

Recovery from psychosis: A mental health inpatient perspective.

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### Statement of Terms

The term 'mental health inpatient' has been abbreviated throughout this thesis using the acronym 'MHI'.

The terms patient, mental health inpatient (MHI), service user and client may be used interchangeably in reference to the other authors' work or participants' accounts.

## Research Summary

**Background:** Within the recovery literature there has been a drive towards obtaining service users' conceptualisations of recovery as opposed to medicalised conceptualisations, in order to inform service provision. The focus remains on community populations who have described recovery from psychosis as a journey involving rebuilding the self, finding hope, and reclaiming a purpose in life. There is limited literature conceptualising recovery from psychosis for those accessing MHI services.

**Aims:** To gain a deeper understanding of MHIs' lived experiences of recovery from psychosis and to conceptualise recovery from psychosis through MHIs' descriptions.

**Methodology:** In-depth semi-structured interviews were conducted with MHIs and analysed via interpretative phenomenological analysis (IPA).

**Results:** Five superordinate themes and accompanying subordinate themes emerged. The superordinate themes developed were: "*My future is just being ripped out in front of me*": Living with psychosis is a struggle; "*Would you want to be in here?*": Traumatic experience of being in hospital; "*I know roughly why I got ill anyway and what caused this*": A journey towards reaching an understanding; Recovery/Rehabilitation/Recuperation: A process of evolution; and "*You need all the help you can get*": Facilitators of Recovery. Living with psychosis is a struggle reflects the struggles experienced which appeared to hinder recovery. The experience of hospitalisation was described as traumatic and was seen by many as preventing recovery. Recovery was described as an evolutionary process involving reaching an understanding about individual experiences. Facilitators of recovery were identified.

**Conclusions:** This study highlighted that for the participants interviewed, MHI settings are not settings where everyone can be in recovery or approaching recovery however the concept of recovery is viewed. For some participants recovery appeared to be an 'empty signifier' that

is meaningless and is a word used by services that does not necessarily correspond with some of their experiences of MHI settings.

## **CHAPTER ONE: INTRODUCTION**

This study explores the lived experiences of mental health inpatients (MHI) living with psychosis and their views on recovery. This chapter focuses on defining psychosis and explaining its conceptual development, introducing theories for conceptualising psychosis, exploring recovery and the development of recovery models, and examining the context of current MHI care. This chapter concludes with the results of a qualitative systematic review, followed by the research questions and aims.

### **1.1 Part I: Understanding psychosis**

#### **1.1.1 Defining psychosis**

Historically the medical conceptualisation of mental illness has been favoured in understanding experiences of psychosis. More recently there has been increased support for viewing psychosis within a psychological framework and incorporating individual accounts of experiences (Cooke, 2014). These perspectives will be explored to provide the reader with an understanding of how the definition of psychosis has developed, beginning with the current psychiatric conceptualisation.

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) combines the psychoses into one chapter (American Psychiatric Association [APA], 2013). All disorders within this chapter are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganised thinking, grossly disorganised or abnormal motor behaviour, and negative symptoms (APA, 2013). Hallucinations are “perceptions occurring in the absence of corresponding external or somatic stimuli” (Arciniegas, 2015, p. 716). Delusions are false beliefs that are fixed even if evidence is provided

that contradicts them (Arciniegas, 2015). Disorganised thought can be indicated by changes in an individual's speech, such as providing contextually inappropriate answers and shifting to unrelated topics of conversation (APA, 2013). Disorganised behaviours refer to behaviours that are not synonymous with the situation, such as displaying an inappropriate emotional response to a given situation (Tandon et al., 2013).

Within the psychoses, a distinction is made between positive and negative symptoms. Positive symptoms are those that were not present prior to the onset of psychosis, such as hallucinations and considered an addition to the individual's psyche (Andreasen et al., 1994). Negative symptoms are defined as the absence or reduction in behaviours that are normally present prior to the onset of psychosis such as social withdrawal and absent emotional responses (Buchanan, 2007).

The current psychiatric definitions focus on the observable symptoms, which is consistent with traditional psychiatric conceptualisations (Bertolote, 2008). The National Institute for Health and Care Excellence (NICE, 2014) provides the following conceptualisation:

“Psychosis and the specific diagnosis of schizophrenia represent a major psychiatric disorder (or cluster of disorders) in which a person's perception, thoughts, mood and behaviour are significantly altered. The symptoms of psychosis and schizophrenia are usually divided into ‘positive symptoms’, including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and ‘negative symptoms’ (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect).” (p. 5).

### **1.1.2 Medical conceptualisation of psychosis**

Emil Kraepelin changed the way in which mental illnesses were defined by coining the term ‘dementia praecox’ which he described as an incurable psychotic disorder

(Kraepelin, 1893). Dementia praecox was described as a progressive condition leading to irreversible mental defects (Adityanjee, Aderibigbe, Theodoridis, & Viewig, 2002).

Kraepelin believed that age of onset, family history and personality characteristics were useful in making distinctions between dementia praecox and manic-depressive insanity (Adityanjee et al., 2002). The latter was deemed to lead to better outcomes due to it involving periods of remission with no or little cognitive defect (Mondimore, 2005).

By the late 1920s dementia praecox was replaced by Bleuler's schizophrenia. Bleuler defined schizophrenia as a disturbed thought process characterised by associative splitting (Ashok, Baugh, & Yeragani, 2012). He viewed several symptoms as being directly caused by the disease process and stated that others were responses to environmental factors and the struggle of an ailing psyche (Adityanjee et al., 2002). He argued that dementia praecox did not always end in deterioration (Maatz, Hoff, & Angst, 2015). Bleuler was seen to be the instigator of a psychological approach to schizophrenia (Berrios, 2011). In 1952 when the DSM was published dementia praecox was no longer recognised. From this point onwards psychosis continued to be defined by psychiatry as a set of symptoms, however, there was increased hope regarding prognosis due to medical advances.

In the 1950s antipsychotic medication was introduced as a treatment for psychosis. Alongside this came the development of the dopamine hypothesis. Trials administering antipsychotics to animals found an increase in the animals' metabolism of dopamine (Carlsson & Lindqvist, 1963). The dopamine hypothesis was later reconceptualised due to advances in scientific knowledge (Davis, Kahn, Ko, & Davidson, 1991; Howes & Kapur, 2009). Animal studies and neuroimaging data highlighted that dopamine metabolites were not universally elevated in patients with schizophrenia (Howes & Kapur, 2009). Davis et al.

(1991) found that regional brain dysfunction in patients with schizophrenia was indicated by reduced blood flow in the frontal cortex which correlated with reduced dopamine levels. These findings differentiated between specific areas of the brain and the production of negative and positive symptoms.

Howes and Kapur (2009) suggested that multiple factors including genes, substances, stress and fronto-temporal dysfunction lead to dopamine dysregulation. ‘Aberrant salience’ theory helped describe how psychosis resulted from dopamine dysregulation altering how the brain appraises stimuli (Roiser, Howes, Chaddock, Joyce, & McGuire, 2012). Evidence has accumulated over the years to support this hypothesis (Hirvonen & Hietala, 2014; Toda & Abi-Dargham, 2007; Seeman, 2009), whilst others have highlighted its limitations resulting in the oversimplification of a complex experience (Lau, Wang, Hsu, & Liu, 2013; Moncrieff, 2009).

One of the difficulties with defining psychotic experiences as a mental illness is the difficulty in separating psychotic from normal experiences due to our mental health existing on a continuum (Keyes, 2002). Experiences such as paranoia to a certain extent can be part of the ‘normal’ developmental process (Meissner, 1981). Classifying such experiences as a mental illness can be perceived as stigmatising if the individual does not experience them as distressing. Other issues with diagnosis include its reliability, validity and utility (Cooke, 2014). Individuals’ experiences and the emotional impact are real but the explanation that it is caused by an illness called ‘psychosis’ may not be accurate and meaningful for the individual (Insel, 2013).

Clinicians and researchers have explored alternative ways of reporting and understanding people's experiences. The British Psychological Society (BPS, 2011) has supported this paradigm shift due to:

“Clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences...but which do not reflect illnesses so much as normal individual variation...This misses the relational context of problems and the undeniable social causation of many such problems” (p. 1).

The alternatives proposed include developing psychological formulations.

Formulation involves a collaborative process of developing a shared understanding of a person's difficulties whilst considering their social circumstances, life events and the meaning they have made as a result (Johnstone, 2017). Focus has moved towards collating personal accounts from those with lived experience of psychosis. Within these accounts, diagnosis was viewed as a loss or change in identity leading to reduced self-esteem (Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). These perspectives have supported clinicians to think differently due to the significance of multiple losses and the impact on self-esteem and identity. This is not considered within the medical model, highlighting a disconnect between how psychosis is categorised and how it is experienced (Gee, Pearce, & Jackson, 2003; Krupa, Woodside, & Pocock, 2010; Wagner & King, 2005).

### **1.1.3 Psychological conceptualisation of psychosis**

The following section will focus on the dominant psychological conceptualisations of psychosis; systemic, cognitive behavioural, and the links with attachment theory and trauma. Both systemic therapy and cognitive behavioural therapy (CBT) are recommended as frontline interventions for adults experiencing psychosis (NICE, 2014).

**1.1.3.1 Systemic conceptualisation.** Bateson provided the beginnings of a psychological understanding of schizophrenia based on the ‘double bind situation’ occurring within a family (Bateson, Jackson, Hayley, & Weakland, 1956). A ‘double bind situation’ was defined as involving two or more people, one being the ‘victim’ (Bateson et al., 1956). This situation occurs as a result of repeated experiences of conflicting communications in which the ‘victim’ has no opportunity to ignore, leave or appropriately respond (Gibney, 2006).

Hoffman (1982) suggested that it is not the system that causes the symptoms, but the presence of symptoms that contributes to the system responding in such a way. The system responds in a contradictory way as a result of the family attempting to communicate their concern and provide containment (Gibney, 2006). This theory helps to explain the impact power and defence mechanisms such as denial, splitting and projection may have on an individual’s experience and presenting symptomology (Watzlawick, Beavin, & Jackson, 1967).

High levels of expressed emotion (EE) within families has also been highlighted as a contributing factor to the maintenance of psychosis (Amaresha & Venkatasubramanian, 2012). EE refers to a caregiver’s attitude towards an individual with a mental health difficulty and has been shown to be a significant psychosocial stressor related to relapse (Butzlaff & Hooley, 1998). The components of EE are critical comments, hostility, emotional over-involvement, positive regard and warmth (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). Brown, Birley, and Wing (1972) found that the likelihood of relapse and readmission increased when patients were discharged home to their family as opposed to living in lodgings, and that prolonged contact with family influenced their level of functioning and degree of symptomology (Brown et al., 1972). High levels of EE within

families are associated with increased relapse rates from schizophrenia (Bebbington & Kuipers, 1994; Brown et al., 1972; Kavanagh, 1992). The development of high EE and the mechanisms by which EE increases relapse are still not fully understood (Barrowclough & Hooley, 2003). EE has not been found to be predictive of relapse within Asian families, suggesting predictive validity may be culturally specific (Hashemi & Cochrane, 1999).

**1.1.3.2 Attachment theory.** This theory is connected to the systemic conceptualisation due to the acknowledgement of the psychological impact of interactions between the caregiver and individual. Attachment theory suggests the formation of close affectional attachments are a universal need and that distress is modulated via attachment behaviours (Bowlby, 1980). Early interpersonal experiences inform internal working models and representations of the self and others, which influence future functioning in relationships (Berry, Barrowclough, & Wearden, 2008). Interpersonal difficulties are often significant for those experiencing psychosis (Penn et al., 2004), and have been recognised as contributing to an individual's vulnerability to developing psychosis (Read, Van Os, Morrison, & Ross, 2005).

Individuals experiencing psychosis are more likely to have an insecure avoidant or dismissive attachment style (Couture, Lecomte, & Leclerc, 2007; Dozier, 1990; Ponizovsky, Nechamkin, & Rosca, 2007). This attachment style is signified by a lack of orientation towards an attachment figure, appearing both physically and emotionally independent of the attachment figure (Behrens, Hesse, & Main, 2007). The failure to develop an internal secure base as a result of early attachment difficulties may make it more difficult to integrate and explore psychotic experiences (Birchwood, 2003) and has been linked to a 'sealing over' recovery style (Drayton, Birchwood, & Trower, 1998; Tait, Birchwood, & Trower, 2004).

This recovery style involves difficulty understanding and recognising psychotic experiences leading to avoidant coping strategies, which have been linked to relapse and impaired social functioning (McGlashan, 1987). A 'sealing over' recovery style has also been linked with less engagement with services (Tait et al., 2004).

Individuals experiencing psychosis reported having less caring and less expressive parents, which links with the impact of EE within families (Onstad, Skre, Torgersen, & Kringlen, 1994; Willinger, Heiden, Meszaros, Formann, & Aschauer, 2002; Winther Helgeland & Torgersen, 1997). The role of individual attachment style has been associated with eliciting different levels of EE such as an individual with a dismissive attachment style being more likely to receive criticism from relatives due to their tendency to behave as though they are self-sufficient and rejecting of support (Berry, Barrowclough, & Wearden, 2007).

Interpersonal difficulties in psychosis can be conceptualised as attachment strategies that were developed as adaptive responses (Berry et al., 2007; Mallinckrodt, 2000). Internal working models developed as a result of previous interpersonal relationships have been suggested to be significant factors in influencing an individual's response to hearing voices (Birchwood, Spencer, & McGovern, 2000). Individuals with a fearful attachment style who are more likely to have a negative view of others and low self-efficacy may be more likely to believe the voices are more powerful than them and of a malevolent nature, leading to increased distress (Birchwood & Chadwick, 1997).

The way an individual copes with stressors can determine the onset and course of psychosis (Nuechterlein & Dawson, 1984). An individual with an avoidant attachment style

is more likely to have negative expectations regarding help-seeking and may attempt to regulate their distress using avoidant coping styles which has been linked to poorer outcomes (Mikulincer, 1998). This attachment style has also been associated with increased vulnerability to developing negative symptoms due to the tendency to avoid when distressed (Bartholomew, 1990).

Viewing current psychotic behaviours as functional in the context of previous experiences supports less critical attitudes from others and can also support the individual to recognise that their internal working model of the world and their coping style may no longer be protective (Adshead, 1998; Sable, 1997). This reduced critical attitude towards an individual can lead to 'parental blaming' which is a critique of attachment theory (Bolen, 2000). Therefore, when applying attachment theory, it is important to consider the dynamic nature of parent and child characteristics and the way they interact with wider social factors such as deprivation (Cook, 2000).

**1.1.3.3 Trauma.** There is significant evidence emphasising the importance of acknowledging particular life events that are common of those presenting with psychosis, including trauma, abuse and discrimination (Bentall, Wickham, Shevlin, & Varese, 2012; Kilcommons & Morrison, 2005; Read, Bentall, & Fosse, 2009; Varese et al., 2012). If these experiences are overlooked due to treating psychosis rather than trauma, this may hinder recovery.

