 5.1). A website ([www.mentalhealthexperience.jimdo.com](http://www.mentalhealthexperience.jimdo.com)) was also made available, containing details of the study, including participant information sheets. These non-contact methods of recruitment allowed the study to be made known to people who were unlikely to attend SU groups in person, e.g. those with a lower level of commitment, and/or those with reduced mobility.

#### *Snowballing recruitment*

Potential participants were asked if they would mention the study to any people they knew that they thought fitted eligibility criteria and who might be interested, and flyers were made available for anyone who wanted them. This use of the snowballing method (Goodman, 1961) was to allow the recruitment of participants other than service user group members. However no additional participants made contact with the researcher as a result.

#### ***Screening process***

Potential participants who self-selected either by giving their contact details to the researcher in person or by emailing or phoning the researcher, were telephoned and screened for eligibility. In order for the researcher to be able to sample theoretically from the database of screened potential participants, the researcher also took demographic and study-relevant details such as

experiences of mental health staff with lived experiences disclosing to them, residential mental health care and types of mental health difficulties. Following the telephone call, potential participants were also sent a copy of the participant information sheet (Appendix 2).

### ***Phases of recruitment and interviewing***

#### *Recruitment phase 1*

Recruitment at three service user groups and telephone screening resulted in 16 people giving consent to be contacted for screening. 12 people were available for a screening telephone call and all were eligible and added to the research database.

#### *Interviewing Phase 1*

An initial participant was chosen from the database and interviewed. Following initial analysis and memo-writing, amendments were made to the interview schedule to involve questions exploring a possible category (“severity of client’s own difficulties affecting how practitioners are seen”).

#### *Interviewing Phase 2*

Two participants were theoretically sampled from the research database to further explore the category “severity of client’s own difficulties affecting how practitioners are seen”. Following interview and initial analysis and memo writing, a tentative category to be investigated was established (“effects of age”).

### *Interviewing Phase 3*

Two participants were theoretically sampled from the research database to further explore the category “effects of age” (their ages were in a range that had not yet been covered by the previous three participants.) Following the initial analyses of these and comparison with previous interviews, direct questions about an emerging category, “staff with different diagnoses being perceived differently” led to the development of direct questions about this issue being included in the interview schedule.

### *Recruitment Phase 2 – purposive recruitment*

New potential participants who may themselves have had the types of mental health problems that were seen as being unfavourable in mental health staff, such as psychosis, were recruited from two voice-hearing service user groups. Three people consented to be contacted for screening, were screened and were added to the research database.

### *Interviewing phase 4*

Two participants who attended voice-hearing service user groups were theoretically sampled from the research database to further explore the category “types of mental health problems unfavourable in mental health staff”.

### *Interviewing phase 5*

A category “upbringing influencing views on mental health staff with lived experience” had emerged during the analysis and focused coding of the

previous interviews. This led to the theoretical sampling of a participant (from the initial phase of recruitment) who was not European to add further depth to this category.

#### *Feedback phase*

Following analysis, an initial draft of theory in the form of a flowchart (Appendix 10) was circulated to participants (n=8) and service user consultants (n=6). Their verbal and written feedback was analyzed and incorporated into the final analysis.

#### ***Recruitment of consultants***

Potential participants were invited, at the screening stage, to offer feedback on a draft of the study results, as consultants, independently of their potential role as participants in the study. Consultant details are available in Appendix 6.

#### ***Interview procedure***

Participants were interviewed by the researcher in the following community locations: an office in the building where their service user group met; an office in a public library local to the participant, and two offices in the researcher's university in central London.

In line with guidance from Involve (2012), a £10 payment was offered to participants as a token recognition of the value of their time and input, and because it is thought that payment serves to reduce the power differential between researcher and interviewee. The payment of £10 was determined,

on the basis that it was a large enough amount to be meaningful, or at least not insultingly small, but not large enough to disproportionately encourage people to take part (or cause disappointment if a person was not invited to be interviewed).

Again in line with guidance from Involve (2012), travel expenses were offered to participants so that they were not at a financial disadvantage by taking part in the study.

Participants gave written consent before the interview began, and again following the interview, reconfirming that they were happy for their interview to be used. The interviews were recorded on a digital recorder and the recordings transferred to an encrypted memory key. Following transcription of the recordings, they were destroyed. The transcriptions were edited to remove identifying details of the participants and any other individuals or institutions that they mentioned, such as names, locations, nationalities etc.

## **Data Analysis**

### ***Initial coding***

Transcribed interviews were coded on a line by line basis, describing what is happening in the transcript, using the noun form of a verb (the gerund), e.g. "Considering increased empathy". Such descriptive in Grounded Theory aims to focus the researcher's attention upon what is happening in the data, as opposed to using codes which reflect the researcher's preconceived notions (Glazer and Strauss, 1967) The use of verbs is also thought by Charmaz (2006) to increase the likelihood of codes being conceptualized as active or dynamic parts of a theory, rather than static descriptions. Where



participants used language in a specific way to describe their experiences, 'in vivo' codes were created where the participant's language, rather than a code invented by the researcher, was used to demarcate units of sense.

### ***Focused coding***

As the open coding continued, the researcher noticed any emerging themes which resulted from synthesizing the open codes. This led to the development of slightly more abstract, conceptual codes, which could then be used to label larger sections of data, and also to label data in different places in the same interview, or in different interviews. These focused codes (Charmaz, 2006) were identified mostly by frequency of the open codes which could be described by them. The emphasis placed upon certain issues by participants (indicated by phrases such as 'the most important thing to me is') also was used to select focused codes.

### ***Memo keeping and continuous comparison***

Memos were kept from the beginning of the data analysis, in order to develop theoretical ideas about the data. They chronicled ideas about what was being suggested by the data. The memos led to open codes developing into focused coding. The memos were used to compare categories and make sense of them they allowed for the drawing together of possible ways in which the focused codes could work dynamically with each other to create an active theory. (Appendix 9).

### ***Development of theory***

Utilizing the ideas in the memos, focused codes were organized into tentative analytic categories (and sub-categories), which were more

dynamic and explanatory of the way in which ideas interacted in the data. These explanations were then made explicit and the existing open and focused codes, as well as the interview texts themselves, were examined in the light of these theoretical ideas. Ideas were abandoned when they were not supported by the data, and new ideas generated using an iterative process.

### ***Using diagrams***

Diagrams were used to develop an understanding of the way that certain ideas in the data inter-reacted. Ultimately, these led to the development of tentative, abstracted understandings of the data, and the final stage of theoretical coding took place. This coding was then used to develop a practical flow chart diagram of the theory, which was then shared with participants and consultants. Feedback from this was analyzed using the techniques outlined above. This feedback resulted in changes being made to theoretical categories (such as the development of a new category 'Being stable and recovered') and new theory being generated which explained both the feedback and the earlier data.

### ***Saturation***

Following the development of theory as described above, and by the means of constantly comparing data within and between interviews, codes and categories, the researcher came to a point where it appeared that 'theoretical sufficiency', had been reached. This was a point at which the categories which had been created were sufficiently supported or grounded

in the data to support the theoretical understanding of them. This concept comes from Dey (1999), in Charmaz, (2006).

### **Service user involvement**

Service users were consulted at the proposal stage, with regard to:

- Relevance of the topic area as a concern.
- Ease of accessing local service user groups.
- The anecdotal likelihood of finding research participants with personal experience of mental health practitioners with lived experience.

This resulted in the study proceeding as it was seen to be relevant and feasible, taking into account 'insider knowledge'.

At the planning stage, service users were consulted about:

- Interview length – resulting in the shorter one hour interview as opposed to one and a half hours as initially proposed by the researcher.
- Research interview process – resulting in refreshments being offered to the participants.
- Information being given before interview – resulting in participants being told that the interview process overall would take 1.5 hours (to take into account the consent process and payment of £10 and travel expenses) even though the interview itself was to last only up to an hour.

Service user feedback was sought in the development of study materials. As a consequence:

- The interview schedule was shortened and three questions of lesser relevance to the study removed.
- The information sheet was shortened from three to two pages in length, removing all but the most essential information and the language simplified, allowing for greater accessibility.
- The flyers were changed to make them appear more attractive visually, and the text was simplified.

At the recruitment stage, service user feedback following the researcher's initial recruitment talk resulted in changes to future talks such as:

- A greater focus on the possible benefits of the study for service users.
- Shorter sentences.
- More time for questions.
- Less academic background and more personal reflection.

Following data analysis, participants and consultants were invited to feed back on the initial results draft. This resulted in changes to the theory and coding structure.

### **Quality Standards**

The analysis was conducted in line with quality standards suggested by Mays & Pope (2000), Elliott, Fischer and Rennie, (1999), and Charmaz (2005, 2006). Validation and triangulation methods were incorporated into the design of the study to allow for independent verification of the categories

and the emerging theory.

- A section of the initial coding table and emerging themes was read by the research supervisor, allowing for an independent assessment of credibility and resonance, in keeping with Charmaz (2005).
- Validation was also carried out by checking the coding of an interview transcript and resulting themes with a clinical psychologist familiar with Grounded Theory (Madill, Jordan & Shirley, 2000).
- Drafts of initial models and theory were discussed with the research supervisor, and trainee clinical psychologists also working in Grounded Theory, again to allow for assessment of credibility.
- An initial draft of the results was created in the form of a flowchart and circulated to participants and other potential participants; their feedback also allowed for an assessment of resonance and usefulness.
- The results were compared with some preliminary findings of a large-scale survey of mental health practitioners and clients (Lovell, 2016) where questions were asked regarding attitudes towards practitioners with lived experiences, as a form of triangulation.
- Transparency of analysis was promoted by the researcher keeping detailed memos describing how simple data developed into codes, how these developed into themes, and how themes developed into theory explaining the data.
- Consideration was given to deviant case analysis throughout the analysis, in order to create theories that explained all not just some of the data.

- Possible biases were identified by the researcher reflexively considering how her identity and life experiences, as well as the research methods themselves, could have impacted upon the interpretation of the interviews.
- Reflexivity was supported by the researcher keeping a reflective journal and discussing interpretations in research and peer supervisions.
- Bias was also avoided by making sure that a wide range of perspectives were reported upon in the analysis.

### ***Reflexivity in co-creating meaning***

One key aspect of social constructionist grounded theory is the position of the researcher as a co-creator of meaning along with the participant. Thus, the researcher needs to be able to assess their impact upon the participants and the data. To achieve this, Charmaz (2006) and Ramalho et al. (2015) emphasize the need for the researcher to work reflexively, that is, to think critically about themselves, and how their experiences, knowledge and worldview interact with the participants and the data. In order to promote reflexivity throughout the study, the researcher kept a reflective journal, (as recommended by Charmaz, 2006, and other GT theorists), in which she was able to think about how her world views and experiences influenced her responses to the data. See Appendix 11 for extracts from reflective journal. She also reflected upon the developing theory with her supervisor and with

her peers, both trainee and practicing therapists, some themselves with lived experience of mental health issues.

### ***The researcher's position***

In the current study, the researcher's educational background (a graduate involved in postgraduate study) and ethnic origins (White British), was similar to most of the research participants'. Similarly to some of the participants, the researcher had previously experienced depression and used NHS mental health services (accessing cognitive analytic therapy in her early 20s), and had not had the experience of receiving care from a mental health practitioner who disclosed that they themselves had lived experiences of mental health difficulties.

Unlike her research participants, as a trainee practitioner with lived experience, the topic was also personally relevant to her professional practice. The researcher chose to only disclose this to her clinical supervisors on placement where relevant, and not initially to her academic tutors, as she felt her experience of depression fifteen years ago had had no current impact upon her ability to study. Her previous research into stigma and discrimination from a client perspective also had alerted her to the possibilities of experiencing discrimination in her professional academic life, which also had informed her decision not to disclose.

She has a strong commitment to social justice and aligned herself to the aims of Community Psychology (e.g. Rappaport, 1987), which place the empowerment of those disadvantaged by existing power structures at the centre of decisions around the kinds of research to be undertaken.

### ***Sensitizing concepts***

The researcher's previous work researching stigma and discrimination experienced by mental health service users had sensitized her to concepts pertinent to the study. These concepts include issues of power in the NHS; the disability model of mental health, the recovery model and concepts relating to stigma and self-stigma. Carrying out the literature had also sensitized the researcher to the concepts such as the importance of the relationship between the disclosing practitioner and the client, and the possibility of hope as an outcome of disclosure.

### **Ethical Approval**

Ethical approval was granted for the study, which included current and past National Health Service (NHS) Mental Health Service users, by the National Research Ethics Committee North West – Lancaster, on July 17<sup>th</sup> 2015 (see Appendix 4.1). Ethical approval was also granted by Royal Holloway University of London, on September 30<sup>th</sup> 2015 (see Appendix 4.2).

The main ethical considerations were to manage any distress experienced during or as a consequence of taking part in the interview, and to have in place a robust strategy for management of this distress and any risk related issues that came up during the course of the study. The researcher held discussions with the leaders of service user groups that took part in the study to establish a protocol for linking service users with appropriate NHS and voluntary support organizations, should they require further support following the interview. A 'sources of support' document was created (see Appendix 7) and was available to participants at interview.



Participants were also informed of limits to confidentiality if they disclosed any risk related information at any point in the interview process, at the beginning of the screening interview and also at the beginning of the research interview.

### **Chapter 3 – Results**

The analysis of the transcripts is presented below, using extracts from the transcripts to illustrate the themes.

#### ***Summary of results***

Analysis of the data has resulted in five theoretical codes. These are presented in Table 4 below. They are composed of fifteen focused codes, which themselves are made up of a number of specific properties which were developed initially during early coding stages.

The interrelations between the theoretical codes and their properties are shown in a diagrammatic model at the end of the chapter. This organizes the interrelating focused codes into four stages: factors important before or regardless of practitioner disclosure; factors important when considering disclosure; factors important when disclosing and factors important following disclosure.