Multiple studies have evidenced the effects psychosocial stress can have and further implicated this in the development of psychosis (Johns et al., 2004; Van Winkel, Stefanis, & Myin-Germeys, 2008; Wiles et al., 2006). An increased risk of experiencing psychosis has

been associated with repeated exposure to traumatic events (Shevlin, Houston, Dorahy, & Adamson, 2008).

The traumagenic neurodevelopmental model of psychosis highlights that the structural and biochemical abnormalities found in the brains of those diagnosed with schizophrenia are also evident in the brains of traumatised children (Read, Perry, Moskowitz, & Connolly, 2001). Attachment, coping resources, limited social support and psychodynamic defences have been identified as potentially mediating between childhood adversity and mental health difficulties developing later in life (Bebbington, 2009; Read et al., 2001; Read et al., 2009). These studies have helped to illuminate the specific experiences and characteristics of an individual which may be hidden by a diagnosis.

Sexual trauma in childhood has been linked to increased risk of experiencing hallucinations (Read & Bentall, 2012). Experiences of chronic victimisation such as bullying have been linked with increased risk of paranoid delusions due to these experiences affecting the way unpleasant experiences are appraised (Bentall & Fernyhough, 2008). Evidence has also linked the content and form of psychotic symptoms with the specific nature of the trauma (Fowler, 2000). This way of understanding psychotic symptoms may be more meaningful to the individual and takes account of their experiences.

The presence of traumatic experiences has been correlated with negative outcomes in psychosis including increased misuse of substances, increased symptom severity and higher rates of relapse (Doering et al., 1998; Mueser et al., 1998). The mechanisms through which traumatic events influence the course of psychosis are still being strongly debated (Read et al., 2001).

**1.1.3.4 Cognitive Behavioural conceptualisation.** Cognitive behavioural models suggest that some individuals who experience attachment difficulties and trauma may form negative beliefs about themselves and others which can lead to the development of psychotic symptoms (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Several cognitive models of psychosis have been developed including a cognitive model of the positive symptoms of psychosis (Garety et al., 2001) and a cognitive model of persecutory delusions (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002).

The cognitive model of positive symptoms of psychosis provides two explanations for the development of positive symptoms (Garety et al., 2001). The first is that a triggering event in a person predisposed to developing psychosis facilitates a disruption of cognitive processes (Garety & Hemsely, 1994). This leads to material from the individual's memory intruding into their consciousness (Hemsely, 1993). An alternative explanation of this disruption is that the individual experiences difficulties with self-monitoring. This failure to recognise one's own intentions and actions may lead to the individual experiencing them as 'alien' (Frith, 1992). Emotional changes occur in response to the triggering event and subsequently influence the content of cognitions. At this point individual differences in cognitive processes play a significant role as those with biases and deficits in understanding social situations are more likely to experience increased negative affect in response (Garety & Freeman, 1999). This model also emphasises the influence of social adversity, deprivation and early traumatic experiences on creating cognitive vulnerabilities, which may reinforce external negative attributions (Garety et al., 2001). Isolation can also lead to limited access to alternative explanations of experiences (White, Bebbington, Pearson, Johnson, & Ellis, 2000). If an individual is able to reject the idea that their experiences are being externally controlled then they may be able to make sense of their experience in relation to the

triggering event and cognitive biases and experience hallucinations without becoming delusional (Peters, Joseph, & Garety, 1999).

The second explanation for the development of positive symptoms is that a triggering event disturbs affect but does not cause a cognitive disruption. This results in activating biased cognitive appraisal processes and maladaptive schemas leading to an externalising appraisal of the triggering event or the disturbed affect. In this explanation delusions could therefore occur without hallucinations (Garety et al., 2001). The factors posited as being involved in the maintenance of psychosis are emotions, dysfunctional schemas, adverse social environments, biased reasoning processes, as well as insight (Garety et al., 2001).

The cognitive behavioural conceptualisation of psychosis integrates aspects of the medical conceptualisation such as biological predispositions as well as psychological theories of trauma and attachment.

#### **1.1.4 Cultural and spiritual conceptualisations of psychosis**

Cultural and spiritual contexts can impact on how hearing voices and experiencing hallucinations are understood. Hearing voices has been linked to experiencing a spiritual crisis, leading to personal and spiritual growth or access to a deeper understanding of the world (Menezes Jr & Moreira-Almeida, 2010; Romme & Escher, 1993). Therefore, how the experience is defined and understood depends on whether it is perceived as a symptom of mental illness (Laroi et al., 2014).

Due to the rise of cultural diversity within society, it is important to consider how different cultures may view experiences (Haworth, 1998; Kirmayer, 1989). The difficulty in

studying culture and ethnicity is that they do not occur in isolation and other factors including age, gender, class and education are likely to contribute (Pote & Orrell, 2002). Studies have shown that non-western conceptualisations of mental illness are more diverse than western conceptualisations. In East Africa they do not follow rigid classification systems like western cultures do (Littlewood & Lipsedge, 1989). Amongst certain tribes diagnosis is viewed as negotiable and disagreements over whether an individual is 'eccentric' or mentally unwell are frequent. In a study focusing on perceptions of schizophrenia across different ethnic groups, Afro-Caribbean participants did not view unusual thought content as a symptom as frequently as the White British participants and the Bangladeshi participants were less likely to view hallucinations as indicating a mental illness (Pote & Orrell, 2002).

Psychiatry can be considered to be a Western discipline and therefore Psychiatrists' training is led by Western nosology of medicalised concepts when interpreting behaviours or experiences as symptoms. This can result in a reductionist and pathologising view in multi-cultural societies where multiple belief systems exist.

### **1.1.5 Current conceptualisation of psychosis**

The current conceptualisation of psychosis remains dominated by the medical model with an emphasis on diagnosis, pharmacological interventions and biological underpinnings. Stigma is a significant area of concern in relation to diagnosis, particularly in regards to psychosis where people are often perceived as dangerous and unpredictable which can lead to rejection, isolation and exclusion (Angermeyer & Matschinger, 2003; Link, Monahan, Stueve, & Cullen, 1999; Link & Phelan, 2001). The individual's social and financial situation can be overlooked when a person is diagnosed and the focus placed on the individual as the

‘problem’ (Dean & Murray, 2005; Jarvis, 2007). This can prevent changing environmental factors that may improve the individual’s quality of life and their experiences.

Psychological and service user led conceptualisations have led to advances in the interventions available and have supported the growth of hope for the prognosis of psychosis. This increased hope has supplemented the recovery narrative and challenged the traditional medicalised view of recovery.

## **1.2 Part II: Recovery**

### **1.2.1 Defining recovery**

Recovery from psychosis has gathered greater interest over the last few decades and much controversy exists today about how to define recovery and whether it should be defined. This section begins with a focus on the development of the medical conceptualisation of recovery before moving on to consider service users’ conceptualisations. Critiques of recovery are then considered along with descriptions of recovery models.

The WHO European Mental Health Action Plan (2013) encouraged a push towards more service user led thinking on recovery, as opposed to traditional clinical recovery, as a result of the disagreements around defining recovery (South London and Maudsley NHS Trust, 2010). Clinicians’ views of recovery tend to be guided by symptom and functional remission (Wunderink, Sytema, Nienhuis, & Wiersma, 2009). This medical understanding locates recovery within an illness framework of understanding and links recovery with a pervasive reduction or complete removal of symptomology (Slade, Amering, & Oades, 2008).

### **1.2.2 Historical development of recovery**

There has been much debate regarding the long-term prognosis of schizophrenia, which Cohen and Cohen (1984) linked to the ‘clinician’s illusion’. This illusion existed due to clinicians treating those acutely unwell and generalising this to the population, resulting in a skewed perspective. Progress has been made in moving away from the Kraepelinian idea that psychotic disorders lead to a progressive deterioration (Ebert & Bar, 2010). Longitudinal studies have found that approximately 40% of patients with a diagnosis of schizophrenia reach social or functional recovery (Crumlish et al., 2009). Some research suggests that a full social recovery can be achieved without antipsychotic medication and by emphasising social and emotional support (Wunderink, Niebor, Wiersma, Sytema, & Nienhuis, 2013). These findings support that recovery from psychosis is possible and brings the emphasis of the medical model into question.

**1.2.2.1 Deinstitutionalisation.** Institutionalisation began to be thought of as iatrogenic and a harmful way of responding to mental health difficulties. As a result of the 1962 Hospital Plan MHI services were built on general hospital sites and community mental health teams were developed (The King’s Fund, 2015). Community care was initially criticised due to increased levels of homelessness which was linked to asylum closures (Coid, 1994). Longer-term studies highlighted improved quality of life, increased independence and social networks for the majority of people accessing community services (Thornicroft, Bebbington, & Leff, 2005; Trieman & Leff, 2002). Deinstitutionalisation was supported by the belief that recovery was more achievable due to advances in treatments. By 1948 the National Health Service (NHS) was established which aided access to interventions.

**1.2.2.2 Advances in treatment.** Chlorpromazine was introduced in the 1950s to treat patients with ‘erratic’ or ‘unmanageable’ behaviour and was found to be beneficial in supporting patients to appear calmer (Casey et al., 1960; Shen, 1999). Clozapine was later introduced due to chlorpromazine not appearing to work with treatment resistant patients (Ayd, 1961). Following this, several other antipsychotic medications such as risperidone were developed which are still used today.

Psychological therapy for psychosis began being implemented at the end of the 19<sup>th</sup> century (Brenner, Hoffman, & Heise, 2001). Psychoanalysis developed within the field of psychosis when Federn proved that transference was possible with this population (Bachmann, Resch, & Mundt, 2003). By the 1950s systemic theory had developed and family therapy remains a recommended intervention for psychosis today (NICE, 2014). Prior to the development of CBT, psychosocial management and operant conditioning were used in the treatment of psychosis (Skinner, 1938). CBT has now been specifically tailored for psychosis and has proven to be effective for those experiencing persistent symptoms as well as those that are resistant to medication (Butler, Chapman, Forman, & Beck, 2006; Sensky et al., 2000).

The rise of treatments for psychosis has resulted in recovery becoming a focus within NHS services. In 2001 The National Workforce Team and the Support Time Recovery (STR) steering group concluded that service users required companionship, someone to listen to them and work with them to resolve practical difficulties (Morris, 2006). This led to the role of STR workers being developed to support service users with their recovery, including unemployment. Unemployment rates are high within the mental health population and are a significant barrier to recovery (Mental Health Foundation, 2015). Recovery colleges were

developed to inspire hope and enable people to access employment and education opportunities (Taggart & Kempton, 2015).

### **1.2.3 Service users' conceptualisations of recovery**

Service users' views of recovery have supported the move away from singling out the importance of clinical recovery and focusing on a phenomenological approach to understanding recovery. Wilken (2007) conducted a meta-analysis which resulted in five clusters of factors emerging. Motivational factors around generating hope and belief about recovery were identified, as well as being able to manage the illness and developing the psychological skills to perceive life and identity in a new way. Increased social and community participation were highlighted as supporting recovery, including housing and income as well as support from services and the social network. Kelly and Gamble (2005) identified hope, mentorship, spirituality, growth and being an individual as key to recovery. A review combining both qualitative and quantitative studies found personal wellbeing and social inclusion as being signs of recovery (Jose et al., 2015).

A systematic review focused on personal recovery in mental illness developed a framework conceptualising recovery based on stages linked with the transtheoretical model of change (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Personal recovery was found to involve feeling connected, holding hope and optimism for the future, having a meaning in life, feeling empowered and finding one's identity (Leamy et al., 2011). A greater emphasis on stigma and spiritual influence was found for individuals of black and minority ethnic origin (Leamy et al., 2011). Wood and Alsawy's (2017) review focused specifically on recovery from psychosis and developed three themes involving the recovery journey and the facilitators and barriers to recovery. The recovery journey was described as stages of change

with the potential to relapse. The stages were identified as acknowledging the self prior to psychosis and reconciling past experiences such as trauma, before experiencing an episode of psychosis and attempting to make sense of this. The third stage involved accepting psychosis and integrating psychosis into one's identity followed by rebuilding one's life and sense of self. Facilitators of recovery included social support, spirituality, personal agency and hope, positive support from services, and environmental resources such as meeting basic needs. Barriers to recovery included stigma and discrimination, substance misuse, social deprivation and negative experiences of medication and mental health services (Wood & Alsawy, 2017).

There is a general consensus in the recovery literature that symptoms can be present throughout recovery and that recovery is signalled by a reduction in symptoms or an ability to live better with these symptoms (Anthony, 1993; Pitt et al., 2007; Wilken, 2007; Wood, Price, Morrison, & Haddock, 2010). Recovery was also not necessarily signified by reduced hospital admissions or the absence of relapse (Law & Morrison, 2014) which highlights the incongruence between service users' conceptualisation of recovery and the current medical conceptualisation.

#### **1.2.4 Survivor movements**

Survivor movements emerged due to international organisations advocating for human rights to be acknowledged within the mental health system due to the abuse and oppression reported within these systems (Adame, 2011; Burstow, 2004; Deegan, 1996). An aim of several survivor movements is to support healing from iatrogenic trauma and advocate for the creation of alternatives to current systems.

In the 1960s the deinstitutionalisation movement was introduced which was propelled by the civil rights movement, women's right movement, anti-racist movements, the introduction of anti-psychotic medication and politicians seeking cheaper alternatives (Hirsch, Kett, & Trefil, 2002; Minkoff, 1987). Critiques have spoken about such movements aiming to achieve social order due to the individuals directing the reforms being from the same social classes as the perpetrators of abuse (Cohen, 1985). Dain (1980) explains:

“Therapy and humane care [are often] confused with the desire to rid society of a disturbing class of people” (p. xxvii).

Antipsychotic medication has been viewed as a form of chemical control to replace the physical control of asylums (Cohen, 1985). Today's movements aim to expose the power relations within mental health care and shift the political discourses that are deemed to be oppressive.

The International Hearing Voices Movement (HVM) is an example of a survivor movement that promotes the idea that hearing voices is a meaningful human experience (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014). A direct development of this movement were the 'hearing voices groups' (HVGs) who provide an alternative approach for individuals who have not found traditional mental health services helpful (Corstens et al., 2014).

'Recovery in the Bin' is another example of one of these movements. They are a user led group of mental health supporters and survivors who are critical of the neoliberal 'recovery' model. They have offered a recent critique of a psychological conceptualisation of mental illness. 'The Power Threat Meaning Framework' (PTMF) has been developed by Psychologists to provide an alternative to psychiatric diagnosis (Johnstone & Boyle, 2018). Scheherazade (2018) argues that this 'paradigm shift' is a form of Psychologists asserting

their power and voice about how to categorise mental illness using psychological language and emphasises how this battle between psychiatric discourse and psychological discourse continues to be disempowering for the individuals living through an experience that is continuously defined by others. This movement is highlighting the potential injustice in professionals conceptualising individuals' experiences for them, regardless of their professional background and supports the need for service users to be able to conceptualise their own experiences.

### **1.2.5 Critique of recovery**

The medical definition of recovery has been criticised for holding a reductionist and persecutory view of individuals which can lead to missing the true nature of the distress and what phenomena such as hearing voices is attempting to communicate to the individual and others about their lives and the world (Cushman, 1995; Laing, 1959; Leitner, 1999; Pilgrim & McCranie, 2013; Rose, 2014). A further critique is that the conceptualisation of recovery focusing on future goals and strengths implies that weakness and deficit must be present (Harper & Speed, 2012). The recommendation is to move the focus from individual vulnerabilities and address social causes of distress (Boyle, 2003).

Beresford (2015) highlights concerns with the ideology of recovery. He raises the difficulties in critiquing the recovery movement due to the 'ideals' this movement holds and the optimism it can provide. Beresford (2015) highlights the vague and value-laden definitions of recovery and the focus being on personal change and an individual having control over their life. Whilst at the same time mental health services are facing significant issues with underfunding and the austerity policy leading to welfare cuts, undermining the security of those experiencing mental health difficulties and potentially increasing stigma,

anxiety and exclusion (O'Hara, 2014). Recovery may therefore be impossible within the current socio-economic climate. Recovery originated within a medical model and suggests that support can be withdrawn once an individual is 'recovered', which fails to recognise the reality of mental illness and the potential need for ongoing support (Morrow, 2013).

To a certain extent the recovery movement has been focused on employment regardless of the suitability or quality of employment (Harper & Speed, 2012). This push to being 'recovered' fits with policies such as the government welfare reform policy, which questions whether the recovery movement is a way of serving neo-liberal aims (Beresford, 2015). Neo-liberals posit that individuals should take care of themselves and not rely on the state which mirrors the focus of psychiatry in regards to individualised explanations for emotions and behaviour and a level of disregard for social issues (Beresford, 2015). This focus on individualisation creates greater social injustice which can negatively impact physical and mental health. The wider the gap becomes in social and financial equality, the more unwell people appear to become at either end of the scale (Wilkinson & Pickett, 2010).

The recovery model has informed the structuring of services and has involved creating recovery teams and providing targets on treatment length. This is advantageous for some individuals to support them not to create a sense of dependency on services, however, for others it has resulted in premature discharge leading to relapse. This reflects that recovery is not a 'one size fits all' approach despite government policies and services responding as though it is (Harper & Speed, 2012; Slade et al., 2014).

Some are arguing for a 'Social Model of Madness, Distress and Confusion' to place mental health within the current context of the social justice struggle (Beresford, Nettle, &

Perring, 2010). Some service users argue that being ‘unrecovered’ is just as valid as being ‘recovered’, highlighting their rejection of the neo-liberal influence on recovery. They are not completely rejecting recovery but argue that it is being used to place pressure on individuals to recover and is masking greater coercion to promote removal of services and placing blame on the individual (Recovery in the Bin, 2018). These critiques further highlight the need to listen to how service users make sense of their experiences and the ways they think services and society can meet their needs.

### **1.2.6 Recovery models**

Recovery models focus on building resilience and control over life rather than full resolution of symptoms (Davidson et al., 2006; Ramon, Healy, & Renouf, 2007). Current policies and mental health legislation have supported the integration of recovery models internationally into mental health services (Bonney & Stickley, 2008). The Empirically Validated Stage Model (Andresen, Oades, & Caputi, 2003) and the Tidal Model (Barker, 2003) will be discussed due to one specifically being developed within acute settings and the other developed for recovery from schizophrenia.

**1.2.6.1 The Tidal Model.** This model was developed from several studies focusing on the power dynamic between nurses and patients (Barker, 2001). The model employs a respectful approach and helps individuals and their families understand mental illness in the context of their life experiences (Alanen, Lehtinen, Rakkolainen, & Aaltonen, 1991). As a result of the nurse and patient developing this mutual understanding, a person centred, context bound form of care can be established (Barker, 2003).

The model describes three forms of care; critical, transitional and developmental which represent the hypothetical stages of care. The primary aim of this model is to co-create through talking, the meanings and values the person attaches to themselves, others, and their experiences. All aspects of an individual's care involves this co-creation including assessments and care plans. This co-constructed narrative is written in the individual's own voice and provides an immediate description of how the individual perceives the world, this is added to as the individual's understanding, perceptions and needs change. This narrative identifies what the person feels they need and how these needs should be met (Barker, 2003).

The Tidal Model has been praised for its empowering stance and placing the importance on the individual's story and needs rather than professionals prescribing this. The emphasis on co-creation supports the individual to build a feeling of security and hope in regards to professionals with the aim of them feeling secure enough to begin recovery (Barker, 2003). Nurses implementing this model have reported experiencing positive therapeutic engagement with patients (Cook, Sadler, & Phillips, 2005). Other research has highlighted a reduction in the number of serious untoward incidents following the implementation of the model (Gordon, Morton, & Brooks, 2005).

**1.2.6.2 Empirically Validated Stage Model.** This model was developed with the aim of being 'faithful' to the experiences of people with mental illness who have recovered. Qualitative studies were reviewed to provide a definition of recovery and to develop the model (Andresen et al., 2003). A psychological definition of recovery appeared the dominant definition within the reviewed literature which refers to "the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination" (Andresen et al., 2003, pg. 588). Personal accounts focused on the experience

of schizophrenia as a learning process; transforming them into a better, more enriched person (Watson, 1994; Whitwell, 1999).

This model identifies four components of recovery involving finding hope, redefining identity, finding a meaning in life, and taking responsibility for recovery (Andresen et al., 2003). Re-establishing important goals were considered pervasive in that hope engenders belief in achieving goals, identity and meaning can be found in the pursuit of goals and taking responsibility applies to actively pursuing goals. The five stages identified in recovery include moratorium, awareness, preparation, rebuilding and growth (Andresen et al., 2003). Moratorium depicts the stage of confusion, denial, confused identity, hopelessness and withdrawal followed by awareness, where the individual experiences the beginnings of hope that recovery is possible. Preparation is when the individual starts to identify their strengths and weaknesses and involves learning about mental illness, skills to recover and beginning to connect with peers. The rebuilding stage involves working towards a positive identity, personally valuable goals and taking control of life. Part of this process involves taking responsibility to manage illness, risk taking and moving on from setbacks. The final stage of growth signifies the outcome of the process of recovery. An individual in this stage will be able to manage illness and stay well even in the presence of symptoms and maintain faith in recovery whilst living a meaningful life (Andresen et al., 2003). This model has been validated via the development of the Stages of Recovery Instrument (STORI) (Andresen, Caputi, & Oades, 2006).

### **1.3 Part III: MHI services**

#### **1.3.1 Context of MHI services**

MHI settings provide 24-hour care for people experiencing an acute episode of mental health and considered to be in crisis. The objective of MHI services is to provide assessment and, if appropriate, treatment in order to stabilise patients, reduce risk and provide a safe and therapeutic environment. Comprehensive multi-disciplinary assessment is undertaken and evidence-based treatment provided. The delivery of care is informed by national standards and frameworks, mental health legislation, best practice evidence and NICE guidelines for disorder-specific treatment and assessment (Department of Health [DoH], 2007; Joint Commissioning Panel for Mental Health, 2013; MCA, 2005; MHA, 1983, 2007; NICE, 2014).

As a result of government spending cuts, the provision of MHI beds has significantly reduced across the UK. Concerns resulting from this led to the Royal College of Psychiatrists [RCoP] setting up an independent Commission. The main concern was people not having quick enough access to specialised acute care (RCoP, 2015). Several recommendations were made including introducing waiting time targets, providing local acute beds rather than sending people out of area, ensuring adequate housing and social care to reduce delayed discharge, and having adequately resourced Crisis Resolution Home Treatment Teams (CRHTT). Evidence suggests that fully funded and resourced CRHTTs can lead to financial gains due to reduced MHI activity (Parsonage, Grant, & Stubbs, 2016). The 'Five Year Forward View for Mental Health' has also identified the importance of Early Intervention for Psychosis (EIP) to prevent inpatient admission. The aim is for at least 60% of people with EIP starting NICE recommended treatment within two weeks of being referred into a specialist EIP service (NHS England, 2016).

### **1.3.2 Experience of MHI services**

Research has identified that hospitalisation can be experienced as non-therapeutic and stigmatising (Barker, 2003; DoH, 2002; Ford, Durcan, Warner, Hardy, & Muijen, 1998).

Some individuals have reflected on their admission as traumatising, particularly in regards to how they were admitted to hospital (Jones & Crossley, 2008). Feelings of shame and personal failure have been linked to becoming a MHI, as well as a loss of identity after repeated admissions, becoming a professional patient as opposed to a person (Jones & Crossley, 2008). Identity can become associated with one's behaviour and a struggle to be viewed as an individual (Lilja & Hellzen, 2008).

Coercion is a prominent theme throughout service users' experiences of MHI settings, including involuntary admission and treatment as well as the restricted nature of the environment and lack of personal freedom (Gilburt, Rose, & Slade, 2008; Wertheimer, 1993). Freedom was often referred to in terms of physical freedom and individuals' lack of freedom being a removal of a basic human right. This lack of freedom was also linked to exacerbating distress (Gilburt et al., 2008). A lack of control due to inactivity and removal of responsibilities were also highlighted as problematic (Lilja & Hellzen, 2008; Norton, 2004).

Personal safety and the safety of others also dominated individuals' narratives. A lack of safety and feeling vulnerable was linked to ward-based violence and the use of physical or medical interventions from staff, some experiencing this as traumatic (Bonner, Lowe, Rawcliffe, & Wellman, 2002; Chaplin, McGeorge, & Lelliott, 2006). The impact of being confined in hospital and the use of physical interventions were reported to lead to patients feeling vulnerable and helpless (Koivisto, Janhonen, & Vaisanen, 2004). Discrimination, racism and a lack of cultural competency has also been reported (Secker & Harding, 2002).

Dissatisfaction with the care received as a MHI is reflected within the 2016 Adult Inpatient Survey which found that MHIs reported a poorer experience of care across all areas; respect and dignity, confidence and trust, information sharing, coordination of care and emotional support (Care Quality Commission [CQC], 2017).

Some patients experiencing psychosis described feeling safe when staff were around which was important when compared with how out of control they described feeling as a result of psychosis (Koivisto et al., 2004). MHI treatment was also viewed as providing an opportunity to rest the brain and recover (Lilja & Hellzen, 2008). Other research highlighted the lack of resources in MHI settings, in regards to staffing levels and how the staff appeared to be too busy to talk with patients (Hopkins, Loeb, & Fick, 2009; Stenhouse, 2011).

### **1.3.3 Recovery in MHI services**

Research into how effective MHI care is has been largely neglected in favour of focusing on alternatives to MHI care (Bowers, Chaplin, Quirk, & Lelliott, 2009; Muijen, 2002). The focus of MHI care continues to be the stabilisation of an individual and reduction of risk to a level that can be managed in the community. Psychiatry remains the dominant culture within MHI settings and psychiatric staff have been shown to have a symptom-orientated approach (Hellzen, Kristiansen, & Norbergh, 2003).

In 2008 'The pathway to recovery: a review of NHS acute inpatient mental health services' was published by the Healthcare Commission. This review assessed the quality of MHI settings across the UK. The key findings were that a greater focus needed to be placed on the individual in regards to involvement in planning their care and that further improvement was needed in meeting individual needs in particular individuals from black

and minority ethnic groups (Healthcare Commission, 2008). Additional findings included ensuring safety of patients and staff to create an environment conducive to recovery, providing appropriate interventions and establishing more effective pathways in and out of hospital, including robust discharge planning.

It is apparent that MHI settings are focused on medicalised recovery such as symptom improvement and reduced risk (Hellzen et al., 2003). This may be linked to the dominant medical influence within these settings and lack of resources as a result of continued budget cuts within mental health. Patients who have shared their experiences of MHI settings have highlighted some positive aspects such as providing a rest, however, the general consensus is that of a potentially traumatic, stigmatising experience that restricts engagement with the community and fulfilment in life (Barker, 2002; Jones & Crossley, 2008; Lilja & Hellzen, 2008). A nationwide review of MHI settings has highlighted the need to involve patients in their care planning and implement recovery models (Healthcare Commission, 2008). A systematic review focusing on MHIs' views on recovery from psychosis will follow to establish an alternative conceptualisation of recovery from psychosis to the dominant medical narrative and promote the voices of individuals accessing MHI services to develop a meaningful recovery narrative. The question informing the systematic review is how do MHIs experiencing psychosis describe recovery from psychosis?

## **1.4 Part IV: Systematic review**

### **1.4.1 Article identification**

Relevant papers for this review were identified by systematically searching four electronic databases. To maximise the number of relevant articles identified search expanders

were applied along with search limiters to ensure the relevance of articles. The search strategy and inclusion flow diagram are set out in appendix A.

#### **1.4.2 Article review procedure**

**1.4.2.1 Quality appraisal.** Dixon-Woods et al. (2007) compared several methods of appraising qualitative research and found that inconsistencies arose regardless of the appraisal method used. One of the possible consequences of appraisal is excluding papers that are assessed as being of poor quality, however, in the appraisal of quantitative research broader quality criteria such as adequate randomisation are frequently used as inclusion criteria, indicating a discrepancy between appraisal of qualitative and quantitative research (Dixon-Woods et al., 2007). Booth (2011) suggests that critical appraisal is flawed due to limitations with the research, the reviewer and the appraisal tools themselves, whether this be collectively or individually. The decision was taken to include all articles identified as relevant irrespective of their quality.

There is a lack of consensus around the appraisal of qualitative research both in regards to the methodologies used and the theoretical perspectives taken (Gomez, 2009). The Critical Appraisal Skills Programme (CASP, 2010) was systematically applied to screen all of the relevant articles. Quality appraisal information is available in appendix B.

**1.4.2.2 Data analysis and synthesis.** The process of thematic synthesis outlined by Thomas and Harden (2008) was followed to create a systematic synthesis of the relevant literature. Processes of synthesising qualitative research is still debated due to the view that qualitative research is not generalisable and that synthesising could lead to de-contextualising the findings (Sandelowski & Barroso, 2007). However, it is necessary to synthesise

qualitative research in order for the findings to be accessed by a wider audience (Thomas & Harden, 2008).

Thematic synthesis supports the interpretation of detailed experiential accounts which fits with this project's ontological and epistemological position. Following the guidance recommended by Thomas and Harden (2008) the data extracted was the data under the headings of results or findings. From this selection of data, only the relevant data to the review was included. All relevant data was entered into word documents verbatim. In order to become adequately immersed in the data each article was read twice (Cruzes & Dyba, 2011). The process of line by line coding and development of themes was done manually in order to stay close to the data.