Table 4. Theoretical Codes, focused codes and their properties

<b>Theoretical Code</b>	<b>Focused codes</b>	<b>Properties of the codes</b>
Having relevant lived experience	1. Experiencing increased empathy in relationship with practitioner	Experience leading to understanding
		Expecting practitioner with lived experience to feel more empathetic towards service user
		Feeling empathy towards practitioner
		Increased trust
	2. Being similar to service user's lived experience	Relating to service user's current issues
		Similar diagnosis to practitioner important
		Similar emotions and behaviour
		Similar circumstances
		Not being the only one
	3. Helpful information from relevant lived experience	Hope to similarly achieve
		Hope that practitioner can offer helpful insights based on lived experience.
	4. Lived experience causing barriers to relationship	Need to be treated as an individual
		Practitioners with lived experience might over-identify
Practitioners having difficult feelings		
Experience of stigma may inhibit practitioner help seeking and disclosure		
Being a competent mental health practitioner	5. Needing to be trained	Training to overcome barriers caused by lived experience
		Appreciate practitioner being good at their job
	6. Forming a helpful relationship	Needing to respect practitioner
		Being treated as a human

	7. Avoiding role reversal	Roles reversing when practitioner becomes mentally unwell
		Roles reversing when focus of session moves to practitioner's concerns
Being stable and recovered	8. Perceiving practitioner's difficulties	Not wanting to be able to perceive practitioner's difficulties
		Worried by not being able to perceive practitioner's potential difficulties
		Not wanting practitioner to be irrational
		Wanting practitioner to self-manage difficulties
	9. Getting better versus having to live with it	Moving from a physical health viewpoint to a mental health viewpoint
		Depression can be lived with
		Being hopeful is affected by viewpoint on getting better or living with it
		Supportive working practices
Being influenced by the NHS context	10. Role of the NHS in supporting practitioners with lived experience	Support wellbeing with good working practices
		Making sure practitioners are well enough to work
	11. Role of the NHS in ensuring continuity of care	Continuity of care affects formation of relationships with practitioners
		12. Disclosure and practitioners role affect each other

Being influenced by mental health stigma	13. Worrying about practitioner being discriminated against	Disclosure harming career
		Other service users may be malicious
		Keeping practitioner's lived experience confidential
	14. Seeing lived experience as a shameful weakness	Mental health issues are a weakness
		Practitioners need to be strong
		Shamefulness of lived experience
		Vulnerability when unwell
	15. Associating mental health issues with violence and unpredictability	Not wanting people with severe difficulties to become practitioners
		Not believing in causal relationship
		Not wanting to hear about frightening experiences

**Theoretical code 1: “Having relevant lived experience.”**

***Experiencing increased empathy in relationship with practitioner***

An important consideration for participants was the shared nature of the practitioner’s, and the service user’s, lived experience. They felt that a practitioner’s similar experiences would lead to increased empathy and an enhanced ability to understand the service user’s feelings. This understanding could exist without the service user knowing about the practitioner’s lived experience, and so was relevant before and after disclosure:

*Participant 3: That’s it, that’s the key. That’s the centre of everything for me, yeah, do they get it?*

This understanding is also conceptualized as empathy, which was seen as a valuable quality in the practitioner:

*Interviewer: ...Could you tell me a bit more about how it could be positive?*

*Participant 1: Well, there would be, you’d feel there’d be a natural empathy, really”*

Participants expected to feel more empathetic towards practitioners following disclosures of similar lived experiences:

*Participant 6: I think I'd be able to empathize with them more.*

Other participants described a feeling of being glad for the practitioner, and hope for themselves, following disclosure of lived experience because of the similarity between them and the practitioner:

*Participant 4: My initial instinct is "Wow, that person's done it". That gives me hope I can do it. I perceive ...someone who's come from a similar position as my own, their success, as something extremely positive... It's like an empathetic kind of, "Yeah I get it now." Yeah. "Well done dude, or girl", yeah.*

More than half of the participants believed it would be possible to trust the practitioner more, following a disclosure of lived experience. This can be, as in the quote above, because the participant is more confident that their experiences will be better understood by the practitioner. However, participants also talked about trust being a kind of transaction. They thought that being disclosed to, demonstrates the practitioner's trust in them:

*Participant 8: So if someone shared that [lived experience] with me ...I would be humbled if they trust me to share that with me.*

Being trusted in this way seemed to lead to the client trusting the practitioner:

*Participant 7: And also, if she...if she trusts me enough to be able to say, "yep, I have a mental health problem" that feels to me already like...she's put a bit of trust in me so I'm happy to return the favour*

Over half of the participants thought that the similarity in a service user and practitioner's lived experiences would lead to a decrease in the sense of isolation with their difficulties:

*Participant 2: The way I see it, you're not alone! ... you're not alone... You're not the only person.*

***Being similar to the service user's lived experience***

When thinking about whether they would want a practitioner to disclose their lived experience to them, participants talked about the importance of the lived experience being relevant to them (focused code 2: "Being similar to service user's lived experience"):

*Interviewer: Are there any other things that you'd want them to take in to consideration about you when they're making that decision?*

*Participant 4: Just, only really is it relevant to me, how would it affect me. Is it relevant and will it be beneficial? I think those are the only, for me those are the only two real factors.*



Participants wanted to hear about a lived experience if it was relevant to something they were discussing or dealing with at the time:

*Participant 7: ... I think it depends on who they tell, how much, and ...I...I don't want to know what [is] irrelevant in the session.*

One important aspect of relevance described was a close similarity between the practitioner and service users' mental health diagnosis:

*Participant 5: I think it would need to be the same diagnosis as me. I don't feel I would find it helpful meeting someone with schizophrenia who controls it with medication and functions 99% of the time perfectly fine and has a degree and has done the career and everything. I would still be thinking well this doesn't really help me because... this isn't the issues that I face. So if someone really did have the issues, not I mean you can't have an exact match, but a closer match.*

Another type of relevance was similarity of the practitioner and service user's experience of strong emotional states, such as feeling suicidal:

*Participant 1: ....if the user was feeling down and suicidal ... it might be helpful because he, the practitioner could say, I do know where you're coming from...I have been this deep myself before.*

Participants alluded to similarity of experience regarding practical issues associated with having mental health difficulties:

*Participant 6: ...had there been someone that's actually experienced homelessness and mental health difficulties then I would have trusted that person to help me work through that because if someone had experienced this then they can stop me falling through the net or stop me kind of getting worse...*

Similar experiences of discrimination or stigma were also thought to be relevant:

*Participant 7: .. my counsellor at [name of charity] has [lived experience].. It's easier to trust, because she knows...what it's like to be on the wrong side...of mental health services...and the wrong side of society, really.*

### ***Helpful information from relevant lived experience***

Many participants thought that practitioner's specific relevant lived experience of overcoming a similar difficulty could be a helpful thing to disclose, as it would give service users information about how to manage or overcome the difficulty:

*Participant 6: [it would be] helpful if they can understand "Right I've had this experience and this happened to me and I did this and then I recovered from it." ...And then through that experience they would*

*therefore filter back to the person, like “Well I suggest that you do this and do that and follow this pathway or this process or this theory ...and then you’ll recover from it”.*

However, two participants felt that there is not a guarantee that this will be helpful for the client, as even with shared experiences, people still are different:

*Participant 1: Er, that is, it, bothers – despite all the similarities, they say there are - even with two people with bipolar there are so many differences*

Another participant was concerned that they would be perceived unfavourably if they did not take the advice offered as a result of lived experience:

*Participant 5: So again though I suppose there’s that danger that if someone said “This is what worked for me”, if you reject that there’s also a fear that you’re not trying. There’s always this “You’re not trying hard enough to fix yourself and work on yourself”.*

### ***Lived experience causing barriers to relationship***

Participants also explored the ways in which relevant lived experience might create a barrier to the relationship with the practitioner.

One concern was that practitioners would over-identify with the client's experience:

*Participant 3: ...they would bring their own experiences too much to the table ... they might make, they might fill in a gap or two...they might not be getting ... an entirely true picture of the subtlety potentially of what you're...of what you're expressing...that's working in exactly the same kind of area*

Another concern, which links to concerns about the practitioner's level of recovery (discussed in focused code: perceiving practitioner's difficulties), is that the practitioner might experience a triggering of feelings which were caused by the shared lived experience, when they are talking about the experience, which would affect the relationship:

*Participant 6: If I've experienced quite bad abuse or trauma, right, that I'm trying to work through and I'm trying to work with someone who's also experienced that...talking through stuff, it might be difficult because if the [other] person starts experiencing the same feelings then it would be difficult to detach from them.*

Lived experience may also mean that a practitioner has been exposed to and internalized stigma, meaning that they find it difficult to find help, leading to difficulties in working through their issues (which is discussed in theoretical code 3: "Being stable and recovered"), and also difficulties in disclosing at all:

*Participant 7: [practitioners with lived experience] live in the same society we live in, and one is always made to feel bad and inferior and some things when someone has mental health problems, and so... they would be... exposed to the same nonsense... [so]...they can't normally just drop "oh I've got mental health problems" and they can't just think "oh cool". ...I think that's when you get the therapist getting really defensive, if you accidentally touch a button, and then there's "help I've got feelings—oh what?"*

## **Theoretical Code 2: "Being a professional mental health practitioner"**

### ***Needing to be trained***

The majority of participants (7/8) made the point that they required their practitioner to be competent in their role as a result of training:

*Participant 4: Personally I'm not opposed to...[a practitioner with lived experience]... as long as the person is well trained and stable.*

Participants felt that training would allow the practitioner to overcome difficulties arising from having relevant lived experience. Referring to the possibility that a practitioner might over-identify, a participant said :

*Participant 3: I'm not saying that would happen...because hopefully that would be trained out of somebody...*

Referring to the situation where practitioners had experienced difficult and similar experiences to the service user, a participant said they would want to know that the practitioner had been trained to deal with that situation:

*Participant 6: If I'd experienced trauma and then I'm working with someone who's working through trauma or abuse.... I'd want to know if they've experienced that as well, and also if they'd had specific training to work through that because if they've experienced it and then had training then it would help*

Participants also cared about whether the practitioner was good at their job, and attributed this to training or study (the participant below used the word 'research' for study):

*Participant 8: Yeah, and they know, like why I was happy with my therapist because she had a word, the right word for everything that I said to her. So that I believe it's along [because of] research. ..So if you do a lot of research you always help*

Participants felt that the personality of the therapist was important in their ability to do their job well:

*Participant 8: I believe the personality of the therapist helps a lot...*

Others thought that personal factors in the practitioner were also associated with their ability to be good at their job. A key factor was a non-judgmental attitude. This was associated with having lived experience in general as

opposed to shared lived experience with the client:, and contrasted with expertise gained from study:

*Participant 7: I want someone [as a practitioner] who's actually been down in the dirt, not in a nasty way, someone whose lived and not going to sit there and judge me according to some stupid textbook where people probably don't even know what they're writing...*

*Interviewer: it doesn't have to be the same [experience as you] ?*

*Participant 7: I just want them to have had a life*

### **Forming a helpful relationship**

Participant's views about a practitioner disclosing were in some cases, reliant on their views of the practitioner:

*Participant 3: if I thought the person was amazing...then it would take... an awful lot to change my mind on them... if someone that I had taken to and respected hugely .. confronted with, knowledge of something quite extreme, I possibly wouldn't... find it necessarily a problem....*

They also thought that practitioners shouldn't disclose unless the client respected them:

*Participant 7: if they know that the client wouldn't respect them ... there's no, no benefit to be had... [in disclosing]*

Participants valued being treated as a person by practitioners, whether or not they had lived experience, and gave examples where they felt like they had been treated that way:

*Participant 2: Well I don't want to be taken like a special case when I walk in, as well, I don't like that, it wasn't like with [therapist name], I was treated as a person. Because I'd walk in and go "How you doing this morning [therapist name]?". He goes: "I'm alright "...It's normal, you know.*

Many participants also assumed that a service user, knowing that a practitioner had lived experience, would see the practitioner as more "human" as a consequence:

*Participant 7: In my heart it makes a huge difference...if somebody's in a position of power it [having lived experience] makes them a bit less ... dubious ...and [makes them] trustworthy and normal and human*

One aspect of a practitioner being 'human' was being friendly and having a sense of humour:

*Interviewer: Was there anything else that made you think that he had himself experienced things?*



*Participant 1: Well that he was very friendly, , he had a sense of humour as well ....*

Others felt that using humour would be a helpful way for a practitioner to make the disclosure of their lived experience easier for the client to manage:

*Participant 4: I kind of like the kind of slightly jovial approach.... just yeah making it [the disclosure] light so it's easy to take onboard so it's taken with a little bit of a chuckle, a little bit of laughter rather than, "I'm your doctor. I have bipolar. I am stable."*

It was also felt that a practitioner being more friendly or informal would lead to better outcomes for the client:

*Participant 1: I think ...if you're too er...straightjacketed, as a, as a...professional...Then...the help you can give ..... the achievements you might make over any longish period of time ...are likely to be...not of any substance or depth*

It was also thought important that the helping relationship had been given time to develop before a disclosure was made:

*Participant 3: I certainly wouldn't take to the issue as well, as if I'd had some sessions already and already felt... Yeah ..you know, respectful of them*

### ***Avoiding role reversal***

While participants welcomed being treated as a person, as part of their good working relationship with the practitioner, they were very clear that they did not want to be in a situation where their role in relation to the mental health practitioner's role became confused or reversed. This is described in the focused code 7: "Avoiding role reversal". Role reversal describes situations where the client appears to be providing support or therapy for the practitioner.

The two main situations where role reversal was thought to occur were i), where the practitioner began to have symptoms of their mental health issue to the point that the client would need to support them or take action, and ii) during or following disclosure, if the focus of the session with the practitioner moved from dealing with the client's experiences to talking about the practitioner's lived experiences, either current or in the past. Participants described that if they were aware of their practitioners becoming symptomatic in the session they would feel that they needed to try and help them, thus reversing the roles of client and practitioner:

*Participant 3: If they were ...very much appearing to be in a depressive episode, then that...makes the roles a bit uncomfortable...particularly as I feel a great deal of empathy...because I think I'd just try and, help them, and then that muddles the roles a bit, and I'd worry more about their state of mind.*

Participant worry that they may not be believed, or will be thought to be malicious if they alert others to their practitioner's symptoms:

*Participant 7, written feedback: If I comment on my worker having problems that affect their work with me I get pathologised even more and become branded even more difficult and get treated worse. I've tried that.*

Participants described the risk of the focus of the session turning to the lived experience of the practitioner. One felt that a practitioner who had disclosed to her, had done so more because of their own needs, rather than for the benefit of the service user:

*Participant 5: , It felt like she was having a bad day and needed to off-load and that's where she went. The pressure valve just let out and that's what came out of her mouth.*

Participants were concerned that role reversal would deprive them of things that they were entitled to, such as time spent on their concerns. A similar idea was expressed in the joke made by four participants, that if roles were reversed then they should be paid, with the implication that without being paid, role reversal was depriving them of something they should be receiving.

*Participant 2: ... if you're going to tell someone something without it being about him, then I'd say that, then I want some extra minutes to talk*

*Participant 7:... if I, I'm supposed then to cure her, then I would have an issue... I've had that kind of thing in the past.. and I'm sort of "why don't I get paid?" [laughs]*

### **Theoretical code 3 – Being stable and recovered**

#### ***Perceiving practitioner's difficulties***

Every participant mentioned that it is important that practitioners are well enough to practice without their difficulties impacting upon their clinical work. One participant described how a practitioner, who had not disclosed to her, appeared to have difficulties with her mental health, and that this was anxiety provoking:

*Participant 5: My perception of her, from the moment I met her, was that she was slightly unhinged...she was incredibly intense in her manner ... and as soon as I started to tell her something she would kind of pounce on something...I felt like her stress levels and anxiety must be really high and I kept thinking "Is she the best person to be helping people"...it made me anxious.*

The participant goes on to say that they also then faced a dilemma about whether to attempt to find support for the practitioner. This relates to the focused code 7: "Avoiding role reversal", discussed above:

*Participant 5: ...the real dilemma, should I say something to one of my staff like "Can you speak to her supervisor and see if she's okay because she doesn't seem okay to me".*

Most participants report they would be concerned about practitioners with disclosed lived experience showing apparent signs of mental health difficulties:

*Participant 1: Well [a practitioner having lived experience] ...might bother me if they were still, if they were actually displaying signs of ... mental health problems*

More than half of the participants differentiated between the practitioner being 'cured', and the practitioner managing or overcoming their symptoms in order to be able to function, suggesting that being able to function was all that they required of the practitioner:

*Participant 3: Well they don't need to truly get better, do they, they just need to be able to...function....I don't know that they'd even need to be wholly [recovered]...if I couldn't tell how they were doing then I would think it's fine*

Contrastingly two participants were concerned that following a disclosure of lived experience, they would have to rely upon the practitioner's reports of

how fit they are to practice. This meant that they worried practitioners were affected by their mental health issues but that they (the participants) might not know about it:

*Interviewer: What kind of feelings do you think it [disclosure] might bring up?*

*Participant 2: Well maybe solidarity...You know, solidarity to think well you know, it's like "Well if you've got to that place, and you're able to, you know, I mean you may tell me that but I don't know"...if they're still functioning with it – are they still dealing with it? I mean, who knows?*

One factor which may influence participants' fears in this area is the idea (mentioned by three participants) that practitioners work in mental health as a way of working through their own difficulties, meaning that a practitioner may have undisclosed issues:

*Participant 5: And he said also "why do you think anyone becomes a psychiatrist? It's because they haven't resolved issues in their past and they're trying to figure it out"...*

Participants implied that service users would not want the practitioner's work with them to be influenced by mental health issues, because firstly, they did not want to experience role reversal, as described above, and secondly they implied that the practitioner might therefore be irrational or unpredictable:

*Participant 4: I think I can understand why people might think to themselves: "Oh but are they stable? Is this person [practitioner] going to start, you know, doing a mad dance" as I might do, in the middle of the room for no apparent reason because their medication's worn off.*

Another participant focuses upon the effects of mental health symptoms upon the practitioner's ability to work, by making a comparison with a practitioner who can't do their job properly because they have a physical illness:

*Participant 7: I don't want to have to have anybody who is my therapist telling me about MI5 hunting them or so on... Yeah, and equally if somebody's got an absolutely horrible cold or whatever, I don't want to be with them, never mind about catching it, but I don't want to have to deal with a therapist who is almost out cold*

Participants were clear that they felt it was the responsibility of the practitioners, to maintain their own wellbeing. More than half made reference to this idea:

*Participant 4: I think that if the therapist does suffer from mental health problems then they should know they need to keep abreast of their issues.*

Some participants mentioned the idea that how they maintain their wellbeing would be helpful information for the practitioner to give to the client when they disclose:

*Participant 1: ...the practitioner making it clear that, you know, its, it is.. a struggle for them, and that still, but that they've managed to get on top of it with the help of medication and...and friends and family and all the rest of it*

### ***Getting better versus having to live with it***

When participants drew the distinction between 'getting better' and being able to function even though some symptoms remain, some participants suggested that this was related to seeing mental health in a similar way to physical health. One participant felt that there was a process, by which you initially expect mental health difficulties to be treatable in the same way as physical ones, but then cease to believe this to be possible:

*Participant 3: I think ... that when you do seek help for mental issues, that ... like anyone's physical issues, you want to get better. ... after a certain number of years... you start to understand that actually better isn't really the... state that you'll achieve.*

Similarly, another participant discussed how they had previously used their understanding of physical health issues as a framework to understanding the role of practitioners in mental health. This had led them to expect a certain level of expertise and for practitioners to have "all the answers",



which may imply a cure or treatability, or at least a thorough understanding of mental health issues:

*Participant 5, written feedback: I found that being an 'MH patient' I could only draw on experiences with GP or physical health consultants who are cast as specialists due to studying, not due to having had a broken arm that healed, for example. So being told you are 'ill' and, there was ... an expectation that practitioners should have all the answers based not on their own experiences, but because they have studied and treated others with the same illness as your own.*

The participant reported that it was upsetting when she heard practitioners make statements implying that the 'definite answers' she had expected from them were not available:

*Participant 5, written feedback: Being told by a psychiatrist that a lot of MH staff go into the field as a way of understanding their own issues was quite a shock as was being told by a psychotherapist that no-one has all the answers. It makes sense now, but at the time I felt disappointed and quite angry at such 'specialists' pulling back the Wizard of Oz curtain... getting me to see the real world at a time when I felt fragile and in need of definite answers.*

By saying "It makes sense now", the participant is also suggesting that there may be a process by which an initial understanding of mental health issues

in a medical framework gives way to a different position where they do not expect 'all the answers', and can also understand the role of lived experience in mental health care.

One aspect of the distinction between getting better and being able to function even though symptoms remain, was that different diagnoses were thought to have different likelihoods of either 'getting better' from or having to be 'lived with'. Nearly all participants mentioned that they thought depression was the kind of difficulty that had to be lived with, and that this was unproblematic:

*Participant 1: Yes. Erm, and...a lot of people would, even people who are actually, permanently depressed, can be perfectly alright, and erm, it's just that they happen to live in a very low key world*

*Participant 5: someone ... might have had a bout of depression 10 years ago, got treatment, worked through it, figured out how to get through and is now in a career path and occasionally gets the blues but knows how to deal with it...*

One participant contrasted depression as being something that they didn't think you would 'get better' from, with hoarding, which they still wished to get better from. They felt that they would not be able to get hope from a practitioner who had not 'got better' from hoarding:

*Participant 3: But depression I wouldn't...to me that's, that's you know, I don't think getting better from depression is, is potentially a likely thing...but hoarding, it's a bit more solid, yeah, exactly, precisely. It feels like it's a sort of more practical issue that one would hope that you would be able to conquer eventually.*

*Interviewer: I'm just picking up on hope there, because I'm just wondering, thinking that if you've got a therapist who's also still hoarding, I wonder how much hope that can give you*

*Participant 3: Well none at all which is why I stopped going to the self-help group to be honest, because of all the other people who haven't managed to overcome*

However, there is a possibility that if the client feels that the difficulty is one that can be lived with, a practitioner who discloses their lived experience can give hope that the client will similarly be able to manage their difficulties:

*Participant 2: So, you're like, hearing someone else, having gone through something similar, and then come out or found their peace or managed to navigate...or managed to level themselves and deal with it you know. It's...it gives you hope...It gives you hope, it gives you hope in feeling that, generally, I can generally overcome this and deal with it on my own. It's still there but I'm, you know relaxed, you know, it's in the back of your mind you know,*

It may be that clients are more receptive of practitioner's lived experience when they are not expecting to 'get better' but rather to live with the difficulty. An association may be being made between a more medically framed view of mental health (such as expectations of 'getting better') and the value of training rather than lived experience. This may mean that if clients expect to 'get better', they will not value lived experience as much as training. Secondly, the existence of a practitioner who is living with a difficulty that a client wishes to go away altogether ('get better' from) may remove the client's hope that it will ever "get better" for themselves. However, if their hope is to live and manage the difficulty, the embodiment of someone who has managed to do that successfully, in the person of their practitioner, gives hope.

#### **Theoretical Code 4 – Being influenced by the NHS context**

##### ***Role of the NHS in supporting practitioners with lived experience in their wellbeing***

One participant described how they felt it was important that practitioners with lived experience in the inpatient setting were supported in their wellbeing by being able to debrief, but felt there would be a risk of such support not being available because of staffing levels:

*Participant 5: ... whether or not there is adequate staff support for that. ...I think that would be the main thing... are they able to kind of debrief when times get bad ... from the stress levels on the ward...Is*

*there an exit for them to say “I’m having a really bad day today?” Or is it “Well we’re very short staffed so get on with it?”*

Half of the participants made reference to the role of the NHS in making sure staff with lived experience are well enough to work. One described how they felt that there should be NHS policy where practitioners with ‘severe’ mental health issues need to show they are able to work:

*Participant 1: It’s when you get to the, the more serious of the mental health problems that there needs to be... an actual policy ... as a practitioner, you would have to erm display...that you are... OK*

Others described how they feel it should be the responsibility of a mental health team to step in if they felt a practitioner’s difficulties were affecting them:

*Participant 5:... I kept thinking how can somebody like this be working in an environment with people who are mental health professionals and nobody’s taken her to one side and said, “Is everything okay? You seem a bit...”*

### ***Role of the NHS in ensuring continuity of care***

Participants pointed out that the enhanced feelings of being understood (as discussed in focused code 1: “Experiencing increased practitioner empathy” above, that might result from a practitioner disclosing, might lead to a client

becoming upset if they were then unable to see the practitioner again, due to a lack of continuity of care:

*Participant 5: ... You have no continuity of support ... you know, "what if someone tells me [about their lived experience] and I think "Oh she actually gets me, she's been through it!" and then I don't see her for a week - how unhelpful is that? Because I spend the whole week thinking "I really want to talk more to this person because it was really helpful. Oh. They've been put on a different ward now".*

This would suggest that having an ongoing relationship with a practitioner was necessary for disclosure to take place (described in focused code 6: "Forming a helpful relationship" above). Another participant suggests that without having time to build up relationships with practitioners, the right point for disclosure may not be arrived at:

*Participant 1...it comes down to when you're seeing somebody, building up a relationship ....with that person...after a while, that relationship had got to a point where the professional felt that it [disclosure] would be useful... And I think one of the problems that you do tend to get is, erm, you don't, when you're in the system, you don't actually have necessarily a long enough time to build up a relationship with your doctor and any other [practitioners]*

***Disclosure and practitioner's role affect each other***

Another way in which the NHS context affected participant's views of mental health staff with lived experience was in relation to the practitioner's specific NHS role. One participant felt that there was a difference between disclosures coming from practitioners with a more 'practical' role, such as social workers, and from practitioners who were more oriented to discussion of thoughts and feelings, such as psychologists and psychiatrists. They felt uncomfortable with the idea, that there was more likelihood of boundaries being blurred when disclosures came from someone who was more involved in the 'nitty gritty' of their day to day life, such as a social worker, leading to the client asking more questions about the social worker's life. This was compared to the therapist whose focus is on the client and their thoughts and feelings:

*Participant 5: My social worker it feels more like she's involved in my day-to-day and the therapist is all about where are you in your head and how does that translate to how you express yourself emotionally...Yeah, because they're [the social worker] very much enmeshed in the minutiae of your life...So all that kind of real nitty-gritty, day-to-day [information] ...and it does feel incredibly conversational and the natural thing again out of politeness is to say "Oh tell me about you".*

Other participants felt that there was a difference between practitioners with different roles disclosing which was based on the fact that different roles carried different levels of power and status. Two participants mentioned that they would be more affected by psychiatrists disclosing than by other practitioners. One relates it to their early belief that a psychiatrist would have high status, and to the stigmatizing idea (discussed in theoretical code 5: Influence of stigma) that a mental health problem was a weakness that would not be congruent with such status:

*Interviewer: ...do you think...which kind of practitioner, makes a difference?*

*Participant 3:...yes...I suppose to me a psychiatrist is a kind of rarer beast if you like...I think I would expect a bit less vulnerability from them potentially...yes I saw one when I was very young, it was the [name of decade]... one had a very different attitude towards any kind of medical practitioner ...you know, a lot more respect...I think I probably wouldn't expect to know, actually.*

The other participant would be relieved to find out that their psychiatrist had lived experience, more so than if it was someone with less status, such as a nursing assistant. This relates to their belief that lived experience would result in the psychiatrist treating them like a human being (as discussed in focused code 6: Forming a helpful relationship above"). They feel it would be particularly meaningful because they are aware of the psychiatrist's status as someone who makes powerful decisions about them.



*Participant 7: when, psychiatrists, a consultant or so, because I so innately distrust them, if they would say something in an appropriate way, it would be a huge relief [near tears] ...So say it's a nursing assistant, it's like, "yeah, big deal", sort of like it doesn't register. But with a psychiatrist, it would be like [big exhale] you know, someone who's actually got real power over me, might actually be sensible inside! Inside...yeah in their heart...if they've had mental health problems and they've become a psychiatrist, they might actually act like we are human beings..."*

#### **Theoretical code 5 – being influenced by mental health stigma**

Participants are clear that they live in a world where mental health issues are stigmatized. This was mentioned by all but one participant. For example:

*Participant 4: Yeah, there's still a lot of negative stigma towards mental health illness.*

#### **Worrying about practitioner being discriminated against**

Participants suggested that a practitioner's career could be seriously harmed by disclosure, if a service user made their diagnosis public:

*Participant 4: they could say something to a client about their own personal experience in a confidential space, and then the client could ... divulge this information to the World Wide Web, which could be*

*very hazardous to someone's professional career when all they've been attempting to do is help someone.*

Some participants explicitly thought that disclosure would decrease their colleague's confidence in their practice:

*Participant 1: Well, erm, their colleagues might feel they couldn't actually trust them... [because of ]... firstly being too sympathetic or empathetic to the user rather than, erm, having to, if you like, take a ... take a firm, take a firm line sort of thing.*

Others felt that that disclosure would make a practitioner seem unprofessional and lacking in knowledge:

*Participant 8: People won't trust you because... you see what would you know? You're not professional".*

Participants also thought that some service users may use the information given by a practitioner in a malicious way, for example by filing a complaint relating to the disclosure:

*Participant 7: ..if say they [other service users] knew my social worker had a mental health problem, "oh my god!" they would probably kick the shit out of her, all the time... and also, some people have got a nasty habit of filing complaints against their workers and so I think, in*

*that setting, there are quite a few people who, who might use it ...as a weapon*

The degree to which other service users, but not the participants themselves, were thought to be likely to behave in such ways may also indicate a level of self-stigma.

Given the potential for professional harm that participants feel may be caused by their practitioner's lived experience being public, it is not surprising that many feel that service users are obliged to keep the practitioner's disclosure confidential. Indeed, one participant suggested that the practitioner might directly ask the service user to keep the diagnosis secret:

*Participant 1: if the practitioner felt that there was something to be gained by it...to take that patient into your confidence and say look, I'm, I don't want everybody to know this, mmm-hm, but in your case I think it would help that you, to know that I actually suffer from very similar problems to you*

### ***Seeing lived experience as a shameful weakness***

It appears that age was a factor which was associated with some stigmatizing views. For all three of the participants aged over 58, the need for a practitioner to demonstrate that they are well enough to practice

(discussed above in the focused code: “perceiving practitioner’s difficulties”) is related to the stigmatizing view that having difficulties with mental health is shameful and weak:

*Participant 3: If time was taken off and I was aware it was because of... a depressive episode ...being the age I ... would feel a bit disappointed ...But then, then you can break your leg and have time off so, ... we're all trying not to see the distinction aren't we but erm...Something that was installed in me from childhood, that mental illness was a weakness, you know, I was the weak one, I was the vulnerable one, whereas the rest of my family, were so robust, you know*

One participant states that they require “strength” in a practitioner who is helping them, and implies that for this reason, they would not be able to trust someone who has lived experience, as they lacked this:

*Participant 8: ...Still, I think that someone who is supposed to cure me or to help me must be strong...So even though, oh at some point she had a problem and she was sectioned, I wouldn't trust them, sorry to say this. I wouldn't trust someone.*

Another participant also states that clients want strength in a practitioner, but feels that managing mental health issues appropriately is a manifestation of such strength:

*Participant 1: ...most patients are looking for ...or users are.... are looking for to get some strength from the people they're seeing. But there's no reason why that strength shouldn't come from someone who is actually not...completely...clear of issues themselves.... In fact, you could even turn it around and say...actually, if you were a professional you could say, actually I do have issues myself, but erm I have managed to get on top of them*

All three of the older participants used language around disclosure that implied that having lived experience was shameful:

*Participant 1: ...most professionals wouldn't want to admit to, too soon...*

*Participant 3: erm, confronted with, knowledge of something quite extreme*

*Participant 8 And...I think it would have to be... not a general... confession...*

Other participants made the point that others perceive mental health issues as shameful. One participant suggested that disclosing lived experience at the outset of therapy would give the impression that it was something shameful that the practitioner had no choice about disclosing, and chose the example of paedophilia, a highly shameful issue, to illustrate it:

*Participant 4: I wouldn't like that [announcing lived experience at the outset]. I think for me that would kind of make it feel like, so look it's*

*almost like when a paedophile has to disclose in America. It's like "Hi I've moved to the neighbourhood, my name's Cuthbert<sup>1</sup> and I like little boys. I'm going to number 56 to tell them." ...It's like when someone goes "There's something I have to tell you". . it's never a good thing is it?*

Relating to the issue of lived experience being a weakness, participants of all ages suggested that when a person was experiencing mental health problems they were themselves vulnerable. One participant felt that a practitioner disclosing lived experience would be dangerous for the client, as the client may be vulnerable and be oversensitive to the practitioner:

*Participant 6: I think in some cases it [practitioner disclosing lived experience to a client] can be quite, it can be dangerous and detrimental because as other stuff is happening to you during the psychotherapeutic process maybe you're quite vulnerable, maybe naive I mean someone who's suggestible or whatever...You get quite affected by external stimuli. So you're kind of hyper vigilant... sometimes hyper sensitive.*

Participants reported, following a practitioner disclosing, that they felt they were less robust than other practitioners:

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<sup>1</sup> This name referred to a hypothetical character (not the participant!) and so did not need to be removed for the purposes of anonymity.

*Participant 7: that said, if I think I've upset her that makes me more nervous than if I thought she was all ... rough and ready.*

### ***Associating mental health issues with violence and unpredictability***

Most participants mentioned a link between mental health difficulties, unpredictability, and violence. Some of the older participants espoused it themselves:

*Interviewer: What aspects of personality do you think would play a part ?*

*Participant 1: I think the...the...it would also depend on the diagnosis because of the user, and ...if they tend to get violent or aggressive*

*Participant 8: [if] someone's suffering bipolar I wouldn't trust someone who is there to help me when, because I've dealt with bipolar people. One day they are happy as Larry and everything is sunny, and the next day you can't even talk to them*

Participants with these views felt (unsurprisingly) negatively about the potential for practitioners with such diagnoses to work as practitioners:

*Participant 1: ...I mean I don't think, you would (laughs) get a job in in the NHS if you were schizophrenic. ...I mean I think that would be ...too, that would be too difficult to erm, to deal with because it's so unpredictable and er, difficult*

*Participant 8: If she [a practitioner] just says that she's bipolar I would say "Bye, bye I don't deal with you." Because before [then] I would have noticed something was wrong with her.*

Others acknowledged the link between mental health issues and violence, whilst pointing out that they themselves do not think that there is a causal relationship between the two:

*Participant 7: I don't know, I think, the only time I would be worried would be if they had a track record of violence... but disregarding the mental health problem or not, I'm just interested in, erm... I don't think hearing voices makes you any more likely to have violent outbursts. It's just something I don't want to be a victim of.*

Participants felt some aspects of mental health lived experience could be too frightening or extreme to hear about when a practitioner discloses.