The data was systematically coded and initial themes of a descriptive nature were produced. A process of 'constant comparison' was utilised within and across the data to ensure the codes were similar in content (Cruzes & Dyba, 2011). Analytic themes were developed from comparison of coded segments in order to take analysis to a level beyond the data (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). A summary of the reviewed articles are presented within appendix C.

#### **1.4.3 Systematic review: MHI's views of recovery from psychosis**

Six articles were reviewed and the findings were synthesised in order to explore MHIs' views of recovery from psychosis. A review of the quality of the articles is presented in appendix B. All articles provided a clear statement of their aims, employed an appropriate qualitative methodology, recruitment strategy, and data collection process. None commented on the relationship between the researcher and participants. Ethical issues were clearly

considered within four articles. Forchuk, Jewell, Tweedell, and Steinnagel (2003) was the only article that did not include a clear statement of their findings. Wood, Price, and Morrison (2013), Noiseux and Ricard (2008), and Ramsay et al. (2011) were the only articles that covered all the areas of valuable research including linking findings to previous research, discussing implications and limitations and identifying further research areas.

Six major themes and additional subthemes were identified. An overview of the content of identified themes and subthemes is presented in Table 1.

<b>Main Themes</b>	<b>Subthemes</b>	<b>N</b>
<b>1. Influence on well-being</b>	External transformation (observable changes and symptom reduction)	6
	Internal transformation (emotional changes and changing self-concept)	6
<b>2. Fight for survival</b>	Finding a reason/desire for living	6
	Standing up to psychosis	4
<b>3. Activating Recovery</b>	Meeting basic personal needs	5
	Holding hope for the future	4
	Finding a recovery cheerleader	6
<b>4. Process of acceptance</b>	Coming to terms with illness	4
	Accepting the self/Reconnecting with the self	3
	Being accepted by others	5
<b>5. Getting back to reality</b>	Recouping losses	6
	Entering back into society	4
	Reclaiming responsibilities	6
<b>6. Obstacles to recovery</b>	The misconceived illness	5
	Cast out by society	3
	Loss of faith in treatment and services	6

Table 1: Table of Themes and Subthemes from systematic review

#### **1.4.3.1 Theme 1: Influence on well-being**

All articles involved discussion of the influence of psychosis on the individual's well-being. When describing recovery all articles referred to the reduction of symptoms, which consequently led to a change in emotional state. These ideas have been conceptualised into two subthemes of external transformation related to symptom reduction and observable changes, and internal transformation related to emotional changes and how the person views themselves.

##### ***External transformation (observable changes and symptom reduction)***

A considerable focus was placed on symptoms such as hearing voices, visual hallucinations and lack of sleep. Symptom reduction or improvement was viewed as indicating the start of recovery:

“Among individuals who defined recovery as getting on with life, symptoms were typically described as improved or reduced”. Author (Yarborough, Yarborough, Janoff, & Green, 2016).

Many spoke of others noticing that they were in recovery and there being an observable improvement or ability to cope. This external transformation was noted to have a positive effect on the individual and others:

“Socially, I'm more approachable, and other people can get near to me, and that makes my support group feel safe. They see I'm getting better and stop being anxious about me”. Participant (Noiseux & Ricard, 2008).

##### ***Internal transformation (emotional changes and changing self-concept)***

Internal transformation incorporates both the change in the emotional state of the person as well as the change in how they view themselves. In regards to emotions, participants described having a more positive outlook on life and a general sense of feeling better within and about themselves. This internal transformation was described as finding an ‘inner peace’:

“I think [recovery is] also having inner peace and being able to function in society without fear that’s unreasonable”. Participant (Yarborough et al., 2016).

#### **1.4.3.2 Theme 2: A fight for survival**

Living with psychosis was described as being a difficult experience similar to that of a battle or a fight. Noiseux and Ricard (2008) described psychosis as a “descent into hell.” Developing the motivation to want to win the battle and fight to live beyond psychosis was seen as the person moving into recovery. Several articles contributed to this theme.

##### ***Finding a reason/desire for living***

Beginning the fight for survival appeared to be when the individual discovered a reason for living. People living with psychosis have spoken about the many losses they experienced which in turn led them to feel hopeless and perceive that their reason for living had been lost due to loss of employment, relationships and education opportunities. This can sometimes lead to the individual experiencing an internal conflict:

“Despondency over a symptom-dominated existence clashes with the desire to live. The spark of hope that people suddenly sense is ignited by the friction between their ‘abhorrence’ of a continued existence with their symptoms and their desire to live a better life.” Author (Noiseux & Ricard, 2008).

This subtheme also encompasses experiences of appreciating and respecting life again:

“I’m feeling a lot better. Things like getting up in the morning and enjoying a cup of coffee and listening to the birds and that kind of stuff. It’s really nice.” Participant (Forchuk et al., 2003).

##### ***Standing up to psychosis***

The next phase in the fight for survival involves standing up to psychosis in order to begin to reclaim life. This was expressed in multiple ways including taking back control of life and no longer allowing psychosis to be more powerful than oneself:

“I didn’t know who I was anymore. I wasn’t myself, but a disease-an anonymous patient in the system. Then, all at once, there was a flash in my mind, I was so sick of being mistreated by everyone that I thought to myself, enough is enough.” Participant (Noiseux & Ricard, 2008).

Reclaiming some control over life was sometimes expressed as acknowledging the presence of psychosis but allowing oneself to be more present and exerting control and power over the illness:

“Recovery means to me being able to say I have a mental illness, but it’s not me, it’s not who I am, it’s not all me, I’m over here and I have this mental illness, instead of it taking over my whole life.” Participant (Yarborough et al., 2016).

### **1.4.3.3 Theme 3: Activating recovery**

Activating recovery describes the factors deemed important for supporting the individual to begin the process of recovery. Not all factors were included within all articles, however, they all included at least one factor that participants felt vital to their recovery.

#### ***Meeting basic personal needs***

Basic needs included getting enough sleep and having an adequate diet and shelter. Having stable accommodation was identified as providing a sense of safety and security, a vital foundation to begin recovery. There was some consensus that recovery could not begin until the person’s basic needs were met or were in the process of being met:

“Bottom line, I guess recovery means to me. . . focusing on the things I can do to stay as healthy as possible. In other words, eating, getting some sleep, so real basic survival sorts of things” Participant (Yarborough et al., 2016).

#### ***Holding hope for the future***

Participants described the importance of being hopeful for the future in terms of activating the recovery process. Several articles described moving from a position of helplessness and pessimism to holding hope for things to change. This process of finding hope occurred at different times for different individuals:

“...You have a grasp for the future. You feel like it's going to occur no matter what. If you don't have any hope, you will burn out really quickly, especially with something like schizophrenia. It's not something that you can run low on.” Participant (Barut, Dietrich, Zanoi, & Ridner, 2016)

### ***Finding a recovery cheerleader***

Having a support network was recognised as important by participants in all articles and was the most frequently discussed activator to recovery. Support networks included family, friends and others with mental health difficulties that they had connected with through support groups and accessing services:

“The most important statement was ‘how much support I get from friends and loved ones’ with almost two thirds of participants noting that as important (65%).” Author (Wood et al., 2013).

Particular qualities were discussed in relation to those supporting them such as providing consistent support and being alongside them in their recovery journey:

“She was always the one that cheered me on. She wouldn't just get on the side lines of the race, she'd get right in there with you. She always fought for me and tried to make sure I was happy.” Participant (Barut et al., 2016).

#### **1.4.3.4 Theme 4: Process of acceptance**

This process of acceptance involved three further stages; coming to terms with the illness, accepting and starting to reconnect with the self, and being accepted by others.

#### ***Coming to terms with illness***

Participants reported this being a particularly difficult part of living with psychosis. For some it was something that they never experienced and this was seen as prohibiting recovery due to them denying the treatment on offer to them:

“I'm not going to take any medicine because it's going to hurt me, or it's not benefiting me, so it's going to hurt me. I just try to deal with taking my medication, which sometimes I have to force myself to take it because I don't want to. Because I don't think I need it.” Participant (Barut et al., 2016)

This process of coming to terms with illness was described as being a unique process, taking longer for some due to extended periods of denial as a feature of psychosis. This

process involved being sceptical about recovery, feeling lost and looking for answers, beginning to become conscious of psychosis and how it impacts them whilst accepting it as part of one's life and adjusting:

“It's learning how to manage what my particular form of bipolar disorder is. . .it means not being afraid of it, and it means there's things to understand. . . understanding what it is, what all the pieces are, understanding what my own. . . strategies are. . .” Participant (Yarborough et al., 2016).

### *Accepting the self/Reconnecting with the self*

This acceptance of the self led to increased self-esteem and self-worth and supported the participants to begin to reconnect with others through the process of reconnecting with themselves. This reconnection included becoming more attuned to one's feelings as well as their senses:

“It's when a person rediscovers feelings of pleasure, by which I mean when they re-experience their senses of seeing, hearing, touch, feel, and taste...” (Noiseux & Ricard, 2008).

This reconnection allowed the participants to begin enjoying themselves again through a process of valuing themselves enough to embrace their passions as well as rediscovering their abilities related to these.

### *Being accepted by others*

This leads on from accepting the self and involves the person gaining a sense of belonging and inclusion from others. For some this was through connecting with peers with similar experiences and for others it was being trusted by family and friends again:

“Being trusted around children was often taken as a sign that family members now recognised participant's improvement.” Author (Forchuk et al., 2003).

Being accepted was often described as being the opposite to what participants experienced when they were diagnosed or when they were initially hospitalised. Many descriptions involved no longer being stigmatised as a result of psychosis:

“It means to be part of a group where they don't pick you out and say, "Look, this person's something that we don't want to be." It's to be part of a group and to be included...” Participant (Barut et al., 2016).

#### **1.4.3.5 Theme 5: Getting back to reality**

Within all articles there was a reference to returning to a state of ‘normality’ or getting back to how they were before experiencing psychosis. For those participants who did not class themselves as being in recovery, this return to ‘normality’ seemed impossible which may have been linked to their lack of acceptance of the presence of psychosis or the fact that their basic needs remained unmet, preventing the ability to hold hope for the future and be able to consider recovery.

#### ***Recouping losses***

All articles identified multiple losses as part of experiencing psychosis, particularly in terms of being hospitalised. These losses included practical losses such as loss of employment, loss of accommodation and loss of education as well as social losses; breakdown of relationships, loss of role in society and loss of purpose. Emotional losses included the loss of self-esteem and self-worth, loss of confidence and loss of hope in oneself as well as the future. For the majority recovery involved recouping some of these losses:

“Education was a priority for more than a third, many of whom wanted to go to college or complete high school”. Author (Ramsay et al., 2011).

It was acknowledged that not all losses may be recouped including opportunities lost due to the timing of illness and the fact that recuperation takes time and effort. For those losses unable to be recuperated there was hope in alternatives such as developing new relationships:

“Recovery was defined by many as the process of regaining what had been lost, although this differed across participants. For some it meant redefining a new self, for others it meant repairing old relationships, and for others it meant needing to move on to build new ones.” Author (Yarborough et al., 2016).

### ***Entering back into society***

For some this explicitly involved leaving hospital and for others they were clear that recovery could start prior to discharge. This theme did overlap with recouping losses and reclaiming responsibilities due to it involving ‘returning to normality’ and reintegrating back into society. Some described this as being physically present in the community again by returning to work and attending community activities. For others it appeared to indicate doing the same things as people in society who do not have psychosis do:

“I think recovery means. . . being able to do the things that anybody else can do. It means going to work, it means driving a car, it means being able to take care of your kids. . . it just means living a normal life similar to everybody else that doesn’t have bipolar disorder” Participant (Yarborough et al., 2016).

### ***Reclaiming responsibilities***

The reclaiming of responsibilities led to participants becoming more trusting and confident of themselves due to them believing that they could begin to lead a ‘normal’ life. Responsibilities did overlap with some of the losses they hoped to recuperate such as employment and education:

“Over half of participants reported wanting a job. Some had specific employment goals (e.g., establishing a barbershop) while others placed value on “finding a stable job.” Author (Ramsay et al., 2011).

Others described reclaiming responsibilities as small steps towards independence and regaining of roles. The key factor identified in all reclaiming of responsibilities was trust:

“Recovery means overcoming your limitations. . . showing that you can have autonomy and take care of your bills and your lifestyle, and all the things you need to take care of, and you’re in control of your life.” Participant (Yarborough et al., 2016).

#### **1.4.3.6 Theme 6: Obstacles to recovery**

The final theme present within all articles emphasised the struggle involved in recovery and the multiple obstacles encountered. There was an indication that there may be experiences of being ‘knocked off track’ (relapsing) as a result of these obstacles but with the

factors associated with activating recovery the individual could return to recovery. For others these obstacles had prevented them from starting the journey of recovery.

### ***The misconceived illness***

This misconception of what psychosis is and how people living with it will behave appeared to have a profound effect on the ability to recover. Misconceptions included believing that people with psychosis were dangerous and needed to be separated from society, others involved the misconception that psychosis meant you were cognitively limited and incapable of working. There was a general consensus that people misunderstood psychosis and appeared scared of people living with it. Within some of the articles this was referred to as experiencing stigma or discrimination:

“The bizarre behaviour of people living with schizophrenia may make people ill at ease, but it doesn’t make them dangerous” (Paul). Almost all the participants mentioned that symptoms of schizophrenia are generally ignored or misinterpreted by members of the victim’s social circle.” Participant/Author (Noiseux & Ricard, 2008).

“Participants recalled how relationships changed as family and significant others began to define and treat them according to behaviors that were associated with diagnoses. Some talked about the difficulty of asking for help from family or friends when loss of autonomy and self-determination were costs.” Author (Yarborough et al., 2016).

### ***Cast out by society***

Experiences of being excluded or ‘cast out’ by society were referenced within most articles. This was described as being a painful and isolating experience due to participants’ longing for a sense of belonging. For the majority, recovery was not considered possible unless they felt included by society and regained a sense of belonging. Feeling ostracised often resulted from the actual process of going into hospital or being given a diagnosis. Some participants referenced being diagnosed as becoming ‘stuck’ with the illness for the rest of their lives which they felt had a detrimental impact on how they were perceived by others:

“For most people, mental illness is something like toxic waste. Everyone is in favour of treating it, but not in our backyard and especially not with us all having to be present.” Participant (Noiseux & Ricard, 2008).

“It's miserable because I feel like I'm at the bottom of the garbage pile, almost, if that makes any sense. Everything's just dumped on you and nobody remembers what's at the bottom of the garbage pile, so they empty it and throw it away.” Participant (Barut et al., 2016).