*Interviewer And if they, are there any times when you think that [disclosure] would be the wrong thing for them to do?*

*Participant 2: ...no I don't I don't necessarily think, unless it was something that was completely like a revelation or something they've done or said something, like it was horrible or evil or, then...*

This interacted with the idea of shared lived experience (discussed above in focused code 2: "Being similar to service user's lived experience"), as



participants felt that even frightening or extreme disclosures would be acceptable if they were similar to something that the service user had experienced:

*Participant 4: I mean I don't want to know, you know, if they were sectioned because they went and beat someone up. I probably wouldn't want to know that, unless I had been sectioned because I beat someone up*

#### **How the codes inter-relate throughout the process of disclosure**

The model in Figure 1. below describes the different factors that are relevant at any time, when considering disclosure, when disclosing and after disclosure. The factors in the first stage “at any time” are relevant at all stages but have only been depicted once, for clarity.

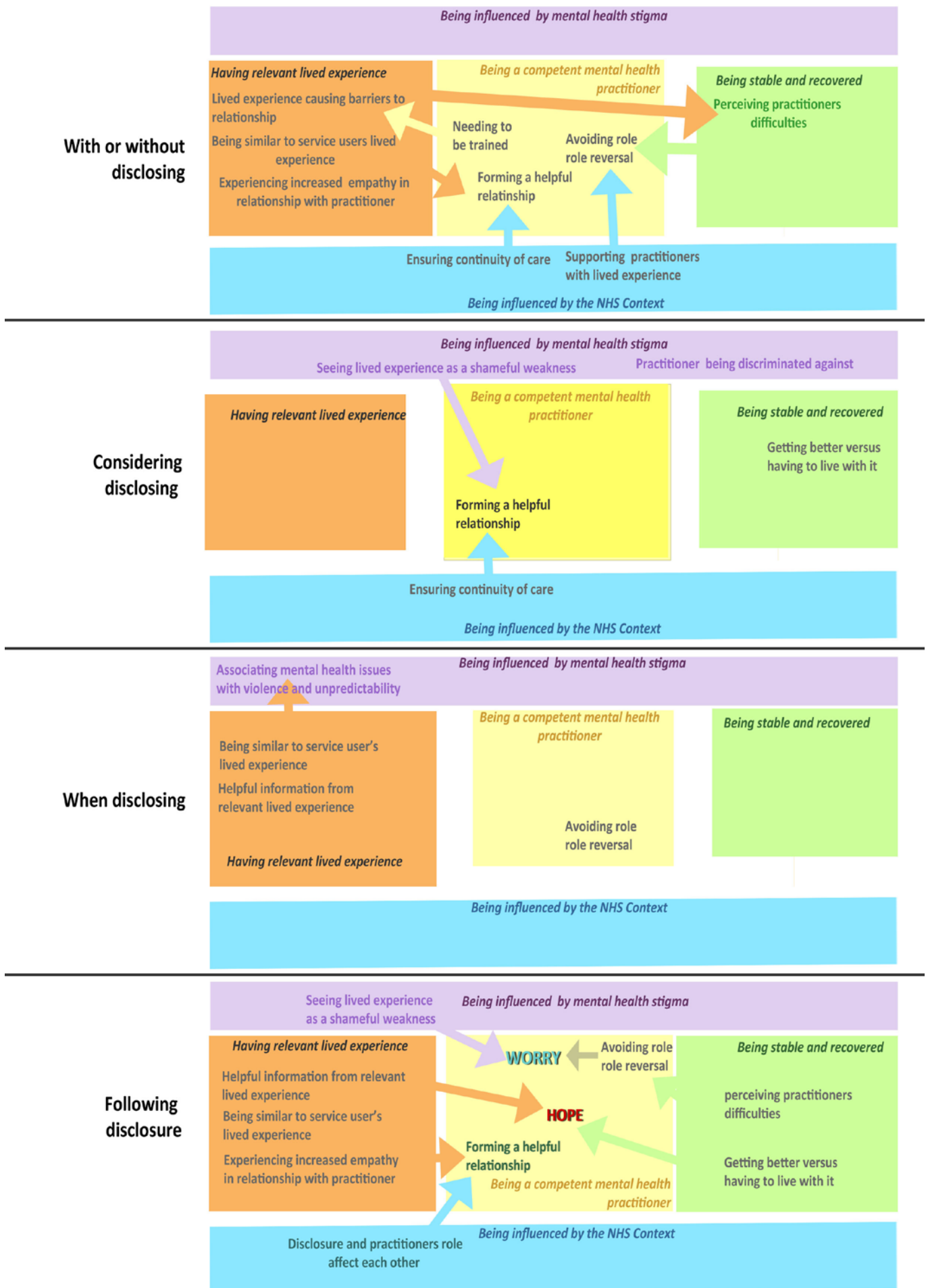


Figure 1. Model showing importance of aspects of focused codes at different states of disclosure

## **Explanation of the model**

### ***Stage 1. With or without disclosing***

Relevant lived experience as defined in focused code 2: "Being similar to service user's lived experience", is thought to allow practitioners to better understand service users' issues and show empathy (focused code 1: Experiencing increased empathy in relationship with practitioner), which may assist the formation of a helpful relationship (focused code 6: "Forming a helpful relationship"), as service users may feel they are being treated as a person and develop respect for the practitioner. This may be assisted by the NHS allowing for an ongoing relationship (focused code 11: "Role of the NHS in ensuring continuity of care").

The similarity of the practitioner's lived experience (focused code 2: "Being similar to service user's lived experience") was also felt to have problematic elements, causing barriers to the helpful relationship (focused code 6: "Forming a helpful relationship") with the service user; although it was thought that training (focused code 5: "Needing to be trained") would help them overcome this. Similar lived experience may be that the practitioner has experienced or fears discrimination and stigma, decreasing help-seeking for any difficulties. This may impact upon a practitioner's ability to manage their own issues (focus code 8: "Perceiving practitioner's difficulties" ) which could result in them becoming symptomatic while working with their clients (focus code 7: "Avoiding role reversal"). The focus code 11: "Role of the

NHS in supporting practitioners with wellbeing” moderates focus code 7:”Avoiding role reversal”.

### ***Stage 2 – Considering Disclosure***

In the second stage, “Considering disclosure”, a relationship where the service user respects the practitioner is thought to be key (focus code 6:”Forming a helpful relationship”. This is enhanced by the code 11:”Role of the NHS in ensuring continuity of care”

Other factors affecting respect towards the practitioner were

- i) Client’s views about mental health recovery (focused code 9: “Getting better vs having to live with it”) which mitigate the degree to which lived experience is seen as an acceptable form of expertise.
- ii) The presence of stigmatizing views about mental health issues (focus code 14: “Seeing lived experience as a shameful weakness”).

Practitioners were seen to be at risk of discrimination from others (focused code 13: “Practitioner being discriminated against”).

### ***Stage 3 - When Disclosing***

At this key point, the theoretical code “Having relevant lived experience” is most important, as it is concerned with the relevance of the disclosure to the service user’s present situation or experiences, defined by its similarity (focused code 2: “Being similar to service user’s lived experience”) in terms of diagnosis, thoughts and feelings and an

understanding of the circumstances that might arise as a consequence of experiencing mental health issues. The disclosure also needs to be genuinely helpful, (focused code 3: “Helpful information from relevant lived experience”), taking into account the possibility that clients may not, actually, feel or wish to act in the same way as the practitioner in a similar situation.

It is also important for the disclosures to be short, so as to avoid the focus moving away from the client’s issues to the practitioner’s (focus code 7: “Avoiding role reversal”). Practitioners need to address participants concerns about the practitioner’s self-management and support (focused code 8: “Perceiving practitioner’s difficulties”), and also the service user’s expectation that they will need to keep the practitioner’s lived experience confidential (focused code 13: “Worry about practitioner being discriminated against”).

“Being similar to service user’s lived experience” (focused code 2) mitigates the degree to which clients are influenced by the stigmatizing association between mental health issues and violence. Unless a disclosure is similar to the participants’ experience, they do not want to hear about the practitioner’s experiences that are violent or ‘severe’. Also in the area of mental health stigma, it is at disclosure that clients may assume that they need to keep the practitioner’s lived experience confidential (focus code 13: “Worrying about the practitioner being discriminated against”).

#### ***Stage 4 – Following Disclosure***

In this stage, disclosure has affected the relationship with the practitioner, and also can lead to hope and worry.

#### ***Forming a helpful relationship***

The focused code 2: “Being similar to service user’s lived experience” affects focused code 6: “Forming a helpful relationship” as the service user’s increases in empathy and trust towards the practitioner may enhance the relationship; the belief that the practitioner is more human following disclosure and that they are being treated as a human also are likely to increase empathy and trust. This is also affected by the role of the practitioner in the NHS, it is thought that the disclosure from practitioners with higher status and who talk more about feelings is likely to have more of an impact upon the perception of the practitioner’s ‘humanity’ .

#### ***Hope***

1. The focused code 9: “Getting better versus having to live with it” – influences hope, as service users who feel that they can live with mental health issues are given hope by disclosure as the practitioner’s own recovery can embody the idea that living with it successfully is possible
2. The focused code 2: “Being similar to service user’s lived experience” affects hope, as service users have an increased sense that they are not the only one with their particular experiences, and also the

possibility that they too can similarly succeed as their practitioner has.

3. The focused code 3: “Helpful information from lived experience” increases the service user’s hope as they feel the practitioner can offer helpful insights based on their management of their own lived experience.

### ***Worry***

1. The focused code 14: “Seeing lived experience as a shameful weakness” affects worry. Participants describe how they feel that practitioners are less robust (i.e. weaker) following their disclosure, leading to service users worrying about them and self-monitoring so as not to cause stress to the practitioner.
2. The focused code 7: “Avoiding role reversal” leads to worry as service users are concerned that sessions will become focused on the practitioner’s lived experience rather than theirs.
3. The focused code 8: “Perceiving practitioner’s difficulties” affects worry as service users may worry that their practitioner is being affected in their treatment of them in an imperceptible way. Service users may also worry about practitioners becoming symptomatic in sessions. This could also lead to role reversal (focused code 7: “Role reversal”).

## **Chapter 4 - Discussion**

This study investigated the factors that service users took into account when considering practitioners with lived experience of mental health issues. It also investigated if and how service users would like practitioners to share this information. Eight service users who had used NHS mental health services within the last 5 years were interviewed. Data were collected and analyzed in line with Grounded Theory principles (Charmaz, 2006).

This chapter will start with a summary of the model developed from the analysis. It will then consider the five theoretical codes which underpinned the model in the light of existing research and theory, concentrating on the 'wounded healer' literature and research into peer workers and practitioner disclosures. This will be followed by a critical review of the study, and then a discussion of the possible implications for clinical practice. The implications of this study for further research will be considered, followed by some personal reflections from the research, and a summary and conclusion to end.

### **Key findings**

Three participants had experienced at least one practitioner disclosing their lived experience, allowing examples to be drawn from experience as well as from participant's views. However, there was no difference found between the types of views held by these participants who had directly experienced practitioners with lived experience, and the other participants who hadn't. These three participants did not suggest that having direct experience of practitioners with lived experience affected their views.



There did not appear to be any effects of gender upon the results, but there seemed to be a link between age and stigmatizing views. The factors participants took into account when forming opinions about mental health practitioners with lived experience were conceptualized as five interconnecting theoretical codes. Three related to the practitioner: “Having relevant lived experience”; “Being a competent mental health practitioner”; and “Being stable and recovered”. Two further theoretical codes described contextual factors which were thought to have an effect, namely “Being influenced by the NHS context” and “Being influenced by mental health stigma”.

Analysis of the data resulted in a four stage model, showing which aspects of the five codes were important at the following stages of disclosure:

- i) regardless of disclosure
- ii) when considering disclosure
- iii) when disclosing
- iv) following disclosure.

***Factors important regardless of practitioner’s disclosure***

The theoretical code “Having relevant lived experience” described how the similarity of the practitioner’s and service user’s experiences of mental health issues could lead to the service user perceiving increased empathy from the practitioner, but also could lead to difficulties in the relationship such as over-identification. Other difficulties such as the practitioner

experiencing mental health difficulties in the session with the service user were articulated in the theoretical code “being stable and recovered”. These concerns were amplified by the influence of mental health stigma, (theoretical code “Being influenced by mental health stigma”) and moderated by the possibility of the practitioner’s wellness being supported by their NHS teams (theoretical code “Being influenced by the NHS context”), as well as the practitioner’s training and experience facilitating the theoretical code “Being a competent mental health practitioner”.

***Factors important when considering disclosure***

The theoretical code “Being a competent mental health practitioner” allowed practitioners to develop a good working relationship with service users, and was attenuated by the NHS context, where continuity of care was necessary to allow such a relationship to develop. At this stage the theoretical code “Being stable and recovered” was relevant as service users’ views about recovery influence the degree to which lived experience was seen as a form of expertise. The theoretical code “Influence of mental health stigma” influenced the participants’ views of the acceptability of a practitioner with lived experience at all. Participants also felt that practitioners needed to consider the risk of discrimination and stigma to themselves and their career.

***Factors important when disclosing lived experience***

The theoretical code “Having relevant lived experience” was a key factor in the acceptability of the disclosure, especially in terms of the relevance and

helpfulness of the particular disclosure to the service user's current circumstances. The practitioner's expertise in "Being a competent mental health practitioner" was required to allow them to disclose in a way which kept the focus upon the service user. "Being a competent mental health practitioner" mitigated the concerns articulated in the theoretical code "Being stable and recovered" regarding the practitioner's self-management of difficulties. It also mitigated the theoretical code "Influence of stigma" regarding the possibility that service users would be expected to keep the practitioner's lived experience confidential.

***Factors important following disclosure***

The theoretical code "Having relevant lived experience" affected increases in service user empathy and trust towards the practitioner and the development of hope. The development of hope was attenuated by the theoretical code "Being stable and recovered": the congruence of the service user's views about recovery with the practitioner's disclosed lived experience could increase or decrease hope. Worry was also affected as a service user may have concerns about the practitioner relapsing. The theoretical code "Being influenced by stigma" was thought to increase worry if the practitioner is seen as vulnerable, and the theoretical code "Influence of the NHS setting" attenuated the impact of the disclosure: the effect on service users could be greater if a practitioner with high status such as a psychiatrist discloses.

These findings suggest that participants were concerned only with disclosures that are relevant to them and their circumstances. They wanted the focus of disclosure to remain on themselves, and for roles not to be reversed. Such disclosures were more acceptable coming from respected practitioners. Disclosure could be a jarring experience if the practitioner's disclosure was not in keeping with the service user's beliefs about recovery. The effects of disclosure could be increased empathy, trust and feeling like one is being treated as a human being, and hope. On the other hand, service users could also experience decreases in hope, and worry, if they were concerned about the practitioner's wellbeing. Such concerns may have resulted from stigmatized understandings of mental health issues, or from fear of the practitioner experiencing discrimination. It was thought that there may be a role for the NHS in promoting good relationships with practitioners and service users, and in supporting NHS staff in maintaining their wellbeing.

### **Discussion of theoretical codes in relation to previous findings**

#### **1. *Having relevant lived experience***

One of the key, novel findings of this study was the importance placed by participants upon the relevance to them of the practitioner's lived experience. Henretty and Levitt's (2010) review suggested that disclosures of a shared identity (such as being a member of the LGBT community) were welcomed by service users; it could therefore have followed that disclosure

of the shared identity of being a service user would also be welcome. However, participants pointed out that “even two people with bipolar can be so very different” (participant 1) , and emphasized the importance of the similarity of the particular experience, rather than the identity of being a service user per se. While it has been assumed in the disclosure literature that practitioners disclose in order to seem more similar to their clients (Hill & Knox, 2003), service users in this study valued similarity of experience rather than identity.

The reviews of peer workers (Repper & Carter, 2011; Miyamoto & Sono, 2012) suggest a practitioner with lived experience can offer hope to service users. The participants in this study think that such hope is related to the degree to which the practitioner’s experiences can help service users. Relevance is important because disclosure of less relevant information is thought to take up the service users’ time without helping them.

One explanation for this may be that hoping can be defined as a particular kind of imagining, a cognitive skill used to maintain drive (Snyder, 1994). It is much easier to imagine overcoming a current problem if someone describes themselves overcoming something very similar, than it is to imagine overcoming a problem if they were to describe overcoming something very different.

On a more practical level, a disclosure from someone who has not actually experienced a similar situation may not be as useful as that from someone who has, as the potential for offering helpful specific advice is decreased.

### **1.1 *Feeling empathy (focused code 1)***

It is not unusual for research and theory in the areas of wounded healers, therapist disclosure or peer workers to conclude that practitioners with lived experience will have greater empathy (e.g. Zerubavel & Wright, 2012; Charlemagne-Odle et al., 2014; Telepak, 2010; Stanley et al, 2007; Cain, 2000; Adame, 2011, 2013; Richards et al., 2016; Hill & Knox, 2001, 2003; de Vos et al., 2015; Repper & Carter, 2011; Miyamoto & Sono, 2012; May, 2000). Thus it is not entirely surprising that this study showed that participants who had worked with practitioners with lived experience, and those who hadn't, both had the expectation that such practitioners would have greater empathy as a consequence of their shared lived experiences.

This study also found that service users might develop empathetic feelings towards their practitioners. This is a novel finding and may reflect the fact that no previous qualitative investigations of service user's views on practitioner disclosure of lived experience have been carried out. If feeling empathy towards another person is seen as positive and potentially 'healing', it could be understood in a 'wounded healer' framework, as Jung (1963) suggests that the disclosure of the 'healer's wound' allows the patient to access their own ability to 'heal'. On the other hand, there is the risk of such feelings being un-therapeutic for certain clients if, for example, they habitually prioritize the needs of others more than themselves.

### **1. 2 *Lived experience causing barriers to the relationship (focused code 4)***

Similarly to the findings from Zerubavel and Wright (2012) in the ‘wounded healer’ literature, and studies of practitioners who disclose their lived experience (e.g. Cain 2000, Telepak 2010), this study revealed that service users have concerns that practitioners with lived experience might over-identify with, or have difficult feelings triggered by, the service user. While the participants in this study felt that these might be overcome via training, Cain (2000) reported that practitioners felt that they learned to overcome such issues as they became more experienced, and Zerubavel and Wright (2012) advocated for a more open culture where practitioners can disclose lived experience easily to colleagues and thus be able to work through such difficulties.

### **2. *Being a professional mental health practitioner***

The key aspect of this theoretical code is that a helpful relationship between the client and practitioner is a precursor to any disclosures of lived experience and also has the potential to be enhanced by the disclosure.

Clients defined a helpful relationship as one in which they felt they were treated as a person. This reflects findings from the peer worker literature, where the mutuality of the relationship with the peer worker is thought to be helpful (Miyamoto and Sono, 2012) and is underpinned by ideas in a recovery framework where the development of a positive self-identity (rather than as a “patient”) is thought to contribute to personal recovery (Leamy, Bird, Le Boutillier, Williams and Slade, 2011).

In the psychotherapist self-disclosure literature, Hill and Knox (2001) suggest that the potential benefits of personal disclosures come about via the mechanism of improvement to the relationship. However, in the current study, participants did not focus exclusively upon the relationship with the practitioner, but were also interested in the practitioner's competence. This may reflect the difference between this study, where a range of practitioners with differing roles such as social workers, mental health nurses and psychiatrists as well as psychotherapists were considered, and the self-disclosure literature's focus upon psychotherapists. For psychotherapists, maintaining a therapeutic relationship is one of the key aspects of doing their job well; but while the alliance is highly important in all mental health roles, a social worker (for example) would not be doing their job well if they only maintained a good relationship, as their role also involves offering practical support.

It may also be possible that the emphasis participants placed on the practitioner's competence, rather than just assuming that they would be competent, reflects unspoken concerns about their abilities, which may reflect concerns discussed by Zerubavel and Wright (2012), that 'wounded' practitioners may relapse and therefore become impaired in their ability to practice.

### **3. *Being stable and recovered***

Participants repeatedly emphasized that they required a practitioner with lived experience to be symptom free in their sessions, regardless of whether or not they have disclosed their lived experience. This reflects the distinction



made in the 'wounded healer' literature between an 'impaired' professional (whose difficulties interfere with their ability to function in their role) and a 'wounded healer', who is able to draw upon their experiences to help the client. Zerubavel and Wright, (2012) suggest that the uncertainty around a 'wounded healer's' future functioning is a key threat to their being accepted by other professionals. The current study, which shows that service users' concerns about a practitioner's recovery leads to worry following disclosure, suggests that this uncertainty is also a threat to their being accepted by service users. However, while studies suggest that impaired professionals are a risk to service users' safety (e.g. Smith & Moss, 2009), the current study suggests that service users do not see risk as their main concern but rather wish to avoid role reversal.

### **3.1 Role reversal (focused code 7)**

The study found that service users do not wish to be concerned about their practitioners' wellbeing or to be placed in position where they need to take action on the practitioner's behalf such as reporting their suspected difficulties to other staff. Participants were concerned about practitioners relapsing, but they stated that this was because of a fear of role reversal, and did not mention other possible concerns such as risk. They felt that role reversal could also happen in the absence of relapsing if the focus of the session shifted to the practitioner, either during or following disclosure. This is very similar to the conclusions of Hill and Knox (2001) and Knox and Hill (2003) in the self-disclosure literature. While there are suggestions in the

wounded healer literature (Kiramayer, 2007; Jung 1963) that the client's acknowledgement of the practitioner's "vulnerability" as a result of their "woundedness", promotes healing for the client (when the practitioner is recovered), participants were clear that they expected practitioners to remain in their roles as "healers".

It was clear that participants felt that the only appropriate motivation for practitioner disclosure was the aim to support the service user's recovery. Participants felt that motives such as catharsis (which would principally be of benefit to the practitioner) would result in unwanted role reversal and inappropriate focus upon the practitioner.

Another factor which may influence the experience of role reversal is the degree to which a disclosure is full, partial or not made at all. It is possible to think about disclosure being on a continuum, with no disclosure at one end, and full disclosure at the other. A very 'full' disclosure, where participants are given many details of the practitioner's lived experience, may be experienced as a role reversal, where the focus has shifted to the practitioner. Zerubavel and Wright (2011) suggest that partial disclosure is preferable as it allows focus to be kept upon the service user, suggesting that practitioners should refer obliquely to difficulties in their lives without giving any specific details. However, in this study, participants reported worry about the degree to which their practitioners were recovered and stable as an outcome of practitioner disclosure. It may be that less information leads to less worry, but on the other hand a lack of information about the practitioner's recovery status and stability might lead to greater worry. It was beyond the scope of this study to investigate this and further

research in this area is warranted.

### **3.2 *Getting better versus having to live with it (focused code 9)***

Participant's views about disclosures of lived experience of mental health issues depended to some extent upon whether the particular issue was seen as one to be cured, or something to be lived with. This dichotomy is reminiscent of the difference between clinical recovery, which is dominant in healthcare and conceptualizes recovery as a "return to symptom free normality" (Slade et al., 2014), and personal recovery, which can be defined as "a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness" (Antony, 1993, p527). In this study, participants did not simply espouse one or the other of these approaches, rather, they hinted at a process where their initial desire for clinical recovery for their own issues, changed over to an acceptance of a personal recovery perspective.

Espousing a recovery focused viewpoint was associated with greater acceptance of practitioners with lived experience, which is similar to a finding in the peer worker literature (McLean et al., 2009), that peer workers were most accepted by clients in teams with a strong recovery focus. Where the current study's findings differ though is that they suggest clients may have a recovery approach to one mental health issue but not to another when they have more than one diagnosis, and so the degree to which a practitioner's disclosure of lived experience is useful depends upon the specific difficulty that is being disclosed and whether the client expects a

clinical or personal type of recovery for that issue.

#### **4. NHS Context**

The findings show clients are aware of the influence of the NHS context upon i) the practitioner's ability to form a good working relationship with the service user and ii) the outcomes of disclosing their lived experience to them. With regard to forming a relationship with a practitioner, the study suggests that the NHS context may actually hinder this process if a person does not experience continuity of care with their mental health practitioner(s). This is in keeping with research showing that continuity of care is associated with better outcomes, especially in the field of mental health (Haggerty, Reid, Freeman, Starfield, Adair & McKendry, 2003). Participants suggested that the NHS and individual practitioners take the role of checking that practitioners with lived experience were fit to practice, in other words "the gatekeepers' role" (p489, Zerubavel & Wright, 2012) as discussed in the wounded healer literature.

Clients discussed how, where the power difference between themselves and the practitioner is larger, the disclosure of lived experience has a greater effect, and would be more welcome. It seems that a practitioner disclosing lived experience may result in the power difference between them and the service user appearing to decrease. This is in keeping with arguments made by Repper and Carter (2011), regarding peer workers. They felt that the smallness of the power difference between the peer workers and the service users enhanced the peer workers' ability to help.

Thus a service user perceiving a decrease in the power difference between them and a practitioner may also find the practitioner more helpful.

## **5. *Being influenced by mental health stigma***

### **5.1 *Worrying about practitioner being discriminated against***

Clients assumed they would be responsible for holding confidential any disclosures that their practitioner with lived experience made to them, with the assumption that the practitioner's lived experience would, if known, be a disadvantage to them in the NHS setting. However, practitioners hold that responsibility, not clients, and it is a key point in literature around practitioner self-disclosure that disclosures should only be of information that the practitioner is happy for others to share (e.g. Sweezy, 2005; Bloomgarden & Mennuti, 2005). Telepak (2010), in an interview study of practitioners with lived experience, found that some found it easier to disclose to clients rather than colleagues, which may reflect a fear of workplace stigma and discrimination, as assumed by clients in the current study.

Clients felt that practitioners with lived experience would not be trusted by other practitioners, with the expectation that their careers could be seriously harmed by such a disclosure. The wounded healer literature supports this, with Zerubavel and Wright (2012) suggesting that the responsibility that mental health practitioners have for making sure that their colleagues are fit-to-practice leads them to be cautious about the capabilities of someone with previous experiences of being unfit, especially as their recovery might not be a permanent state. UK studies of NHS staff have shown that practitioners with lived experience report that they do not disclose to their colleagues and

fear discrimination (Richards et al., 2016; Roberts et al., 2013). Similarly, a survey of mental health staff with lived experience in Leeds, (Leeds Inkwell Art Media, 2013), focused on fears of discrimination from staff members. If, as is suggested by large scale studies such as Corker et al. (2013), clients experience discrimination from mental health staff, and there is an “us and them” culture defining staff as qualitatively different from service users in mental health trusts as shown in Morgan et al., (2013), then it would follow that participants have good cause to be worried that practitioners with lived experience may be stigmatized and experience discrimination in the NHS setting.

## **5.2 *Effects of stigma upon participants***

Participants also expressed beliefs about mental health issues which related to a stigmatized view of mental health, which is not surprising, as stigma occurs at a societal level and affects all members of society (Angermeyer & Schomerus, 2012). Stigmatizing views about the violence and unpredictability of people with diagnoses such as bipolar and schizophrenia are commonly held and well documented in the stigma literature (e.g. Crisp, Gelder, Rix, Metzler & Rowlands, 2000). In the current study, participants reported they did not want to hear about practitioners’ experiences of mental health issues that might horrify them. Similarly, Zerubavel and Wright (2012) discuss how practitioners find that other staff members do not want to hear about their lived experiences because of the assumption that they will be horrifying.

Interestingly, participants assume that if a service user has themselves directly experienced something, however difficult, they will not then be horrified by a practitioner's disclosure of it. The self-stigma literature (e.g. Corrigan & Watson, 2002) would suggest that there are circumstances where a person continues to hold stigmatizing views about conditions that affect them directly and see themselves negatively as a consequence. There may be a similar effect for lived experiences of a stigmatized difficulty, in the sense that service users may see practitioners negatively following disclosure, even if the service user had experienced the same difficulty. In other words, the service user's self-stigma means that they would experience the disclosure negatively, judging the practitioner as being in some way discredited by their lived experience, in the same way that they judge themselves.

Some participants in the study expressed views that some practitioners with stigmatized conditions ought not to become practitioners because of the links with unpredictability and violence. Others worried that practitioners would be vulnerable, and therefore not 'strong' enough to provide support. These concerns, which are influenced by societal stigmatizing views (Crisp et al., 2002) are likely to result in service users being worried by a practitioner's disclosure of certain difficulties, such as more highly stigmatized difficulties such as psychosis. If practitioners do not disclose, however, the potential for disconfirming and challenging such stigmatizing beliefs is missed.

### **Summary of key findings in relationship to the research**

The study both produced novel findings and supported findings from previous research. The novel findings were: that service users were interested in the degree to which a practitioner's disclosure was relevant and specific to their concerns; that they were likely to feel empathy towards their practitioner following disclosure; that they valued disclosures from practitioners who were also seen to be good at their jobs, and were more likely to be affected by a disclosure from a practitioner with a high status in the NHS than someone further down in the hierarchy. The expectation of empathy from the practitioner, need for a good relationship with the practitioner, potential for worry caused by barriers to the relationship and the influence of stigma were all anticipated by the literatures around wounded healers, peer workers and practitioner self-disclosure.

### **Critical Review**

#### ***Strengths of the research***

One of the study's main strengths was that it examined the views of NHS mental health service users about a topic on which they have not to date been consulted. Three of the eight participants also had direct experiences of practitioner disclosure, which are thought to be rare. While the Grounded Theory approach does not make claims to representativeness, Charmaz (2006) emphasizes the importance of exploring the issues in a range of contexts and the participants had experienced a wide range of mental health service use, from a single episode of primary care to multiple long-term



hospitalization, allowing the consideration of different contexts for disclosure, such as differing staff roles.

Where possible, validation has been carried out, such as feeding back an early version of the results model to the participants and incorporating their feedback, and a sample of the coding was independently validated.

The findings are comprehensible in the light of previous research; and have brought novel concepts to the area, which may reflect the unique perspectives of service users as opposed to mental health practitioners who have previously been the main subjects of research in this area.

#### ***Limitations of the research***

Recruitment however did only represent the views those involved with mental health service user groups, as unfortunately, no participants were recruited as a result of snowballing methods. This may have resulted in a sample with a greater level of exposure to ideas around empowerment and discrimination than if the snowballing had been successful, or if other recruitment methods, such as sampling from NHS mental health trusts, had been used. This may potentially have biased the results towards favouring practitioners with lived experience. However, the degree to which participants engaged with the service user groups differed, as half reported active attendance of service user groups and half reported only receiving emails and having no further involvement beyond that, so that it is likely participants differed in their levels of exposure to such ideas.

People with higher education were overrepresented and no people who had finished their education at sixteen or below were interviewed, indeed seven

out of eight participants had studied at degree level or above. Service user groups are often less representative of BME service users than the overall population of service users (Sassoon & Lindow, 1995) and this is again an issue in the study where eight out of ten participants were White. This may have reduced the amount of stigmatizing beliefs reported as studies (e.g. Corrigan & Watson, 2007; Cook & Wang, 2010) have shown fewer stigmatizing beliefs associated with higher levels of education and with being white. That said, the views about the provision of NHS services held by service user group members have been shown to be very similar to those held by a random sample of other service users in a similar area (Crawford et al., 2003). This suggests that there are also likely to be similarities between the views of service users regardless of their involvement in service user groups. It is also important to note that issues such as responder bias, where there are systematic similarities between the type of people that chose to take part in research, compared to those who don't, would have been an issue regardless of whether the participants had been recruited from NHS trusts or service user groups.