### ***Loss of faith in treatment and services***

Within all articles there was reference to a loss of faith in regards to mental health services and the treatment offered. Participants referred to medication not working or experiencing unwanted side effects. There was also reference to services being under resourced which affected the level of care they received. For some this loss of faith was only temporary, however, for others it resulted in disengagement from services and non-adherence to treatment plans:

“...It seemed this group felt persecuted and unsupported by services and felt that they could only be dependent on themselves for recovery.” Author (Wood et al., 2013).

“Some participants (8.0%) stated that they did not want help from mental professionals at all.” Author (Ramsay et al., 2011).

### **1.4.4 Summary of systematic review**

This review identified six major themes relevant to MHIs' experiences of recovery from psychosis. Participants described recovery as a process involving internal and external transformations as a result of the influence psychosis had on their well-being. Recovery was linked to a reduction in symptoms and an improvement in how the person viewed themselves, suggesting a combination of medicalised and psychological conceptualisations of recovery.

The experience of living with psychosis was described as a struggle, with the process of recovery being a fight for survival. Participants described a process of finding a reason to

live and regaining some control over their life. Finding meaning in life has previously been identified as key to recovery (Leamy et al., 2011). Recovery was defined as being a process that needed to be activated by the individual through having a ‘recovery cheerleader’, having their basic needs met and holding hope for the future. Hope was also identified within recovery literature from community populations and recovery models (Andresen et al., 2003; Kelly & Gamble, 2005; Leamy et al., 2011; Wilken, 2007).

Once in recovery there was a further process involving acceptance of the illness, acceptance of the self, and acceptance from others. Wood and Alsawy (2017) commented on accepting psychosis as part of the self in their review. Through reconnecting with the self and others recovery was deemed to be in progress. One of the latter phases of recovery was described by participants as ‘getting back to reality’ where they began to recoup losses, entered back into society and reclaimed their responsibilities. This phase can be linked with rebuilding life (Wood & Alsawy, 2017).

The final theme involved the identification of obstacles to recovery. These obstacles included being cast out from society, being misconceived, and losing hope in services. Being misconceived and cast out relates to experiences of stigma and social exclusion (Angermeyer & Matschinger, 2003; Link et al., 1999; Link & Phelan, 2001). Negative experiences of treatment and services were also highlighted as a barrier within previous literature (Wood & Alsawy, 2017).

Themes that appeared to be specific to a MHI population included experiencing hospitalisation as a form of rejection and exclusion that increased stigma. Entering back into society referred to leaving hospital and being back in the community as well as regaining

roles in society. The losses described appeared to be more significant when hospitalised such as loss of relationships, employment and accommodation. The articles that included people who felt they were not in recovery highlighted that ‘normality’ appeared impossible.

This review may be limited due to the small number of articles sourced relevant to the area of interest. However, the aim of synthesising qualitative research is not to locate all relevant research but instead provide enough interpretative explanation within the research area (Doyle, 2003). It could be argued that this small sample provides evidence for further research.

This review included quotations from the authors as well as participants’ quotations that the authors had included in the results sections. Due to not having access to the original data, the use of participants’ quotations within this review could be seen as one stage removed from the original data, with the inability to verify their quality. As a result the origins of the quotations have been noted and have been checked in line with the author’s interpretation of the participant’s quotation. The systematic review guidelines provided by Thomas and Harden (2008) also includes direct quotations from participants within their review.

Some of the participants within the reviewed articles were accessing support from community services and therefore these findings may not accurately reflect the views of MHIs. Some of the reviewed articles did not focus entirely on recovery and instead focused on treatment goals, facilitators of recovery, and concepts such as hope and belonging. The concept of hope has been deemed an integral part of recovery within the community population (Jose et al., 2015), however, it is not clear whether this is also the case for the

MHI population. It could be argued that the findings of this review may not be entirely relevant to understanding recovery from psychosis for MHIs.

## **1.5 Part V: Focus of the present study**

### **1.5.1 Gaps in the current knowledge**

According to current policies MHI settings should be recovery orientated based on how service users define recovery (Healthcare Commission, 2008). It has been evidenced that services and professionals whose practice is guided by recovery models as defined by service users lead to better and more meaningful outcomes for the individual (Gordon et al., 2005). Despite the importance of service user led recovery models there is a clear gap in our knowledge regarding how individuals accessing MHI services define recovery from psychosis. Research has focused on individuals living with psychosis in the community who could be deemed to be at a different stage of recovery. It is difficult to see how recovery models can be implemented into these settings without the contribution of MHIs' experiences becoming part of the academic and wider discourse.

### **1.5.2 Aims and research questions**

The main aims of the present study are:

1. To gain a deeper understanding of MHIs' lived experiences of recovery from psychosis within a MHI context.
2. To conceptualise recovery from psychosis through MHIs' descriptions of their recovery experiences.

The aims will be explored through the following research questions:

1. What is the MHI experience of being unwell or experiencing psychosis?
2. Is recovery possible?

### 3. 3. How do MHIs describe what is meant by recovery

## **CHAPTER TWO: METHODOLOGY**

This chapter begins with a first-person account focusing on the impact of my beliefs on the research process, followed by the rationale for taking a qualitative approach. I then move into a discussion of the theoretical underpinnings of qualitative designs and focus on interpretative phenomenological analysis (IPA). The specific details of the research design, procedure and data analysis process are then discussed along with the ethical considerations. This chapter concludes with a discussion regarding assessing the quality of qualitative approaches.

### **2.1 Self-Reflexive statement**

Reflexivity has come to be acknowledged as a vital process in creating knowledge via qualitative research (Berger, 2015; D’Cruz, Gillingham, & Melendez, 2007). It involves the researcher engaging in an ongoing internal dialogue of critical self-evaluation of their position, as well as actively recognising how this position may impact the research process (Pillow, 2003). Relevant researcher characteristics should be considered including age, race, gender, personal experiences, biases, beliefs, emotional responses to participants and ideological stances (Finlay, 2003; Horsburgh, 2003; Primeau, 2003).

I am a white, 30-year-old female with a German father and a British mother. I am the youngest of four and have one brother and two sisters. I began my interest in Psychology when I studied my BSc and MSc, followed by working within private, charitable and NHS mental health services for six years before beginning Clinical Psychology training aged 28 years old.

My previous clinical experiences were predominantly working within forensic inpatient settings with adults with learning disabilities and within a community child and adolescent service. Clinically, my preference is to work integratively in order to draw on relevant theories and techniques that best suit the individual(s) I am working with. I value systemic and psychodynamic models but am aware that I feel more comfortable within a cognitive behavioural framework.

I have always been drawn to MHI settings due to my perception that this involves working with individuals who may be experiencing the 'worst' point in their lives and feeling that this is when the biggest difference can be made. Whilst working in these settings I have acknowledged my own feelings of hopelessness in regards to the future of individuals accessing MHI services, which has been a common theme in many conversations with the individuals, their families and the systems around them. I have felt disempowered due to the nature of the MHI model and how the majority are medically led, leaving limited space for psychological understanding and for the individual to share their understanding. This has been further compounded by reviewing research within MHI settings which is limited compared with community populations, reinforcing the need for these unheard voices to be amplified.

I had never worked directly with anyone experiencing psychosis prior to commencing this study. From my experience it felt that those with a diagnosis of psychosis accessed medication and rarely accessed psychological therapies. On reflection I wonder whether this was due to the medicalised focus and the view then that those experiencing psychosis may not be able to access talking therapy due to the pessimistic views around the outcomes for such individuals. I also wonder whether it may have been considered 'easier' to provide

shorter term therapy to individuals with diagnoses of depression or anxiety for example. When reflecting I have acknowledged that my own preconception was that this population was the 'hardest' population to engage, which may have led me to continue not to engage therapeutically with individuals experiencing psychosis. This became visible to me during the recruitment process when I began to lose hope due to difficulties with individuals consenting as well as incidents on the wards providing barriers to recruitment.

Whilst conducting interviews it became apparent to me the number of differences between myself and the participants. The majority of participants were male, middle aged, and many were experiencing employment, housing or financial difficulties. I regarded myself to be in a privileged position and was concerned as to how I was going to be able to build a rapport during a one-off interview. My previous experience of working on male wards was with sex offenders and I was aware of the need to keep these experiences separate. I used to experience high levels of discomfort and fear when working in these settings and during the initial stages of recruitment I found these feelings re-emerging. I have come to understand that my fear is not located in the individual but more to do with the unpredictability of the environment and the sense of being trapped.

Other experiences that I think may have had a significant impact on how I might interpret participants' views on recovery is my current work within an addiction treatment programme. The underpinning philosophy of this programme is to be in recovery by following a structured set of steps and holding a belief in a higher power (Bill, 1976). My belief in recovery has significantly changed due to me working with individuals who begin a process of recovery and sustain it, prior to this I feel my belief had wavered due to working with people who were repeatedly re-referred into services. The philosophy of the programme has

also changed my ideas about recovery due to the focus on an internalised personal process rather than a visible external process. This experience has made me aware that I may have previously viewed recovery in line with the medical model which surprised me due to me fighting against this model. On further reflection I feel that after several years working within MHI settings and not actively questioning the medical model, I may have internalised a pervasive pathology of individuals accessing MHI care, viewing individuals in terms of their risks and not appreciating the personal qualities they hold and the internal changes they can experience.

I have attempted to hold these assumptions and preconceptions in mind, however, my experiences and assumptions have invariably contributed to how I have conducted this research and interpreted participants' experiences.

## **2.2 Philosophical underpinning and methodology**

In order to provide transparency the philosophical assumptions underpinning this study are discussed. This includes a summary of my ontological and epistemological position, the related philosophical paradigm and a justification of the methodology.

### **2.2.1 Ontology**

Ontology focuses on the nature of reality and the conditions of existence (Blaikie, 2007). An ontological position is the relationship of the researcher with the reality of their study. There are several ontological positions including: positivism, post-positivism, critical theory, constructivism and realism (Guba & Lincoln, 1994). These positions can be thought of as on a continuum. The realist perspective posits that reality exists independently of the mind and takes a scientific approach to knowledge development. This perspective does not fit with the

way I view experiences as I believe that our minds significantly contribute to our perceptions. My clinical experience has highlighted how different people can perceive a situation given their life experiences, their attachment style and internal working models, which has emphasised the need to view reality as being constructed in line with these experiences and in conjunction with the mind as opposed to a separate entity.

Along the continuum there is further diversity including direct realism and critical realism. Direct realism sees the world as relatively unchanging and concentrates on a single level, whereas critical realism acknowledges the importance of considering multiple levels due to the relationships between the individual and these levels (Novikov & Novikov, 2013). At the other end of the continuum is the relativism perspective which posits that an absolute truth is not found within a single point of view, but a subjective truth can exist in relation to other factors such as the culture or language which the individual refers to (Fletcher, 1996).

I took a relativist ontological position due to me not aiming to find one absolute truth and to instead represent that individuals have different realities regarding their experiences, which are influenced by points of reference such as their culture, belief system and language. I felt this position fit best with my clinical experiences, in particular my experience of developing collaborative formulations and how unique each person's understanding of their experiences is. It also fits with my understanding of systemic concepts and the danger of 'falling in love' with one hypothesis or way of viewing something.

### **2.2.2 Epistemology**

Epistemology is concerned with the study and acquisition of knowledge focusing on the methods, validity and scope, including making the distinction between justified belief

(Swinburne, 2001). Another focus is on the relationship between the knower (participant) and the would-be knower (researcher) (Guba & Lincoln, 1994). Similar to ontology, epistemological positioning can exist along a continuum from realism to constructivism (Manson, 2008). A realist epistemology is grounded in empiricism and linked to the positivist paradigm due to the idea that objective knowledge is likely to be representative of the wider population (King & Horrocks, 2010). Within this paradigm, the researcher is thought to avoid bias and remain objective and detached (Biggerstaff, 2012). This position felt uncomfortable due to my belief that I could never be bias free due to my clinical experiences such as experiencing the frequent divide within mental health teams regarding the conceptualisation of an individual and how frequently individuals accessing mental health services spoke of being misunderstood.

Constructivist epistemology takes a different view in that the mind can actively give meaning to a reality it is responding to (Balbi, 2008). This approach understands knowledge to be constructed via social interactions and is the by-product of this transactional process, inferring that the researcher cannot remain objective and detached (Ponterotto, 2005). This position felt more comfortable due to me reflecting on my preconceptions and how unlikely it would be that I could completely set these aside. My experience of working with families and individuals interacting with multiple systems meant that I felt more aligned with this constructivist position. I have observed how influential a dominant discourse about an individual can be in a team in regards to how they perceive and relate to an individual, which appears to effect how that individual makes sense of the world and others. This epistemology is promoted within the interpretivist paradigm, which is situated within the realms of phenomenology and hermeneutics. Interpretivism suggests there can be multiple realities and constructions which are subsequently accessed via shared meaning (Morrow, 2005).

I adopted a constructivist epistemology due to my belief that I would not remain objective and detached and that my beliefs and values would invariably influence how I interpret participants' data. I also believe that knowledge is gained through the mind and that participants may not have one single objective reality and may instead hold multiple subjective realities. This stance indicates my aim to highlight that the participants are the experts of their own experiences and their understanding is situated within the context and time they are present in. I am also hoping to take an active step away from the medically entrenched model that exists within the majority of MHI environments by opposing the current objectivist and physicalist stances adopted within these services. The medicalised view of experiences such as those named within the DSM is that "reality is as it is, independently of any human perspective on it: and that the ontology of reality is exhaustively physical." (Parnas, Sass, & Zahavi, 2012, p.272). In relation to experiences such as delusions or hallucinations this stance sees these entities as though they can be captured and quantified easily, removing the importance of how each individual perceives and interprets such experiences. An objectivist position is at risk of searching for a single truth focusing on 'a thing' rather than appreciating the individual as a person with a unique experience whose consciousness is embedded in a realm of meaning (Parnas et al., 2012).

### **2.2.3 Taking a qualitative approach**

Qualitative research aims to make sense and recognise patterns among words to construct a rich and detailed picture of the studied phenomenon. It involves phenomenological interpretation linked with subjectivity and the human experience (Leung, 2015). Quantitative research is concerned with numerical data and producing statistical interpretations within a positivist paradigm (Creswell, 1998).

As a result of adopting an interpretivist paradigm to gain a deeper understanding of recovery from psychosis a qualitative methodology was considered appropriate. Existing research on recovery in mental health was considered along with the research aims when selecting a design. Previous research focusing on personal experiences of recovery in mental health has mainly utilised qualitative methodologies including interviews, focus groups and individual case studies (Leamy et al., 2011). Research focusing on service users' experiences of recovery from psychosis has also followed this qualitative trend (Shea, 2010; Thornhill, Clare, & May, 2004; Wood et al., 2010).