At the recruitment stage, talks were given to service user groups, and four participants were recruited following these talks (the other four were recruited by responding to an email mail-out). During these talks it was mentioned that the researcher had lived experience of depression; but this was not reproduced in any written materials nor touched upon in the interviews themselves. Thus 50% of participants were aware of the researcher's lived experience, and it is not possible to know whether or not the other 50% did, although it is less likely. Knowing that the researcher had

lived experience may have influenced participants' responses and decreased their reporting of negative beliefs and concerns about practitioners with lived experience (a form of social desirability bias). All participants reported a positive attitude towards practitioners with lived experience, which may reflect this; however, on further questioning some participants were happy to explore their less positive feelings and reflect upon how they had come to hold these other, less socially desirable beliefs. Participants were encouraged to reflect upon their feelings as well as their thoughts; the interviewer emphasized how important it was to hear what people felt "in their gut" even if it was something they didn't necessarily think was "right", as an attempt to overcome this potential bias.

It is also true that there are limits to what personal information an interviewer is able to conceal during an interview. For example, the researcher was not able to conceal the fact that she was white, or female, which might have an effect upon how participants responded to certain questions. Charmaz (2006) argues that reflection upon the effects of the different positions of the interviewer and participants is the most helpful way to construct meaning, rather than attempting to position the researcher as neutral.

At the methodological level, it was not possible to interview clients who did not speak English fluently, or clients who were currently in an inpatient setting. This may mean that certain considerations, like cultural influences on views of practitioner severity, or the effect of double discrimination on service user views, may not have been fully explored in the current study.

Fewer than half of the participants (n=3) had direct experience of practitioners with lived experience disclosing this to them. There was no indication that these three participants had different views on the topic following this experience, and no seeming difference between their views and those of the other participants. However, this may be an artifact of the very small number of participants, and it may be that a study looking at greater numbers of participants with direct experiences of such practitioners may find differences that did not arise in this study.

The study found that participants in some circumstances experienced partial disclosures from practitioners. This was recorded as 'suspected' lived experience in Table 2, and captures instances where practitioners make comments which suggest but do not describe in full, that they may have had lived experiences of mental health issues themselves. There was not space in this study to explore the differential effects of partial versus complete disclosure of a practitioner's lived experience upon the views of service users.

### **Implications for future research**

As discussed in the study's strengths and limitations above, the current study explored in depth the views of a small number of London-based clients who were members of service user groups, most of whom were educated to university level. Research using the same or a similar paradigm, but involving participants with wider range of educational, socio-

cultural and ethnic backgrounds, should be carried out to allow the model to take into account concerns which may have not been incorporated in the current study.

The current study did not show any particular differences between the concerns of participants who did, and who did not, have direct experiences of a practitioner disclosing their lived experience. However, there were only three such participants in the study. It may be that a study examining a larger sample of service users with direct experiences of practitioner disclosure may result in elaborations of the model. For example, it may be fruitful to assess the longer-term effects of disclosure on the practitioner-client relationship.

The current mental health of participants in this study was in the mild to normal range, and so it is not known what the views of service users who are currently experiencing more severe difficulties would be. The participants in this study had a range of experiences of mental health service use, and half had extensive experience of inpatient admissions, but at the time of interview they were reasonably well and living in the community. It may be that service users with more severe symptoms, for example, in the hospital setting, may have different perspectives about practitioners with lived experience. It could be speculated that they have different abilities at this time to tolerate personal information about their practitioner, and further research in this area is warranted.

Some research (Hill and Knox, 2001) suggests that the mechanism by which self-disclosure can be helpful is via improvement to the therapeutic relationship, but the current study's model suggests that similarity of

experience is another key factor. Furthermore, hope and worry are both likely outcomes. An experimental study could test the assumptions of the current model using a quantitative paradigm. A vignette study could be carried out where factors such as the nature of the relationship between practitioner and service user and the relevance of the disclosure to the service user are manipulated and the degree to which participants rate the likelihood of the service user experiencing worry, hope and an improvement in their relationship with the practitioner are used as outcome measures.

It may also be useful to evaluate the effects of practitioner disclosure upon client outcomes such as hope and worry and the therapeutic relationship, via a questionnaire study of clients who have experienced such disclosures, or by adding in questions about whether clients had experienced disclosure and their experiences of hope and worry and the therapeutic relationship, into existing large scale surveys of client satisfaction in the NHS, such as the Community Mental Health Survey (e.g. CQC, 2015).

### **Implications for clinical practice**

#### ***Changes to guidance***

The current study has developed a model which may help practitioners plan for and understand the likely outcomes of a disclosure, which is often thought to be a risky and unpredictable action on the part of a practitioner (Gibson, 2012). The study suggests that there are risks, such as the client becoming concerned about the practitioner and experiencing role reversal, some of which are predictable. It also suggests that there are likely benefits,

such as an improved working relationship with the practitioner, decreases in feelings of isolation, and increases in hope, when a disclosure happens under certain conditions.

Hope is seen as a key component in many conceptualisations of recovery in mental health (e.g. Bonney & Stickley, 2008; Leamy, et al., 2011). Thus, it would make sense that practitioner behaviour which is likely to increase hope, such as a well thought-out disclosure of a relevant lived experience to the right client (where worry is minimized), is encouraged, and clear guidance given about when a disclosure is more or less likely to be helpful. However, currently codes of practice and ethics are mostly ambiguous or negative about practitioners making disclosures of lived experience to service users. All guidelines state overarching principles about always acting in the service users' best interests. It surely would be more in keeping with the spirit of the guidance to include clear guidelines facilitating the disclosure of lived experience in such a way as to be helpful for clients.

Participants felt a disclosure of lived experience of mental health issues was risky and unpredictable for the practitioner, as they may experience discrimination in the workplace, from both service users and staff. The development of clear working policy which supports practitioners with lived experience, and the development of a culture in which such practitioners are able to be open about their prior lived experience with colleagues, and openly seek help for any relapses, would be a helpful starting point for practitioners. This might be achieved via a decrease in the focus upon risk, and an increased focus upon the potential helpfulness of such lived experience, in guidance and policy.

Given that participants report that the impact of disclosure is greater when it comes from practitioners with higher status, such as psychiatrists, it might be helpful to develop training and best practice guidelines around lived experience of mental health issues that are specifically aimed at these types of practitioners.

Participants also reported that disclosure would need to take place in an ongoing helpful relationship with the practitioner. It would be helpful if allocation of resources prioritized the importance of continuity of relationships between practitioners and clients.

***Factors within the individual practitioner's sphere of influence***

The study suggests that there are a number of ways in which practitioners can use their relevant lived experience to support clients, including planning and carrying out a disclosure of a relevant lived experience in a way that is most likely to decrease worry and increase hope and improve the relationship. Advice following from this study's findings is presented in Table 5 below.



Table 5. Considerations for practitioners with lived experience

When	Helpful	Less helpful
Considering disclosure	<p>Good working relationship</p> <p>Having an on-going relationship with the client</p> <p>Thinking about the relevance of your particular lived experience to the client</p> <p>Having a recovery focus in the team.</p>	<p>Client expecting a cure from mental health issue that you still are actively managing</p> <p>Client belief around mental health being a weakness and practitioners needing to be strong</p> <p>Client belief that your particular diagnosis or issue is violent or unpredictable</p> <p>Client currently under high levels of stress caused by factors irrelevant to issue being disclosed about</p> <p>Disclosure might cause difficulties for practitioner in the workplace</p>
While disclosing	<p>Disclosing a specific fact or incident that is relevant to client</p> <p>Disclosing at a time when issue being disclosed is relevant to the conversation with the client</p> <p>Similarity of disclosed lived experience, e.g. in terms of diagnosis, thoughts and emotions, practical situations relating to mental health issues</p> <p>Keeping focus on the client</p> <p>Brief and to the point</p> <p>Enough session time to also carry out usual activities</p> <p>Letting client know you are stable and managing well</p> <p>Letting client know they do not have to keep your disclosure secret</p> <p>Using humour or a light tone (if in keeping with your usual relationship / client mood)</p>	<p>Acting as if you have a confession to make – don't say 'There's something I have to tell you'</p> <p>Using disclosure for any other purpose except supporting the client, e.g. because you feel the need to "unload"</p> <p>Hinting but not fully disclosing about your lived experience (as you will not then be able to reassure client about your current stability and that they don't need to keep your disclosure a secret)</p> <p>Discussing issues which your client has not got personal experience of and which they might be worried or frightened by</p> <p>Giving impression that you feel client ought to address their issues in the same way that you did in your disclosure</p>

<p>Following disclosure</p>	<p>Being willing to answer any further client questions on the issue but keeping focus on client and relevance of your lived experience to them.</p> <p>Be aware that clients might feel they can trust you more and disclose more about themselves; conversely, clients may also be disclosing less about themselves as they may perceive you as more vulnerable.</p>	<p>Your client may become worried about the possibility of your starting to talk about your lived experience more frequently. Therefore, only refer to the previous disclosure if helpful or relevant, as client may be especially worried at this point about roles being reversed</p> <p>Your client may also be worried that you may relapse so don't ignore your own issues or fail to get the help you need for them.</p>
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### **Personal reflections**

The use of the self is a key factor in constructivist Grounded Theory, as being aware of the researchers pre-existing notions about the topic in question means that to some extent it is possible to discern the effect that the researcher's beliefs, biases and context had upon the research process (Charmaz, 2006).

Reflecting upon my thoughts and feelings about the research process in a diary, and discussing these with my peers and my research supervisor allowed me to make explicit ideas that otherwise may have biased my approach both to participant interviewing and also to data analysis. I noticed in earlier interviews that I often felt conflicted and anxious when participants expressed views which I did not agree with, as it made me worried that my analysis would make my participants seem prejudiced, leading to my changing the topic more quickly than I otherwise would have. Discussions with my peers led me to think about the issues from a more curious, and wider viewpoint, with the idea of using such feelings when they occurred in the interview as a prompt for being more curious and less personally judgmental, with the aim of understanding and making sense of views in a respectful way.

In the data analysis, discussions with my supervisor about the coding allowed me to make sense of the role of the relationship between the client and the practitioner in disclosure.

As a mental health practitioner as well as a researcher, there was a tension between the desire to elicit rich narratives, and the habitual practice of

working therapeutically with clients. I reflected upon how I was initially drawn to validate participants' viewpoints and then summarize, rather than to continue exploring the implications and meanings of their statements, which felt less containing and as if it might be confrontational in some way.

Having worked as a researcher in the field of mental health stigma before training, in a role where I explicitly drew upon my previous lived experience of depression, I was comfortable to mention this as part of the background to the study in my recruitment talks for this research, having done so many times before. I felt that it was important to reduce the power differential between myself and the potential research participants, in the setting of a mental health service user group, by stating that I had also used some mental health services, both to increase the likelihood of people feeling comfortable enough to take part in the study and to decrease the sense of 'us and them' for participants that did take part. I was therefore interested to notice the degree to which participants considered the effects of stigma upon the practitioner, rather than just thinking about the concerns of the clients. It is possible that their knowing or assuming that I was such a professional brought their attention to the experience of the practitioner as well as the client. It was also interesting to experience the disclosure process myself. While I have been happy to disclose lived experience, on placements to my supervisors, in order to reflect with them about my practice and to develop in my work, it was not something I had intended to do in the academic setting. This was because I feared that I would be judged as less able to manage my life related and thesis related stressors.

Thus I feel a strong empathy with the concerns that participants have regarding stigma in the workplace for practitioners.

I was also aware of my status as an educated white, seemingly middle-class woman and noticed how this resonated with participants, the majority of whom were also white and had been educated at least to university level. Some participants showed sympathy towards my situation of having to write a thesis, and shared their experiences of having carried out large-scale academic projects as students. I wondered to what extent this assumed shared identity meant that there were taken-for-granted assumptions in the interviews that I missed.

### **Summary and conclusions**

The study aimed to gain an understanding of the factors that clients took into account when thinking about mental health practitioners with lived experience. It also investigated if and how clients would like practitioners to disclose these experiences to them. The study has resulted in the development of a model, from a client's perspective, of the factors which are important regardless of the practitioner's disclosure, and also when the practitioner is considering, carrying out, and working with a client following disclosure of their lived experience. Novel findings focus upon the importance of the practitioner's disclosure being specifically relevant to the particular client and their circumstances; the client's development of empathy towards the practitioner; and the increased impact of disclosure if the practitioner has a higher status role in the NHS. Other findings were in

line with the existing literature, suggesting that clients value a strong relationship with practitioners before disclosure, that there are potential barriers to the relationship inherent in lived experience, and that disclosure takes place in a context where mental health stigma still informs people's views and behaviour. One interesting question which this study does not resolve, is whether there is yet sufficient acceptance of practitioners with lived experience in the NHS, to enable them to safely disclose to their clients. Clients are well aware of the risks that practitioners face by so doing. It is hoped that the current study will be helpful in adding to the evidence base around disclosure of lived experience in an NHS mental health setting, and be a step towards a reconsideration of advice and guidance for practitioners with lived experience.

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## Psychiatrists

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## Appendix 1 – Final interview schedule

### Appendix 1 – Final interview schedule

Interview Schedule V.3. December 2015

- Payments for participation and travel.
- Discussion of the research project & information sheet.
- Interviewer answering any interviewee questions about participation
- Consent form

#### 1. Demographic background (if any q's missing from telephone screening)

- Are you a member of service user group? What motivated you to join.
- Expand upon already stated MH issues – including diagnosis or description of difficulties- Have you ever spent time in hospital for your mental health. y/n and when for how long.

#### 2. Can you tell me what **contact** you've had with **mental health staff recently** [if not recently, what was most recent contact, when, can you tell me about this please]

Prompt: *Did you see any of these people - a social worker, a CPN, a mental health nurse, a psychiatrist a psychologist a psychotherapist an occupational therapist*

#### 2. What would you feel if you knew that one of these mental health staff had at some point experienced mental health difficulties themselves?

Prompts:

- *What would go through your head, any images, what would it make you think of?*
- *What concerns if any would you have?*
- *How have you come to have these thoughts / concerns? Do you think you always felt or thought this way?*
- *Are there any factors that would make a difference to your feelings?*
- *Do you think you would feel differently if the staff's issue was similar or different to something you've experienced?*

#### 3a. Have you ever known any mental health staff who themselves have lived experience of mental health difficulties?

#### 3b. How did you feel about that?

Prompts:

- *What goes through your head?*
- *any images?*
- *what does it make you think of?*
- *How do you feel about that*

#### 4. What do you think has led you to feel this way

Prompts:

- *What informs them?*
- *Experiences?*
- *Views about service users?*  
*Views about mental health and how it affects you?*
- *Any feelings about practitioner's particular mental health issue*

#### 5. How do you feel about mental health staff with lived experience of mental health difficulties telling the people they are supporting about this?

Prompts:

- *Can you describe the circumstances when you feel this would be a helpful thing to do?*
- *Can you describe circumstances when it wouldn't be?*
- *What kind of things do you feel should be taken into account by the mental health staff member?*  
*What would make a difference to your point of view?*

7. If mental health staff with lived experiences were to tell the people they support about this, how would you want them to go about it?

*Prompts: What would be helpful for them to say? How should they say it?*

*How would it be helpful for them to say this / What would they have to consider / how should and how shouldn't they say it.*

8 Is there anything else you feel is important to say about mental health staff with lived experience of mental health difficulties?

- Debriefing
- Re-consent for interview to be used in research study.

## Appendix 2 – Participant Information sheet

Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey TW20 0EX  
www.royalholloway.ac.uk/psychology

+44 (0) 1784 443526  
PSY-enquiries@rhul.ac.uk



### Participant Information Sheet v2 June 30<sup>th</sup> 2015

This sheet gives you more information about the study and what it involves. Please read this carefully before you decide whether or not to take part. If you have any questions, please ask Elly Lewis-Holmes for more information.