Quantitative research in this area has taken the form of structured questionnaires focusing on preconceived categories of symptoms which can prevent participants from responding in their own way, with the meaning they have made of their experiences (Willig, 2001). This form of reductionism can lead to the complexity of the individual experience remaining uncaptured and tends to be more aligned with a positivist paradigm (Krauss, 2005). Many of these questionnaires were not specifically developed for people experiencing psychosis, suggesting that these measures may not be valid for this population (Allott, Loganathan, & Fulford, 2002).

The questionnaire about the process of recovery (QPR) is a self-report measure examining recovery from psychosis that was developed in collaboration with service users (Neil et al., 2009). Law, Neil, Dunn, and Morrison (2014) provided support for the reliability and validity of the QPR but found some items were not generalisable to a larger sample which resulted in modifications. These modifications involved the removal of items found to have less face validity compared with other items or due to ambiguity in item wording (Law et al., 2014). There are advantages to using quantitative methods such as facilitating

engagement and providing standardised data with the ability to compare across different populations over time (Neil et al., 2009). Due to recovery being an idiosyncratic concept it can be complicated to find a shared definition. This objective shared definition is what often underpins a lot of the quantitative research within recovery, leading to a misconceptualisation (Slade & Longden, 2015).

A method that permits participants to identify important areas and use their own language to talk about their lived experience of psychosis fits with the aims and epistemological stance of this study. The focus of this study is on the quality and depth of information related to understanding individual experiences which is usually achieved via a qualitative methodology (Denzin, 2009; Patton & Cochran, 2002; Willig, 2001).

#### **2.2.4 Consideration of methods**

Several qualitative methods were considered whilst holding in mind the epistemological foundation of the research aims and their compatibility with individual methods. The methods reviewed were grounded theory, thematic analysis and interpretative phenomenological analysis, on the basis that they appear to be the most commonly used qualitative methods (Biggerstaff, 2012; Javadi & Zarea, 2016).

**2.2.4.1 Grounded Theory (GT).** This methodology was developed in 1967 by Glaser and Strauss. Its aim is to uncover basic social processes by moving beyond preconception in order to generate theory (Glaser, 1978). GT has been criticised for its objectivist and positivist stance (Charmaz, 2006) so many different versions have been developed (Dey, 1992). Charmaz (2000) developed constructivist GT in order to move into a more interpretive paradigm, placing emphasis on meaning without making assumptions about the existence of a

one-dimensional external reality. The main critique of GT is around the developed theory being limited in terms of generalisability, as well as concerns regarding the potential for inaccuracies due to the methodology (Allan, 2003; Hussein, Hirst, Salyers, & Osuji, 2014). GT was not selected due to the study aims not relating to developing a theory but instead relating to understanding lived experiences. I was also concerned about the possibility of being able to recruit sufficient numbers in order to engage with theoretical sampling (McCrae & Purssell, 2016).

**2.2.4.2 Thematic Analysis (TA).** Braun and Clarke (2006) defined TA as “a method for identifying, analysing and reporting patterns within data.” (p.79). It involves the researcher immersing themselves in the data in order to identify interesting features relevant to the research questions (Braun & Clarke, 2014). It is similar to other qualitative methods due to the procedures and principles it adopts, however differs due to it providing a method rather than linking to a theoretical framework. TA can be employed in both inductive and deductive methodologies (Alhojailan, 2012). This method has been critiqued due to its descriptive nature and focus on frequency of content as opposed to providing an in depth understanding of an experience (Biggerstaff, 2012). Paying attention to repetition of specific patterns and creating themes from these quantifications can lead to misconceptualising the individual experience (Javadi & Zarea, 2016). TA was not selected due to concerns about providing descriptive understandings rather than interpretative understandings. Some have argued that TA is not a method in its own right due to the process of TA being incorporated into multiple analysis methods (Holloway & Todres, 2003; Ryan & Bernard, 2000). There is a lack of substantial literature on TA compared with other qualitative methods and its flexibility can lead to inconsistency and a lack of rigour when developing themes (Holloway & Todres, 2003).

**2.2.4.3 Interpretative Phenomenological Analysis (IPA).** IPA is a qualitative approach examining how people make sense of significant experiences by focusing on the meanings of these experiences for the individual, which makes it an appropriate method of analysis for this study (Smith, Flowers, & Larkin, 2009). IPA offers the researcher the opportunity to engage with a research question at an idiographic level which is different from most traditional psychology methods (Reid, Flowers, & Larkin, 2005). This method is concerned with focusing on meaning making at the individual, specific level rather than trying to generalise across the whole. IPA acknowledges the importance of language and subjective knowledge to aid understanding of psychological concepts and experiences, which is the focus of this study (Eatough & Smith, 2017).

## **2.2.5 Theoretical underpinnings to IPA**

Exploring the relevant theoretical underpinnings of IPA is important to ensure the method stays true to the ontological and epistemological stance of this study.

**2.2.5.1 Phenomenology.** Phenomenology is the philosophical examination of human consciousness and one's subjective experience of the world (Smith et al., 2009). This study is interested in exploring individuals' experience of psychosis, and their possible experiences and ideas about recovery. Husserl, the founding father of phenomenology (1952/80 in Lavery, 2003) argued that it was wrong to apply natural science methods to human issues, due to these methods ignoring the context and the individual meanings that an individual has. Husserl suggested adopting a phenomenological attitude and bracketing off our natural, taken for granted attitude, by turning our gaze inwards and considering our perception of things and focusing on our psychical experience (Smith et al., 2009). This study aims to explore

participants' lived experiences of psychosis by supporting them to be reflective and access their consciousness, which supports a method of analysis based on phenomenology.

**2.2.5.2 Hermeneutics.** Another aim of this study is concerned with meaning making which involves the theory of interpretation known as hermeneutics. Heidegger (1962/67) highlighted the importance of our fore-conception which are the experiences, assumptions and preconceptions we bring, which may act as an obstacle to interpretation. He argued that the notion of bracketing is not as straightforward as first thought and that preconceptions are often only realised once interpretation is underway. Gadamer (1990/60) also wrote about the complicated dynamic between the interpreter and the interpreted. Both the meaning made by the individual and the meaning made by the researcher of what the individual has described must be considered, which is often referred to as the 'double hermeneutic'. The reason for this is underpinned by the constructionist view that everything is generated as a construction by the individual or by society. Therefore, an approach that considers the making of meaning and the researcher's role in that is required.

**2.2.5.3 Idiography.** The final aim of this study is to develop an understanding of the particular experiences of an individual so an approach that is idiographic as opposed to nomothetic is required. Idiographic processes develop generalisations more cautiously and via different methods (Harre, 1979). The focus is to partly understand the meaning of the experience for that given person which is what this study aims to achieve due to the complexity of individual experience. IPA concentrates on exploring each individual case before highlighting any general concepts (Pietkiewicz & Smith, 2012).

After consideration of the research aims it was deemed necessary to use IPA due to it incorporating the principles of phenomenology, hermeneutics and idiography.

## **2.3 Design**

### **2.3.1 Data collection tool**

Semi-structured interviews are recommended for the collection of data when using IPA (Reid et al., 2005). Individual interviews have the advantage of developing rapport quickly and supporting in depth and personal conversations. The flexibility of the semi-structured format allows the modification of questions in light of the participant's response, promoting the collection of novel data (Smith & Osborn, 2003).

### **2.3.2 Interview schedule development**

Permission was obtained to modify an interview schedule used in a previous study on recovery from psychosis (Wood et al., 2010). The reason for modification was due to the schedule being symptom focused and more in line with clinicians' traditional views of recovery (Wunderink et al., 2009). When developing the interview schedule (appendix D) Smith et al., (2003) recommendations were followed and my literature review on recovery from psychosis helped to highlight areas of interest to be included.

Feedback on the schedule was obtained from six service users accessing a community psychosis team, some of whom had experience of MHI care. Service user led research and input has become increasingly popular within the area of recovery, ensuring the relevance of the research (Gillard, Simons, Turner, Lucock, & Edwards, 2012; Pitt et al., 2007). This input can also support the researcher to gain insight into how best to build a rapport with participants. It was felt this would be crucial due to participants being recruited whilst they

were in the care of a MHI setting and the likelihood of them being distressed, scared and potentially mistrusting of others (Gilburt, Rose, & Slade, 2008).

The following recommendations from service users were implemented:

- Allowing participants to go beyond the 45-minute interview time if they wanted to.
- Providing time at the end of the interview to discuss anything relevant to the study that participants felt they had not been asked.
- Facilitating a debrief at the end of each interview.
- The word ‘recovery’ was not defined in order to allow participants to interpret this how they wished.
- Each participant was asked whether they would use a different word to ‘recovery’ to define their experience.

### **2.3.3 Interview schedule**

The initial section of the schedule aimed to set the context by exploring with them their first contact with mental health services. Smith et al. (2003) recommend beginning with a general question about the experience of the phenomenon to orient participants to the focus of questioning. This also supports the building of rapport with the participant which has been recommended when asking more emotionally evocative questions later on (DiCicco-Bloom & Crabtree, 2006). The preceding questions focused on specific examples of the participants’ experiences to support them to reflect in depth and avoid providing generalised views. These examples included a time when they felt most unwell with psychosis and the impact this had on various aspects of their life, as well as a time when they felt psychosis was more manageable. These areas of questioning then lead on to the participant considering the

concept of recovery, what it meant to them and whether they or others had experienced recovery. The interview concluded with a debrief.

#### **2.3.4 Interview setting**

Due to risk issues participants were not permitted to be interviewed separate from the ward. Herzog (2005) suggested that the location of interviews contributes to constructing reality. A perceived benefit of interviewing participants on the ward was them remaining immersed in their current experience which may have supported them to reflect on this experience. It was also considered that it may be difficult for participants to separate some of their meaning making from the medicalised narrative embedded within a MHI setting.

During the majority of interviews there were several interruptions including alarms, general noise from the ward including shouting, singing and screaming, as well as staff members entering the room. The experience of conducting the interviews in a chaotic and unpredictable environment was reflected on in my reflective journal.

I considered my profession when setting the scene for the interview by providing the participant with an explanation of my role as a researcher. This felt necessary due to the likelihood that participants may have met with a clinical psychologist (CP) when accessing support from mental health services. It was also a helpful way of supporting me to step into the researcher role.

#### **2.3.5 Sampling and sample size**

Participants were recruited from three MHI hospitals where ethical approval was obtained. Purposive sampling was employed to remain consistent with the theoretical

underpinnings of IPA. Participants were recruited as a result of them being experts in the phenomenon being explored (Reid et al., 2005). Purposive sampling aims to include participants with a diverse range of experiences by avoiding the biases of opportunity or convenience sampling.

Based on other qualitative research in this area and general guidelines for sample sizes with IPA, the sample size was kept small to retain an idiographic focus (Smith et al., 1999). There have been some suggestions that having between six and eight participants is appropriate (Turpin et al., 1997) and this appears conducive with the existing IPA literature. Generally IPA researchers are focused more on depth as opposed to breadth (Pietkiewicz & Smith, 2012). The aim was to recruit twelve participants to allow for drop-outs with a view to end up with at least eight interviews to be analysed. Overall ten participants were recruited and participated.

Several demographic factors were considered when recruiting including gender, formal diagnosis, number of hospital admissions and length of stay in hospital. Incidence and prevalence rates for psychosis have frequently been disputed with some studies indicating a higher incidence in men (Aleman, Kahn, & Selten, 2003; Castle, Wessely, & Murray, 1993; Lewine, Burbach, & Meltzer, 1984) and others indicating no gender differences (McGrath, Saha, Chant, & Welham, 2008; Perala et al., 2007). Aleman et al. (2003) reported a ratio of 0.41:1 women to men in reference to incidence rates. Both female and male wards were accessible in regards to ethical clearance and the initial aim was to recruit a sample in keeping with Aleman et al. (2003) ratio, so for a sample of ten, there would be approximately seven male participants and three female participants. The final sample consisted of nine male participants and one female participant.

In regards to formal diagnosis, the aim was to capture as many different diagnoses of psychosis as possible as classified by the DSM-V. For the number of hospital admissions and length of stay the aim was to recruit participants across the range. The idea behind the diversity within the sample was to attempt to understand the phenomenon from more than one perspective. The number of hospital admissions ranged from 2 to 25 with current admission ranging from 18 days to 611 days.

### **2.3.6 Inclusion criteria**

Participants had to have a formal diagnosis of psychosis according to the criteria specified by the DSM-V and be a MHI at the time of their interview. The age criteria for inclusion was 18-65 years old which is in keeping with the admission criteria for adult services.

### **2.3.7 Exclusion criteria**

Non-English speakers were excluded due to the cost of a translator. Those currently experiencing severe thought disorder or those lacking the capacity to provide informed consent were also excluded. Participants who were experiencing delusions were not automatically excluded unless they did not have capacity to consent. The reason for their inclusion was due to the epistemology of the method and the idea that I was interested in the individual meaning making and not in a search for an objective truth or reality (Rhodes & Jakes, 2000). Capacity was determined via discussions with the multi-disciplinary team (MDT) followed by careful communication of the study via the participant information sheet (PIS). The relevant principles of the Mental Capacity Act (MCA, 2005) were applied when determining capacity which included assuming each individual had capacity unless proved otherwise and ensuring that all practicable steps were taken to support individuals to make a

decision about participating in the study. Munthe, Radovic, and Anckarsater (2010) suggest that the process of obtaining informed consent is by counselling and providing information for the participant to understand and make a free decision. The components of this process were implemented to assess capacity and ensure informed consent. Individuals where an acquired brain injury or substance misuse were the cause of their psychotic experiences were excluded, as were those already participating in another study.

## **2.4 Procedure**

### **2.4.1 Recruitment**

Participants were recruited from three MHI hospitals to try and maximise ease of recruitment. In one of the hospitals the Assistant Psychologists (APs) on the female and male ward were involved in approaching eligible patients and sharing the PIS (appendix E) and leaflet about the study. The APs gathered a list of patients who met the eligibility criteria and approached them individually to discuss the study. For those patients that met criteria and expressed an interest, they were then asked by the AP or CP whether they would meet with me to discuss the study further. An email address was available to potential participants to allow them to make any enquiries or alternatively staff could contact me via email on participants' behalf to ask questions or arrange a time to address any queries.

Following on from this discussion, if they consented, I met with them individually to introduce myself, discuss the study using the PIS and obtain written consent using the consent form. For the other two hospital sites there were no APs to support with recruitment so for one site I attended an MDT meeting with staff. Attendance enabled me to present a basic overview of the study and the inclusion and exclusion criteria for the team to highlight eligible potential participants. The CP working on the wards then approached those eligible

and provided them with a PIS and if interested I then met with them to answer any questions regarding the study and to obtain written consent.