#### What are the aims of the study?

The purpose of the study is to collect your views on:

- NHS mental health staff having difficulties with their own mental health
- How NHS mental health staff who have lived experience of mental health difficulties should tell (or not tell) service users about this.

#### What is the background to the study

There is little guidance for NHS mental health staff who have lived experiences of mental health difficulties, around how they should best use these experiences to support the people they care for. Service users' views on this topic have not been researched directly. Discussions with service users who have been consulted report that this is an important topic.

#### Who is organising and funding this study?

The study is hosted by the Clinical Psychology Department, at Royal Holloway, University of London. The Chief investigator is Elly Lewis-Holmes, who is carrying out the research as part of her training in the Doctorate in Clinical Psychology. She has worked as an academic research assistant at the Institute of Psychiatry and University College London, from 2007-2013, prior to starting the training. She is supervised by Dr Lorna Farquharson and Dr Kate Theodore, both Clinical Psychologists and Academic Tutors at Royal Holloway University of London.

#### Who is eligible to participate?

If you can say yes to all three of the following, you can take part in the study

- 1) You have used NHS adult mental health services (for example if you were seen by a Community Mental Health Team or a 'Recovery Team') at some point since 2009
- 2) You currently feel that you are able to understand what taking part involves and make a decision about it
- 3) You can carry out an hour-long interview in English

#### What does participating in this study involve?

There are two main steps to taking part in the study.

##### 1. *Discussing the study with Elly Lewis-Holmes*

Firstly, you need to speak to Elly Lewis-Holmes about the study.

Because of the way that the interviews are being analysed, not everyone who is interested in taking part will actually get interviewed.

##### 2. *Getting interviewed*

Secondly, Elly Lewis-Holmes will contact you at some point before February 2016, to let you know if she will be able to interview you or not.

If she is able to interview you, she will conduct a face-to-face interview with you, which will take about an hour and a half. The interview will take place at a time and date convenient to you. It will be carried out either at the premises of a mental

health service user group in London, or at Royal Holloway University of London's offices in Central London.

You have the right to withdraw from the study at any time without giving any reasons. Even after the interview, if you feel you are no longer comfortable with the study, you can withdraw and all the information collected from you will be destroyed.

**What will happen to the information I give you?**

The interview will be recorded using a digital recorder. This is to make sure that your views are represented correctly in the study. The information you give will be used along with the information from other participants to write and publish a report about service user's views about NHS mental health staff with lived experience of mental health difficulties, and about how NHS mental health staff with these experiences should think about disclosing this to service users.

**How will you keep the information I give you confidential?**

As soon as the interview recording is typed up, it will be erased. Any information that might identify you or your social networks will be changed or made anonymous. The information you give will be used only for this study and it will be stored on an encrypted memory key. Only the researcher and her supervisor will have access to this information.

The only exception where a breach of confidentiality might be required is if there were issues around child protection, risk to yourself or others, or malpractice. We would discuss this with you and explain our professional duty of care before breaking confidentiality.

**What are the benefits in taking part?**

The benefits for taking part are that you will be sharing your views and ideas about this topic and that your insights may help others.

**Will I be paid?**

We believe that those who contribute to studies like this should be rewarded for sharing their experiences. In accordance to government guidance on this, we will pay £10 for taking part in the interview. In addition, we will pay travel expenses that you have incurred coming to take part in the interview.

**What are the risks in taking part?**

There are no major risks in taking part in this study. However, the interviews will involve some discussion of your experiences of mental health staff. For some people, this might bring up some difficult memories. If this happens, we can discuss this and I can help you access any support you might need. Please also feel free to discuss the study with any support systems that you might already have before you decide to participate.

**What should I do if I decide to participate?**

If you decide to participate, please contact Elly Lewis-Holmes.

- Elly will have a conversation with you and ensure that you have understood the purposes of the study and what is expected of you.
- She will ask you if you would like to invite anyone in your social network to take part in the study as well (this is entirely voluntary and will not affect your treatment in the study in any way).
- She will also ask you if you would be interested in commenting on the study's results in February 2016 (this is entirely up to you and is not affected by whether or not you get to be interviewed)

If you are still happy to take part, you will be sent a copy of this information sheet, some flyers if you are interested in inviting anyone else to take part and a sheet with information about how to access local and national support if you find the interview brings up difficult memories.

Then one of two things will happen:

1. If Elly Lewis-Holmes is unable to interview you, she will contact you before February 2016 to let you know this. If you are interested in commenting upon the study results, a set of these will be sent to you in February 2016, and you will be asked to comment upon them and return them in about three weeks.

**OR**

2. If it is possible to interview you, Elly Lewis-Holmes will contact you and arrange an interview. At the interview you will be asked to sign a consent form, a copy of which will be given to you to keep. Then the interview will be carried out.  
If you are interested you will also be given the opportunity to comment upon the study results, and a set of these will be sent to you in February 2016, and you will be asked to comment upon them and return them in about three weeks.

#### **What happens after February 2015**

Any feedback from participants and other interested service users will be incorporated into the results and the final study will be written up. An accessible version of the results will be emailed to anyone who is interested in reading them, including research participants and their social networks. The study will be assessed by Royal Holloway University of London. A version of the study will be sent for publication in an academic journal.

#### **Who has reviewed this study?**

The study has been reviewed and approved by the North West Lancaster NHS Research Ethics Committee, reference number 15/NW/0504

#### **Contact information**

If you have any questions about the study, please contact **Elly Lewis-Holmes** by leaving a message in the following ways

1. By text on this number
2. By leaving a message on the answerphone on this number
3. By emailing to this address: [mentalhealthexperience@gmail.com](mailto:mentalhealthexperience@gmail.com)
4. By visiting this website. [www.mentalhealthexperience.com](http://www.mentalhealthexperience.com) and using the 'contact' button.
5. By writing to Elly Lewis-Holmes, Clinical Psychology Department, Royal Holloway University of London, Egham, Surrey TW20 0EX

#### **Who should I contact if things go wrong or I wish to make a complaint?**

If you have a concern about any aspect of the study, or wish you make a complaint, you can contact Dr Lorna Farquarson, Academic Tutor and Clinical Psychologist, at Royal Holloway University of London, by calling her on

**Thank you for reading this**

## Appendix 3 – Participant consent forms (pre and post interview)

### Appendix 3.1 Consent form before interview

Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey TW20 0EX  
www.royalholloway.ac.uk/psychology

+44 (0) 1784 443526  
PSY-enquiries@rhul.ac.uk



#### CONSENT FORM (Version 2, June 30th 2015)

Study title: **Mental Health Experience Study**

Researcher name: **Elanor Lewis-Holmes**

Ethics reference: **15/NW/0504**

*Please initial the boxes below if you agree with the statement(s):*

I have read and understood the information sheet (June 30th 2015, Version 2); I have had time to consider the information and any questions I had about the study have been answered satisfactorily

I understand that taking part is up to me **and I may stop taking part at any time** without having to explain why and without any consequences

I understand that data collected from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this research. I give permission for these persons to have access to this information"

I agree to be audio recorded for the purpose of this study. I know that the recording will be kept securely on an encrypted memory key until the end of the project in September 2016.

I agree to take part in this research project (the Mental Health Experience Study) and agree for my interview to be used for the purpose of this study

Name of person taking part  
(print name).....

Signature of person taking part.....

Name of Lead Researcher  
(print name) ...**Elanor Lewis-Holmes**.....

Signature of Lead Researcher.....

Date.....

## Appendix 3.2 Consent form following interview

Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey TW20 0EX  
www.royalholloway.ac.uk/psychology

+44 (0) 1784 443526  
PSY-enquiries@rhul.ac.uk



### POST INTERVIEW CONSENT FORM (Version 1, May 21<sup>st</sup> 2015)

Study title: **Mental Health Experience Study**

Researcher name: **Elanor Lewis-Holmes**  
Ethics reference: **15/NW/0504**

*Please initial the box below if you agree with the statement*

Following completing the interview, I reconfirm my consent to participate in this study

Name of person taking part  
(print name).....

Signature of person taking part.....

Name of Lead Researcher  
(print name) ...**Elanor Lewis-Holmes**

Signature of Lead Researcher.....

Date.....

## Appendix 4 – Ethical approval (NHS and RHUL)

### Appendix 4.1 – National Research Ethics Service Approval 17<sup>th</sup> July 2015

Page 1



#### NRES Committee North West - Lancaster

Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Telephone: 0161 625 7818  
Fax: 0161 625 7299

17 July 2015

Ms Elanor Lewis-Holmes  
Trainee Clinical Psychologist  
Camden and Islington NHS Foundation Trust  
Department of Clinical Psychology  
Royal Holloway University of London  
Egham, Surrey  
TW20 0EX

Dear Ms Lewis-Holmes

**Study title:** Mental Health Service Users' Views of Practitioners:  
Mental Health Experience Study.  
**REC reference:** 15/NW/0504  
**IRAS project ID:** 173924

Thank you for responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Carol Ebenezer, [nrescommittee.northwest-lancaster@nhs.net](mailto:nrescommittee.northwest-lancaster@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

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



### Conditions of the favourable opinion

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

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

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

*Sponsors are not required to notify the Committee of approvals from host organisations.*

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

### Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Text for all advertising in the study v1]	1	30 April 2015
Copies of advertisement materials for research participants [Poster to be used to advertise the study]	1	30 June 2015
Covering letter on headed paper	1.0	30 June 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RSA]		01 August 2014
Interview schedules or topic guides for participants [Interview Schedule]	1	21 May 2015
Letters of invitation to participant [Letter of invitation to take part in an interview v1]	1	30 April 2015
Letters of invitation to participant [Cover Letter to Participant accompanying information sheet v1]	1	30 April 2015
Other [List of sources of support for Participants]	1	30 April 2015
Participant consent form	2	30 June 2015
Participant information sheet (PIS) [PIS version 2]	2	30 June 2015
REC Application Form [REC_Form_04062015]	4.0.0	28 May 2015
Referee's report or other scientific critique report [Provisional Approval from Research SubCommittee Royal Holloway UoL]		03 December 2014
Referee's report or other scientific critique report [Response to Provisional Approval - Amendments from E Lewis-Holmes]		
Referee's report or other scientific critique report [Initial Proposal of Study to Research SubCommittee at Royal Holloway UoL]		
Referee's report or other scientific critique report [Full Approval from Research SubCommittee Royal Holloway UoL]	1.0	15 January 2015
Research protocol or project proposal [Study Protocol Version 1]	1.0	02 May 2015
Summary CV for Chief Investigator (CI) [E Lewis-Holmes' CV]		
Summary CV for supervisor (student research) [Dr Lorna Farquharson]		

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/NW/0504	Please quote this number on all correspondence
------------	--

With the Committee's best wishes for the success of this project.

Yours sincerely



pp.  
**Dr Lisa Booth**  
Chair

Email: [nrescommittee.northwest-lancaster@nhs.net](mailto:nrescommittee.northwest-lancaster@nhs.net)

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mrs Sharon Clutterbuck*

## Appendix 4.2 – Ethical Approval from Royal Holloway University of London

Ethics Committee 30th Sept 2015

10/10/2015

Gmail - Ref: 2015/111 Ethics Form Approved



Elly Lewis-Holmes <ellystore@gmail.com>

---

**Ref: 2015/111 Ethics Form Approved**

---

30 September 2015 at 10:20

Application Details: View the form click [here](#) Revise the form click [here](#)

Applicant Name: **Elly Lewis-Holmes**

Application title: **Version 2 Mental Health Service Users' Views of Practitioners: Mental Health Experience Study.**

Comments: Approved.

<https://mail.google.com/mail/u/0/?ui=2&ik=0359ddb287&view=pt&q=Lorna.Farquharson%40rhu.ac.uk&q=tree&search=query&msg=1501d9128d9833aa&si...> 1/1

## Appendix 5 – Recruitment Materials

### Appendix 5.1 - Email sent out by service user groups to mailing lists

From: **Mental-Health Experience-Study** <mentalhealthexperience@gmail.com>  
Date: 17 October 2015 at 11:04  
Subject: Email about Research Opportunity  
To: XXXX

Would you like the opportunity to take part in some research?

The research is to find out what service users think about mental health staff, in particular mental health staff with lived experience of mental health issues.

To do this I am interviewing people who have used adult mental health services in the last five years and asking them what they think about mental health staff with lived experience.

If you would like to be interviewed, or if you would be interested in reading and commenting on the results, please get in touch! You can email on [mentalhealthexperience@gmail.com](mailto:mentalhealthexperience@gmail.com), text on        or leave a voicemail on

Full details of the study are at  
[www.Mentalhealthexperience.jimdo.Com](http://www.Mentalhealthexperience.jimdo.Com)

Please do forward this email to anyone you know who might be interested in taking part!

Thank you!

Elly Lewis-Holmes  
Trainee Clinical Psychologist at Royal Holloway University of London.

## Appendix 5.2 Overview of recruitment talk

- Introduce self – name, trainee clinical psychologist Royal Holloway University of London
- Before clinical training, last century (!) had depression and lived in sheltered accommodation provided by mental health charity
- On recent placement had interesting situation where running a group for service users to learn mental health maintenance skills and was planning to talk about how getting a good sleep routine had helped me when I was depressed – co-facilitator social worker horrified, said I shouldn't ever share lived experience with service users and she knew someone whose client had died following the practitioner disclosing.
- Was intrigued by this, and when it came to thinking about 3<sup>rd</sup> year thesis decided to follow it up. So....
- Carrying out research into service users' views of mental health practitioners with lived experience of mental health issues themselves
- Background to study – West Country surveys suggest at least 1 in 10 and up to half of NHS mental health staff describe selves as having lived experience. Not many studies about service users' views about this.
- My study involves interviewing service users and asking them what they think about mental health staff with lived experience.
- Also asking for people to comment upon the study's findings, you don't have to be interviewed but can still take part this way
- 1 hour interview, audio recorded, typed up, made anonymous, recording destroyed.
- Analysed and written up into report – for my thesis and also maybe published
- Benefits to service users? Adding service user's views to research, hopefully get taken into account in the future. £10 token in recognition of time and effort (not a payment- too small!)
- If you've used services in last 5 years, happy to be interviewed, you can sign up to go on database. Can't interview everyone but everyone welcome to give feedback
- Contact me using details on flier or I can take your contact details now
- Questions

Appendix 5.3 Flier advertising study with researcher contact details

DO YOU HAVE OPINIONS ABOUT  
NHS MENTAL HEALTH STAFF?

WOULD YOU LIKE TO BE PART OF  
A RESEARCH STUDY ?

CAN YOU SAY YES TO THESE TWO STATEMENTS?

♥ I have used adult mental health services in the last five years

♥ I would be interested in being interviewed

**If so – please get in touch!** My name is Elly Lewis-Holmes and I am a trainee clinical psychologist carrying out research at Royal Holloway University of London.

<p><b>TEXT</b></p>	<p><b>ANSWER PHONE</b></p>	<p><b>WEBSITE</b> mentalhealthexperience.com</p> <p><b>EMAIL</b> mentalhealthexperience@gmail.com</p>	<p><b>WRITE</b> Elly Lewis-Holmes, Clinical Psychology Dept Royal Holloway University of London, Egham, Surrey TW20 0EX</p>
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Department of Psychology Royal Holloway, University of London Egham,  
Surrey TW20 0EX [www.royalholloway.ac.uk/psychology](http://www.royalholloway.ac.uk/psychology)

**Appendix 6 – Table showing details of potential study consultants**

<i>Consultant number</i>	<i>Age</i>	<i>Group recruited from</i>	<i>Recruited how?</i>	<i>Gender</i>	<i>Ethnic Background</i>	<i>Educational Level</i>	<i>Employment status</i>	<i>Mental health service use</i>	<i>Diagnosis described as?</i>	<i>Inpatient admissions ?</i>	<i>Gave feedback on study?</i>
1	57	General 3	Face to face	Female	White British	Undergraduate Degree	Working	Current Long Term Secondary Adult MH service	Psychosis Delusional Disorder	Yes frequency unknown	No
2	47	General 3	Face to face	Male	White Irish	GCSE Equivalent	Working	Current Long Term Secondary Adult MH service	Personality Disorder	Yes frequency unknown	No
3	60	General 3	Face to face	Female	White British	A Level Equivalent	Working	Previous, Short Term Primary MH Care (IAPT)	Phobia	No	No
4	59	Voice Hearing 1	Email	Male	White British	Undergraduate degree	Working	Current Long Term Secondary Adult MH service	Psychosis	Yes Frequency unknown	No
<b>5</b>	<b>Did not wish to say</b>	<b>General 3</b>	<b>Email</b>	<b>Female</b>	<b>White European</b>	<b>A Level Equivalent</b>	<b>Did not wish to say</b>	<b>Did not wish to say</b>	<b>Did not wish to say</b>	<b>Did not wish to say</b>	<b>Yes</b>
5	Did not wish to say	General 1	Face to face	Male	White British	Postgraduate Qualification	Volunteering	Current Long Term Secondary Adult MH service	Missing	Unknown	No



## Appendix 7 – Participant sources of support document

List of local and national resources for [insert name of place]

### **National Resources**

#### **Samaritans 08457 90 90 90**

(local rate), 24 hours a day  
email: [jo@samaritans.org](mailto:jo@samaritans.org), web: [www.samaritans.org](http://www.samaritans.org)  
Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress, despair or suicidal thoughts.