#### **2.4.2 Interview procedure**

Face-to-face interviews were conducted by myself, audio recorded and then I individually transcribed interviews verbatim. Interviews lasted between 25 minutes to 1 hour 45 minutes. The average interview time was 46 minutes. Participants were informed on the PIS and prior to conducting the interviews that the interview would last approximately 45 minutes. During the interview the participant was informed when 45 minutes had passed and asked whether they wanted to continue with the interview, none of the participants declined to continue. Transcripts included significant pauses as well as non-verbal responses such as facial expressions and gestures. Any potential identifiable information such as locations participants mentioned were replaced, for example [location], to enhance anonymity.

#### **2.4.3 Data analysis**

There are several texts providing guidance on how to conduct IPA that vary slightly in their method (Flowers, Smith, Sheeran, & Beail, 1997; Smith et al., 1999, 2003, 2009; Willig, 2001). IPA is characterised by a set of common principles which can be flexibly applied rather than a set of steps that have to be followed exactly (Reid et al., 2005). Smith et al. (2009) posit that there is no right or wrong way of conducting IPA and that researchers should be innovative in their approach.

In order to ensure the participant became the focus of the analysis each interview recording was listened to whilst following the transcript. The transcript was then read and re-read several times in order to fully enter the participant's world. My initial observations were

recorded in my reflective journal in order to attempt to bracket off my preconceptions (appendix F). Initial noting took place via free textual analysis where I commented on the content of the transcript, the language used, as well as interpretations around pauses, metaphors and other non-verbal responses. I then moved my focus towards interpreting the text which involved considering a range of provisional meanings for what the participant had said (Smith et al., 2009). The next phase of analysis was the development of emerging themes by working mainly with the initial notes as opposed to the actual transcript, whilst being sure to incorporate the participant's words as well as taking the analysis to a deeper level of interpretation.

For the next stage Smith et al. (2009) recommend finding a way of bringing together the emergent themes via a specific structure. I chose to follow one of the structures provided by Smith et al. (2009) whereby themes were typed out, printed and separated and then moved to connect with similar themes or placed at opposite ends to reflect polarisation. Following on from supervision where I expressed a sense of feeling overwhelmed by the number of emergent themes I utilised the 'OSOP' ('one sheet of paper') method which involved writing down similar themes or concepts on a single sheet of paper in order to reduce the quantity of data (Ziebland & McPherson, 2006). Across the ten interviews 826 themes emerged which were condensed into 5 superordinate themes and 24 subordinate themes. A final table of themes was then constructed and checked against each transcript and with both supervisors. The application of psychological concepts and theories to illuminate understanding by referencing existing theories and literature is present within the results sections of existing IPA research (Flowers, McGregor Davis, Larkin, Church, & Marriott, 2011). Evidence of this can be found within Dickson, Knussen, and Flowers (2008) and Flowers et al. (2011). This approach will be taken when presenting the results from this study.

Reflexivity is the key to validating qualitative research so a reflective journal was kept throughout the process for transparency and to acknowledge potential bias (Cutcliffe & McKenna, 2002; Walsh & Downe, 2006). I used these personal reflections to modify the data collection and analysis process. An example of this would be helping me to process the experience of each interview and set aside each interview from the next. On one occasion when I conducted two interviews consecutively and reflected on them later I acknowledged that I may have allowed the prior interview to guide some of my questioning in the latter interview, potentially due to me thinking that these participants may have shared a similar experience at the same hospital. As a result of this I ensured that if I conducted more than one interview on the same day I allowed for time in between in order to record my reflections and create some distance.

## **2.5 Ethics**

### **2.5.1 Ethical approval**

Ethical approval was initially gained from the Research Ethics Committee (REC) and Health Research Authority (HRA) via the integrated research application system (IRAS) (appendix G). Trust R&D approval was obtained from the two separate trusts where the recruitment sites were located (appendix H). Final approval was obtained from the University Ethics Committee due to the university sponsoring the research.

### **2.5.2 Ethical considerations**

The guidance supplied by the BPS (2014) on conducting ethical human research was adhered to. The ethical components considered were informed consent, risk of harm, confidentiality and anonymity. Informed consent involves providing adequate information about the study in a comprehensible format in order for potential participants to make a

balanced decision about their will to participate. Risk of harm involves potential risks to be highlighted to the participants in order for them to decide whether they want to participate and to see whether potential risks can be managed or minimised further. In research, the risk of harm should be no greater than risks normally encountered in everyday life (BPS, 2014). Confidentiality involves respecting participants' privacy and ensuring they understand and consent to who may have access to their personal information and specific data gathered during the study. The principle of anonymity means that identifiable personal information is not collected or the study ensures that participants cannot be identified.

**2.5.2.1 Informed consent.** In accordance with R&D and HRA recommendations, as well as the MCA (2005), informed consent was obtained from each participant prior to conducting the interview. Participants were given a PIS and leaflet by an AP or CP from the ward, which were developed based on guidance from the HRA. They consisted of a brief introduction to the study and the background literature, the research procedure and what their participation in the study would involve. Participants were encouraged to ask questions and if they were interested in participating I then met with them to answer any questions and to obtain consent if appropriate. The consent form (appendix J) was also developed in accordance with HRA recommendations.

The ability for people experiencing psychosis to provide informed consent has been heavily debated. Numerous studies have found that such individuals were only able to utilise limited information provided during the consent process (Grossman & Summers, 1980). Others have shown that when individuals with psychosis are acutely ill they can make informed decisions just as adequately as the general population (Grisso & Applebaum, 1995). Carpenter et al. (2000) found that providing individuals with schizophrenia more than one

session to view and discuss information resulted in more individuals being able to provide informed consent. These recommendations were incorporated by supporting potential participants to read and discuss the PIS on at least two separate occasions before obtaining consent. Ongoing assessment of capacity took place via the initial meeting with participants when discussing the study and the PIS. If capacity changed prior to conducting the interview then it would not go ahead at that time and if appropriate they would be approached again later to reassess capacity.

**2.5.2.2 Risk of harm.** In existing research for qualitative studies on recovery debriefing was not incorporated into most procedures. Weiss Roberts, Warner, Anderson, Smithpeter, & Rogers (2004) found that all participants in a schizophrenia study strongly recommended debriefing. A debrief discussion was included at the end of the interview to ensure the participant was not adversely affected by the interview. Being a patient and talking about recovery could potentially bring up a lot of emotions both positive in feeling hopeful but also negative about their current situation being in a MHI hospital. It was therefore important to assess the well-being of each participant after their interview. Participants were asked about their experience of the interview and whether there was anything they wanted to discuss that they felt they had not had the opportunity to. If the participants raised anything that I felt concerned about in regards to their own or others' safety then this information was handed over to the nursing team for them to discuss further with the participant and to disseminate to the team accordingly. Each participant was made aware of these limits to confidentiality prior to signing the consent form.

**2.5.2.3 Confidentiality and anonymity.** To ensure confidentiality, participants were interviewed in a private room on each ward. A room was used with no window on the door

and a sign placed on the outside to indicate that the room was being occupied to ensure privacy.

All interviews were audio recorded on a digital voice recorder. All participants were made aware of this via the PIS and leaflet as well as the consent form. Two participants withdrew from participating as a result of not wanting to have the interview recorded. Each recording was transferred directly to the University secure drive following each interview and deleted from the digital voice recorder. Each interview was then transcribed by myself as a word file with any identifiable information deleted. These anonymised word files were kept on the University secure drive and each file password protected, paper copies of the transcript with additional coding were kept in my personal secure locked cabinet within the administration office for the department which is kept locked when the administrator is absent. All completed consent forms and demographic sheets are also kept here. I am the only person who knows the individual passwords to each file.

All interview recordings will be kept for up to five years in accordance with data protection legislation and will be deleted thereafter. Participants were informed of this process on the PIS and consent form. The consent form also included the option for each participant to consent to direct quotes being used in the write up of the study. All of the participants consented to this and all identifiable information was removed from these quotations in the write up. Participants either provided or were allocated a pseudo name for anonymity reasons.

All participants were informed of their right to withdraw at any time via the PIS and consent form. Two participants who had verbally consented to meet with me withdrew prior to providing verbal consent due to their concerns around interviews being audio-recorded.

## **2.6 Assessing quality**

Validity and reliability have traditionally been linked with quantitative research to ensure credible and trustworthy findings. Many have argued that these constructs are also important when conducting qualitative research due to the researcher's subjectivity which can more readily impact the interpretation of findings (Brink, 1993). Qualitative researchers have argued that the quality of their research should be assessed in relation to an appropriate criteria rather than using the criteria for assessing quantitative research (Smith et al., 2009). As a result several guidelines have been developed to assess the validity of qualitative research (Elliot, Fischer, & Rennie, 1999; Yardley, 2000, 2008). Smith et al. (2009) recommend the use of Yardley's (2000) criteria due to it offering many different ways of establishing quality, as well as being applicable to studies of any theoretical orientation. The four principles developed by Yardley (2000) are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

### **2.6.1 Sensitivity to context**

Sensitivity to context can be achieved in several ways including exploring the existing literature in the topic area, paying attention to the socio-cultural context in which the study is located and showing sensitivity towards the data and the process of collection (Yardley, 2000). The idiographic nature of IPA lends itself well to being sensitive to the context. Careful consideration of the ontological and epistemological position took place as well as

detailed exploration of the theoretical underpinnings of research methods to ensure the method was coherent with the research aims and position.

Sensitivity to context can also be achieved by using verbatim extracts to provide participants with a voice which is evident within the results. In regards to showing sensitivity within the interview process I drew on my therapeutic experience to build rapport and was aware of any interactional difficulties during the interview process.

### **2.6.2 Commitment and rigour**

The principle of commitment and rigour partly focuses on the level of commitment and attentiveness to the participant. Rigour can be linked to the appropriateness of the sample in relation to the research aims as well as the quality of the interview and the analysis (Yardley, 2000). Service user feedback during the interview development stage and obtaining feedback from supervisors in relation to the analysis were both ways of ensuring rigour within this study. I also attended a training course in IPA and was able to develop my interview schedule with feedback from peers and supervisors within the IPA field.

### **2.6.3 Transparency and coherence**

Transparency involves how clear the researcher is in describing the stages of the study and coherence can relate to the degree of fit between the research conducted and the theoretical underpinnings of the approach (Smith et al., 2009). For this study the use of a reflective journal to include my preconceptions and other reflections supported the collection of reliable data. The service user feedback incorporated into the development of the interview schedule also helped to avoid leading questions and support participants to talk freely about their experiences. During interviews I ensured I had understood what the participant meant

by clarifying their definition of words or phrases and by summarising and repeating back their words to check for clarity and accuracy.

Larkin and Thompson (2012) recommend verification of themes if it is a single case study as the interpretations can be traced back to that individual participant. If one attempts to verify themes with multiple participants this could become problematic due to the effect of interpreting combined accounts and the time passed between interviewing and data analysis. This could be particularly problematic for this study due to the potential that participants may have been discharged when approached to verify themes and would be at a different time point in regards to experience. The measures taken within this study to ensure validity were providing a clear audit trail and triangulation between locations by recruiting from different hospitals.

#### **2.6.4 Impact and importance**

This principle relates to whether the research tells the reader something useful, important or interesting which will be reflected upon within the discussion.

### **2.7 Dissemination**

Following completion of the Doctorate in Clinical Psychology programme this thesis will be available through the University library. A written summary of the findings were sent to the sites involved and the option of providing an oral presentation to staff members will be offered. This will also be offered at a Trust wide level with the aim of thinking about clinical implications including staff training on MHI wards and supporting these services to become more recovery focused in the eyes of patients.

As part of the consent process participants were given the option of providing consent to be contacted to be offered the opportunity to attend a feedback meeting about the findings of the study or receive a written summary of the findings via a letter.

Conferences focusing specifically on psychosis as well as those discussing recovery from mental illness may be interested in this research such as The International Society for Psychological and Social Approaches to Psychosis (ISPS) and IEPA Early Intervention in Mental Health.

My intention will be to publish within a psychosis related journal such as the ISPS journal-Psychosis: psychological, social and integrative approaches or Schizophrenia Bulletin.

### **CHAPTER THREE: RESULTS**

Within this chapter the five superordinate and corresponding subordinate themes derived from participants' accounts will be presented. Each theme will be illustrated by quotations from interviews to facilitate understanding of participants' lived experiences; highlighting the researcher's analytic interpretations and allowing the reader to develop their own interpretations.

#### **3.1 Demographic information**

Table 2 presents the demographic information of the participants. The sample consisted of nine males and one female with a mean age of 39.2 years (SD=11.4; 21-57). The majority of participants were single and White British. The mean number of hospital admissions was

6.8 (SD=7.3; 2-25) and the mean length of current admission was 94.4 days (SD=182.2; 18-611).

Allocated Pseudonym	Gender	Age	Marital status	Ethnicity	Formal Diagnosis	Number of hospital admissions	Length of current hospital admission
<b>Mohammed</b>	M	37	Married	Indian	Bipolar Affective Type II	10	23 days
<b>Paul</b>	M	40	Separated	White British	Bipolar	2	18 days
<b>Christopher</b>	M	47	Single	White British	Schizophrenia	2	25 days
<b>Sebastian</b>	M	40	Single	White British	Bipolar Affective Type II	2	55 days
<b>Richard</b>	M	28	Single	White British	Paranoid Schizophrenia	4	69 days
<b>Alex</b>	M	50	Single	Iraqi English	Paranoid Schizophrenia	25	611 days
<b>Graham</b>	M	57	Divorced	White British	Bipolar	9	47 days
<b>Miriam</b>	F	26	Single	White British	Schizoaffective Disorder	10+	23 days
<b>Tony</b>	M	46	Single	White British	Paranoid Schizophrenia	2	37 days
<b>Ben</b>	M	21	Single	White British	Schizophrenia	2	36 days

Table 2: Participants' demographic information

Note. M=Male, F= Female

### 3.2 Overview of findings

Five superordinate themes were generated as a result of the analysis. These comprise further subordinate themes which developed from bringing together the emergent themes from the individual transcripts. The theme structures are illustrated in Table 3. A sample of the analysis including the development of themes is presented in appendix K.

Although themes will be discussed separately it is important to remind the reader to appreciate each theme in relation to the others due to the complexity of participants' experiences. It may be that an individual quote may represent more than one theme.