#### **Saneline 0845 767 8000** (local rate on BT landlines)

Open 6pm - 11pm every day or you can email [sanemail@sane.org.uk](mailto:sanemail@sane.org.uk)  
Support Forum: [www.sane.org.uk/DB](http://www.sane.org.uk/DB)  
SANE services provide practical help, emotional support and specialist information to individuals affected by mental health problems, their family, friends and carers.

Mind – national service

#### **InfoLine 0300 123 3393**

Open Monday to Friday 9am to 6pm  
or e-mail [info@mind.org.uk](mailto:info@mind.org.uk)  
Offers advice and support to service users

Online index of resources:

[http://www.centreformentalhealth.org.uk/info/mental\\_health\\_information.aspx](http://www.centreformentalhealth.org.uk/info/mental_health_information.aspx)

### **Local Resources – EMERGENCIES**

*If you or someone you know is experiencing a crisis you can call the*  
**Emergency Duty Team** **Tel: 020 xxxxxxxx**

You can also call  
*A & E xxxxxx Hospital*

*Tel: 020 xxxxxxxx*

### **IN AN EMERGENCY YOU CAN ALSO CALL 999**

#### **Local Resources**

*xxxxxxx MIND*

**Phone – 020 xxxxxxxxxx**

Email - [info@mind-eh.org.uk](mailto:info@mind-eh.org.uk)

*xxxxx Service User Forum*

Meets 1<sup>st</sup> xxxx of every month (except August) from 2-4pm at xxxxxxx

*xxxxxx Recovery College*

Address

**Phone - 020**

Website - xxxxxxxx

**Appendix 8 Transcript and coding sample with second coders validation**

<b>Speaker (interviewer or participant 4)</b>	<b>Transcript – Participant 4</b>	<b>Open code (descriptive)</b>	<b>Focused code (more abstracted)</b>	<b>Second coder’s agreement / disagreement with coding and comments</b>
Participant 4	[laughs] I think that it made me feel more comfortable within myself knowing that he could relate to, you know, because it’s quite difficult opening up to people about certain things.	Feeling understood as consequence of shared experience leading to opening up	Important that practitioner’s lived experience is relevant	Agreement
Interviewer	It is yeah.			
Participant 4	And opening up to someone about a lot of issues I found much easier with a person who I could feel very comfortable around and knew that wasn’t just trying to pick holes in my mind and was actually like “Yeah I actually get that”. Which made me feel more relaxed and easier to open up and I think it was probably easier to help me in that regard because I was more relaxed and more open and felt more confident speaking to the person, which in term made me feel more confident.	Beneficial cycle of being relaxed as consequence of being understood, because of shared experience	Important that practitioner’s lived experience is relevant	Agreement – the “not picking holes in mind” thing is interesting – it seems more pronounced than just being relaxed. Like feeling one’s guard can be put down, they

				are trustworthy.
Participant 4	I probably would have been more impressed because if he would have had ADHD, I mean he had a lot of knowledge of it so he could himself have been diagnosed at some stage, but, and that actually goes for another doctor I saw as well who had a bizarrely high level of knowledge of ADHD who I think either himself or his brother may have suffered from it.	Suspecting lived experience because of high level of insight into issue	Suspecting practitioner has LE	Agreement
Interviewer	Okay yeah.			
Participant 4	But it made me feel, it would have, more I thought about it, made me feel more highly of the doctor because that personal understanding of it I think helps a lot more to deal with the subject matter and the issue.	Insight into condition when experience similar	Important that practitioner's lived experience is relevant	Agreement
Interviewer	So there were two things that you said, one was that it was impressive, was that just because of the second thing you said in because it gave a deeper understanding? Or impressive for was there more in that impressive?			

Participant 4	<p>I think more in that also because if you're struggling with a mental health problem and you can go on to become a ...consultant psychologist or something along those lines then hats off [laughs]. So it's...  ...like "Wow, you know, that is an achievement" and it's also, you know seeing that someone else can rise to the challenge gives you hope for you yourself can rise to the challenge maybe of becoming a consultant or whatever it is which you desire to do. So knowing that someone else has broken through that ceiling or however you want to put it, yeah it definitely instills a bit of confidence and more self-belief.</p>	Practitioner has overcome difficulties	Hope from practitioner because they have overcome difficulties	Agreement
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## Appendix 9 – Memo example

### Being human together / personhood.

Participants described how they valued being related to as a person by their MHP, in particular with regard to being listened to, emphasis upon the human quality of the relationship and the trusting nature of the relationship.

They described situations where the hierarchical nature of the NHS, and sometimes open mental health stigma, meant that they felt devalued as a person in their interactions with mental health staff, for example feeling that their concerns about a mental health practitioner's mental health would not be taken seriously because they themselves, as a service user, had brought it up. They described the difficulty of not having the opportunity to build up relationships with staff members because of staff changing; the difficulty of navigating their own care when they were not feeling well enough to do so, both the result of fragmented care in the NHS.

The degree to which participants are favourable towards MHP with LE, depends in part upon the degree to which they believe such MHP with LE will treat them as people.

Participants feel that they are more likely to be treated 'as human beings' by MHP with LE "...inside...yeah in their heart...if they've had mental health problems and they've become a psychiatrist, they might actually act like we are human beings" p7;

Conversely the fact that the practitioner has lived experience makes the practitioner seem more human to the participants :” Well I mean the fact is that they, it's immense that, it's immensely, the fact that they're human as well  
“ p6

Part of being treated 'as a human being' involved a decrease in formality  
“Once you've got past that, then you can sort of let your hair down a bit ... And, and say “well look, you know, we've done what we have to do , for the sake of, of the law, now lets see how we can get on with ..dealing with you as a person” p1

Participants described that the “humanness” of MHP whose mental health status they did not actually know about, led them to suspect that those practitioners had lived experience “he was...I mean he was...he was actually more friendly than, erm..... you felt when you were seeing him that you were actually, actually dealing with someone, with, not a friend, but someone who did have some sort of real... insight, into what mental illness was. And I suspect actually that he actually had some mental health issues himself” p1.

It seems that this is underpinned by the belief that the ability to relate to people as a human is a quality which is learned through experience rather than academically

“... someone whose lived and not going to sit there and judge me according to some stupid textbook where people probably don't even know what they're writing “

Participants valued being listened to highly  
““I'm not here for you to exercise your academic masturbation, you know....I need you to listen “ p2.

This again relates to the concept of wanting to be understood.

and some drew a connection between having experiences of mental health issues, and caring enough to listen to the experiences of others

“Because it’s like when people don’t listen because they haven’t been there, so they don’t care, yeah.”

p9

However, other participants were concerned that MHP with LE who had not sufficiently recovered (cf taking recovery into account concept) would specifically demonstrate an inability to listen properly

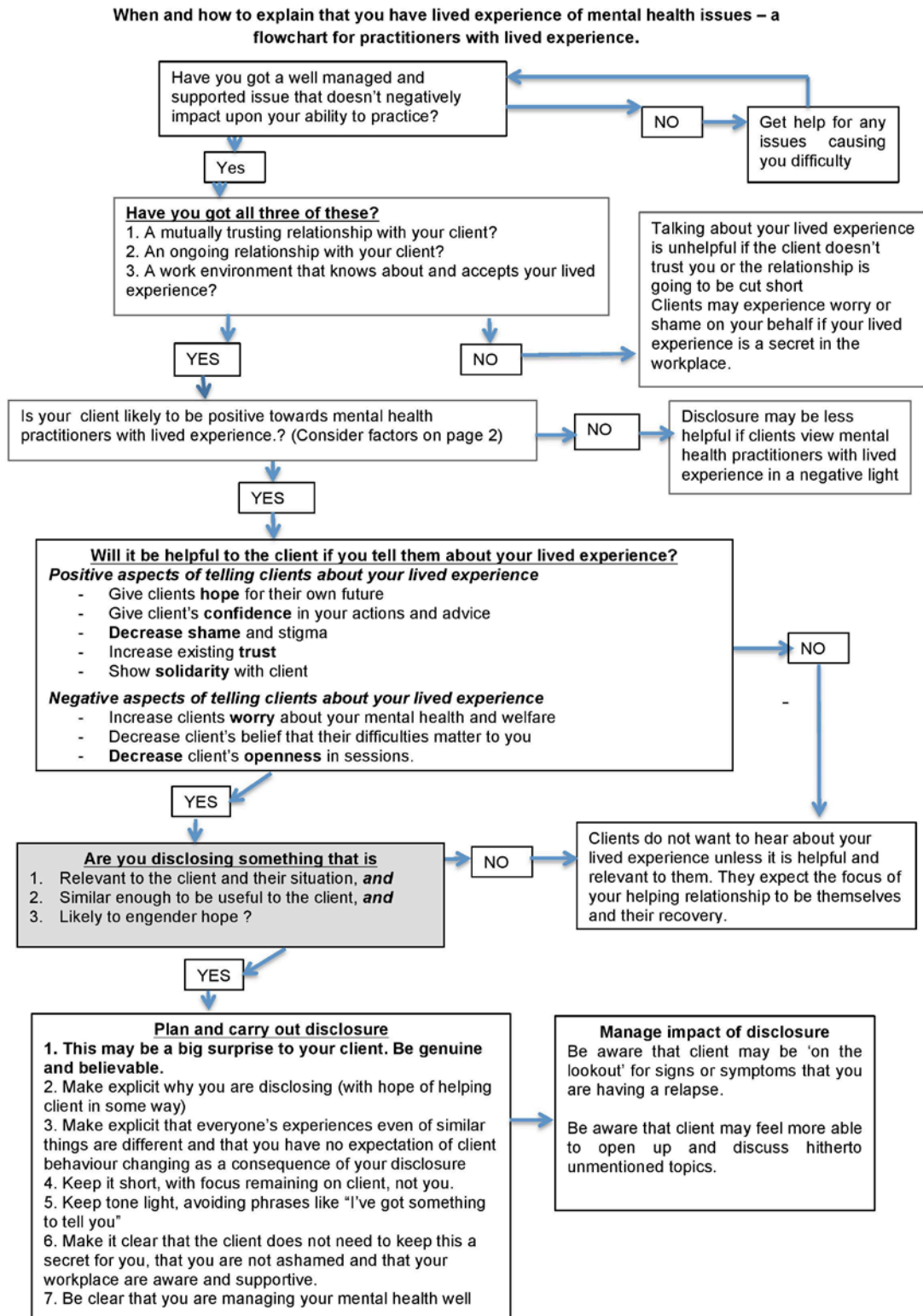
“And as I started to tell her something she would kind of pounce on something before I’d finished the story. And so then she would run with it in a direction, “Oh well you know you don’t want to let them do that because let me tell...”, and I’d be like “No that’s not what they’re doing”, “Okay she’s talking now, okay, I’ll just let her finish...” p5

Participants expect that that they will be more trusting of MHP with LE via a process of where a MHP’s disclosure of their difficulties leads them the participants to feel trusted, and allowing them then to trust the MHP in turn. “.if she trusts me enough to be able to say, “yep, I have a mental health problem” that feels to me already like...she’s put a bit of trust in me so I’m happy to return the favour,” p7

Being trusted by the MHP is likely to be particularly meaningful to participants as they report that the hierarchical nature of the NHS and also the belief that service users might be malicious (forming part of the ‘you become the vulnerable’ theme) means that they have the expectation that they will not necessarily always be trusted or believed by mental health staff.

Not being trusted or believed is invalidating, whereas being trusted allows them to be treated as a believable person.

## Appendix 10 – Initial draft results in the form of a flowchart, and feedback questions



**Important considerations influencing people's views about mental health staff with lived experiences working in the NHS.**

In the main most but not all were **positive about the issue**. The degree of enthusiasm or caution was influenced by the following

1. **Their personal beliefs about recovery** – whether or not the participant believed it would be possible to recover sufficiently from mental health difficulties to be able to adequately support others

- The type of mental health issue played a role in this – depression was seen to be more suitable than difficulties which were thought to be more unpredictable or more severe.
- Mental health stigma also played a role – people were aware of ideas that mental health problems can be seen as a weakness

2. **The quality of the support** that the mental health practitioner with LE would be able to provide

- *Positives include*
  - increased empathy
  - the ability to offer advice based on experience
  - treating the client like a fellow human

- *Negatives include*
  - less time spent on client
  - difficulties separating own MH issues from client's mental health issues
  - general decreases in competence

### **Feedback questions**

1. Many interviewees discussed times when they suspected their mental health practitioner had lived experience of mental health issues. Occasionally they discussed times when they felt the practitioners' mental health issues affected their work. What I'm not sure about, looking back over the interviews, is what people in general would want to happen at such times, so I am asking the following question to anyone who is interested,



please feel free to answer it!

“If you suspect your practitioner is having difficulties which are spilling over into their sessions with you, what would you want to happen next?”

2. In the flow chart (p1), there is not very much that appears after the practitioner actually has disclosed. Do you have any thoughts about what you would want to happen, in the sessions following the one where the practitioner disclosed to you? Please let me know any thoughts you have on this issue

3.a Does this flowchart (p1) and sheet of factors (p2) generally make sense?

3. b Are there important factors that have been left out?

3. c Do you think anything important is missing?

3. d Do you think that anything could be given more detail?

4. Do you have any comments upon the results overall, or upon the issue of mental health staff with lived experience, or the issue of whether they should disclose this, or the issue of how they should disclose this?

**April 3rd 2016 – “Despair”**

Perhaps something that unifies the findings is a sense of despair about the possibility of recovery.

- the idea that you just want to get better – like medical problem but – unlike medical problem – there are no ‘cures’ - just things that help a bit or not.

This is disrupted by the mh professional’s disclosure

And either assimilation or accommodation happens

Accommodation=> hope for getting better, overcoming, added to the despair model

Assimilation – assume that the practitioner hasn’t got better either.

Types of knowledge – facts vs experience – facts associated with medical knowledge – if you want medical knowledge and a cure, then lived experience is the wrong kind of knowledge. However, if you want human contact and understanding, then textbook knowledge gets in the way and lived experience (if relevant) is the right kind of knowledge.

This speaks to an early trust I had in getting therapy – I used to say things like “People have studied it, they must have worked out what works and how to best think about things by now..”. Now more agnostic in my views and more exposed to critical thinking about limits of knowledge. Need to look into interviews again to see if people really do hold these positions consistently or whether they are just being imagined by me because I can identify with that kind of thinking, that hope that experts will sort it out. Also makes me laugh to write “despair” at this juncture, when so much analysis to do and so little time to do it.

**Reflective / analysis diary - 18th April 2016**

Reading through my table I get the sense that these codes are all picking up on a sense of guardedness. A wariness, which one might suggest comes from the near universal depiction of mental health support which doesn’t make any of these things that they worry about, a given.

From a practitioner’s position, I had taken it as a given that the MHP would have symptoms under control; not so the experience of participants who list instances where people seem to have difficulties in the room.