Superordinate themes	Subordinate themes
1. <i>"My future is just being ripped out in front of me"</i> : Living with psychosis is a struggle	1.1 Struggle to survive
	1.2 <i>"I hate myself"</i> : Internal struggle with self
	1.3 <i>"I'm not a psychopath, I'm not genuinely a psychopath, I've just had a lot of hurt in life"</i> : Experiences of stigma
	1.4 <i>"I don't want their help, they didn't help me before why would I want their help now?"</i> : Rejecting help/struggling to accept help
	1.5 <i>"I find it hard to cope so I do draw back to the drugs and alcohol"</i> : A struggle with substances
2. <i>"Would you want to be in here?"</i> : Traumatic experience of being in hospital	2.1 <i>"I'm in a real situation now where I don't feel I have a huge amount of control"</i> : Lack of control
	2.2 <i>"The worst I have ever been dealt with by anyone in the whole of my past, that was just wrong"</i> : Inhumane treatment
	2.3 <i>"Incarcerated, institutionalised. log cabin coglaben hypnogogic fever"</i> : Incarceration creates more problems
	2.4 <i>"They're overworked and there isn't genuinely enough staff"</i> : Concerns regarding resources
	2.5 <i>"It takes for me to come somewhere like this and have a break yeah, for me to start thinking about things again."</i> : Provides a break from life to reflect
3. <i>"I know roughly why I got ill anyway and what caused this"</i> : A journey towards reaching an understanding	3.1 <i>"How the hell did I go from there to there?"</i> : Trying to make sense of the experience
	3.2 <i>"There's a lot of confusion that people think I've actually done worse things than I actually have done."</i> : Being misunderstood
	3.3 Process of proving yourself to others
	3.4 <i>"I understand myself a lot more"</i> : Reaching an understanding
4. Recovery/Rehabilitation/Recuperation: A process of evolution	4.1 Reclaiming a purpose
	4.2 <i>"A fine life is a fine balance"</i> : Finding a balance
	4.3 <i>"Bringing it all back together"</i> : Re-integrating the self
	4.4 Being reborn/evolving
	4.5 Accepting the self and others
	4.6 <i>"Back to life, back to reality"</i> : Getting back on track
5. <i>"You need all the help you can get"</i> : Facilitators of recovery	5.1 <i>"It's god, that's what gets me through this"</i> : Faith in recovery
	5.2 Importance of time in intervention and recovery
	5.3 <i>"Seeing nature reminds me of why I'm alive"</i> : Reconnecting with nature
	5.4 <i>"She's like an anchor, no matter how far I drift, she's always got me"</i> : Support from others

Table 3: Structure of superordinate and subordinate themes

### **3.2.1 Theme one: “*My future is just being ripped out in front of me*”: Living with psychosis is a struggle**

All participants expressed how difficult it had been living with psychosis. Variation existed within individual accounts; however, all participants shared a common experience of a struggle to survive and experiences of stigma. Nine participants described an internal struggle with the self and eight participants reported a struggle with substances. Six participants gave explicit examples of rejecting or struggling to accept help. This theme highlights some of the barriers to recovery including stigma, suicidal feelings and substance misuse.

**3.2.1.1 Struggle to survive.** This encapsulated several different experiences including the struggle with suicidal thoughts and attempts. Several participants also described periods of self-neglect when they would struggle to cook for themselves and neglect their appearance. All participants described struggling prior to their hospital admission due to trauma, bereavement or abuse. This theme was present within all participants’ narratives but differed in regards to the content of their struggle.

Several participants described experiencing suicidal thoughts or attempting suicide prior to their admission:

“Well I was also contemplating, although I wouldn’t have done it, I was contemplating suicide. I had looked it up on the internet, but I wouldn’t have done it, but I was, so that was a bad place to be. My mother would go out walking with me along the beach trying to say look at these lovely trees and it was just like total and utter emptiness and I couldn’t even feel love for, for my children. Yes so detachment.” (Graham, Pg 8, Ln 4).

Graham described his struggle with suicidal thoughts. On reflection it appeared that Graham was reassuring himself that he would not have acted on his thoughts despite researching suicide. His self-reassurance may have been a result of him feeling ready to be

discharged which is something he spoke about later. Graham emphasised the ‘detachment’ he felt from his children as well as the world around him. The language he used conveys the severity of his detachment and emptiness which were common feelings that participants expressed. Feelings of detachment have been linked with depersonalisation which can often occur when stressed, fatigued or when using substances (Hunter, Phillips, Chalder, Sierra, & David, 2003). Graham’s experience of emptiness may be an indication of his hopelessness and disconnection which have been linked with increased risk of suicide (Weishaar & Beck, 1992). All participants referred to feeling hopeless at some point during their experiences.

Participants also expressed their individual struggles in caring for themselves including not eating enough:

“I don’t look after myself because I am highly irritable, my family are highly irritated by me as well, so they won’t cook for me or I won’t eat or I go smoke or I f\*\*\* off outside somewhere and have a drink like a coffee or something like that, but I won’t physically have anything.” (Mohammed, Pg 11, Ln 13).

Mohammed related neglecting himself to the depressive aspect of bipolar disorder, which is something Graham also described. Mohammed identified how his irritability had a negative effect on his relationship with his family, which resulted in them not caring for him and in turn him not caring for himself, representing not only the struggle he faced but others’ struggles with supporting their loved ones. Participants with other forms of psychosis also described this struggle to take care of themselves.

Tony reflected on his life prior to hospitalisation and how he was struggling financially as a result of not being able to work due to psychosis:

“Erm..umm...well I find it hard to erm live on state money, coz at the time when I first got brought in I was on 60 pound a week and I had to pay gas, electric, water and TV licence and I smoked and drunk, and obviously you’ve got to eat and I found it very hard to cope with that. So...I did get in arrears of payments of bills and stuff, so I was pretty messed up.”(Tony, Pg 2, Ln 5).

This struggle to survive due to restricted finances reflects the struggle to live in a society currently impacted by austerity policies. Tony appears to link the restricted financial support from society to struggling to cope within a society that may appear unsupportive and neglectful of his needs. Several participants described financial difficulties which led them to living with family and more able to cope compared with Tony, who to some extent may have felt abandoned by society and his family.

The majority of participants described the difficulties that led to them experiencing psychosis and being hospitalised. These experiences all involved trauma or losses, representing a struggle beginning before the onset of psychosis. Richard spoke about multiple losses followed by several experiences of being rejected. He emphasised the painful impact by describing them as a “dagger in the heart” and “3 sort of blows”. His language illustrates the physical and emotional impact of these events through powerful images of physically violent acts:

“Err I lost my mother and my grandfather in close succession and I was taking a lot of drugs at that time, my mother was ill with cancer, and that was two sort of real sort of daggers in the heart that really sort of unsettled me and I was also unwell. I was too unwell to be at University and they had to ask me to leave the course and they said I could come back when I was feeling more well. So that was 3 sort of blows and then sort of the next year, 2013 I broke up with my girlfriend.” (Richard, Pg 1, Ln 3).

Richard’s description of multiple catastrophes happening in quick succession was a common occurrence for participants prior to hospitalisation. Mohammed, Christopher and Sebastian were the only participants who described a sudden onset of feeling unwell or a single event triggering a deterioration.

**3.2.1.2 “I hate myself”: Internal struggle with self.** Nine participants described various experiences of struggling with how they viewed themselves. Across all of these

interviews participants described reduced self-esteem and/or self-worth. In the wider context these concepts could be linked to participants' internalisation of society's stereotyped or discriminatory views of mental illness and their individual struggle in their change of identity as a result of their experiences.

Ben spoke about his struggle with the external pressures of University as well as the internal struggle of feeling worthless. He described the struggle of trying to improve himself for others but not valuing himself enough to be able to maintain the motivation to carry this on:

"I tried really hard for my dissertation but all throughout that period it manifested as something in my head that was telling me you're not worth it, you're not intelligent enough, that sort of thing. Erm... errr...my ex would sort of say those sort of things, erm because it was maybe ... and you know it would sort of manifest in me sort of still trying to improve my fitness, improve myself, but not really inside having the self-worth and not being able to cope with the things going on."(Ben, Pg 10, Ln 7).

Tony identified his attempts to please others as a way of increasing his self-worth which resulted in him feeling disappointed when he felt he had failed, illustrating the constant grapple of trying to rebuild his self-worth:

"I try and do what me mum says but I don't always achieve it, which is a bit of a disappointment, but err yeah I look up to my mum." (Tony, Pg 8, Ln 18).

These quotes highlight the impact of external responses on how participants viewed themselves which may represent the experience of self-stigma.

**3.2.1.3 "*I'm not a psychopath, I'm not genuinely a psychopath, I've just had a lot of hurt in life.*": Experiences of stigma.** All participants reflected on experiences of stigma in relation to living with psychosis. Stigma was linked to being a barrier to recovery in regards to employment, reconnecting with others, and being accepted by society. Six

participants appeared to refer to experiences of public stigma as opposed to self-stigma. Graham, Miriam, Tony and Ben appeared to have internalised public stigma and applied these stereotypes to themselves in regards to not being able to recover, viewing themselves negatively, or persecuting themselves. This internalising of public stigma and the acceptance of this is known as self-stigma. Self-stigma can undermine self-esteem and self-efficacy which can affect an individual's engagement with personal goals and opportunities (Corrigan, Watson, & Barr, 2006).

Mohammed spoke about his experience of being sacked due to how his employer perceived his diagnosis. Mohammed's experience of discrimination at work is one example of how he may have felt unaccommodated or rejected by society:

“...but they won't accommodate me now because one of the doctors from here wrote that I was likely to have a relapse every 1-2 years, I was quite young then and it was quite potent my illness, because of that they sacked me on ill health with no compensation.” (Mohammed, Pg 9, Ln 11).

Thornicroft (2006) describes the impact of stigma across society and how powerless an individual can feel as a result of the 'perceiver's' rejection. Employment discrimination was experienced by several participants and was considered to be a significant barrier to recovery.

When interviewing Christopher, he explained the importance of the language used and the diagnosis given in regards to how people may respond to him. He was reluctant to use the word “unwell” as he perceived this to be linked to people “making a fuss”, which may have reflected past experiences of him talking about how he was feeling and others responding in a way he found unhelpful. His reluctance to be associated with the 'label' of psychosis may also be linked to an attempt to avoid the negative connotations associated with psychosis:

“I wouldn’t say I am unwell. **Okay unwell was my word, what word would you use?** I would say concerned, because unwell is being like psychosis it’s hard to say to someone you’ve got psychosis so maybe I would be like borderline psychosis, because then they might not make a fuss. I’m not sure if what I had was psychosis because it just happened so I’m not sure.” (Christopher, Pg 3, Ln 1).

Four participants had a diagnosis of bipolar disorder and they spoke about how they were different from other patients. They spoke about seeing themselves as having the ability to function at a higher level, which may link to historical perceptions of schizophrenia leading to poorer functioning compared with other mental illnesses (Cohen & Cohen, 1984). Sebastian described his perception of other patients and his anxiety about accepting support due to his fear of being “labelled”:

“Do I want to take all the services that they may offer like for instance community housing? Err disability allowance things like that. Very nervous about accepting anything that colours me in a certain way, you know erm do I have to admit that to someone? Am I now in a system on that? So I’m very erm kind of...feeling a bit careful, woah woah woah, that’s, that sounds okay but am I now kind of really labelled mental health now. You know I’ve got a lot of respect for everyone in here but erm I still believe I could do something businesswise, I’ve done it before, been successful before. I don’t want to be labelled if I really don’t need to be.” (Sebastian, Pg 19, Ln 11).

**3.2.1.4 “I don’t want their help, they didn’t help me before why would I want their help now?”: Rejecting help/struggling to accept help.** Several participants expressed their struggle to accept help from mental health services due to their previous negative experiences. Some participants described rejecting help until they realised they needed support. This initial rejection of help appeared to delay recovery. Others described needing support but finding the support they were receiving unhelpful. Miriam spoke about her experience of her transition from child to adult services and how this had been poorly managed. Throughout her interview she expressed her hopelessness in relation to recovery and others’ ability to help her which may be linked to her experience of being abruptly rejected by children’s services:

“Yeah and the doctor said no more contact with children’s services, so they just cut it off.” (Miriam, Pg 2, Ln 5).

Ben described initially rejecting help due to not feeling he belonged in hospital. It may be that he felt scared as a result of his sudden admission and had conflicting views about whether he belonged in hospital. Ben reflected on the fact that with some time and space away from hospital he realised he needed support. He described “lying to myself” which may have been a way of defending against the impact hospitalisation may have had on his already depleted self-worth:

“...and then I got sectioned and I was very sort of, soon as I went into the sectioning I was like oh I shouldn’t be here, I don’t, I don’t want to be here, I’m fine, I can be released you know. Erm...and erm then I managed to get released, I got released the next day, erm that was from a 136, yeah and then I guess I could say gradually I realised that I needed, that I needed some support, I had too much stuff going on in my head, in my head that you know I’ve been lying to myself really about...like self-worth and stuff like that.” (Ben, Pg 1, Ln 8).

**3.2.1.5 “I find it hard to cope so I do draw back to the drugs and alcohol”: A struggle with substances.** Eight participants spoke about their struggle with substances. Several spoke about substance use as the reason why they believed they became unwell, as well as causing relapses and others recognised that they had been using substances as a way to cope which had resulted in them becoming more unwell. Christopher reported that he had never misused substances and Miriam did not mention substance use.

Graham described becoming unwell as a result of his drug use and how this spiralled out of control. Mohammed also identified his drug use as a reason for experiencing relapses and struggling to stay well. Graham’s drug use seemed to be a way of connecting with others which maintained his engagement with drugs, even through periods of recovery. Graham appeared to regret using drugs due to him repeatedly becoming unwell:

“I think, I think I got ill through drugs about 3 times so I’d recover, put on weight erm and then but start going back to drugs, to drugs again and the sort of the

friends I was hanging around with... if I could go back in time that's the bit I would change." (Graham, Pg 3, Ln 4).

Sebastian described his drug use as a way of coping with depression and anxiety in social situations. He seemed to have developed his own ways of coping due to having no input from services:

"Err so I did cocaine for a while and yes that may have been me to be honest trying to deal with depression at certain points. When I was younger I had a lot of anxiety erm and I would say depression as kind of bedfellows, naughty bedfellows. You know I didn't enjoy myself when I was out erm therefore I drank quite a lot, so I had a lot of black outs in my time. Erm that was all before I got any kind of mental health diagnosis." (Sebastian, Pg 9, Ln 6).

Several participants described their drug use as a way of coping with intrusive thoughts and anxiety. Others spoke about substance misuse as a form of self-harm in response to painful memories or negative perceptions of themselves. Ben described smoking marijuana as a form of "cathartic release". For him drug use could be seen as a way of releasing the anxiety linked to repressed feelings coming into his consciousness. Ben spoke at length about traumatic events that he was struggling to process which may have been coming to the surface as a result of his hospital admission, either through engaging with therapy or being in an environment that may have resulted in repressed memories resurfacing. Ben appeared to be struggling with his knowledge that substance misuse was not helpful for his recovery but feeling unable to cope without substances:

"Yeah and that's part of self-deprecation and sort of loathing in a way. But I do sort, I do sort of need it sometimes coz I have so much pressure in my chest I feel like I need to smoke, it's almost like a cathartic release, if that makes sense?" Although I feel like I need it, I know I shouldn't smoke coz it's not good for me... but I just really need it to cope sometimes." (Ben, Pg 5, Ln 9).

Several participants reflected on their experiences of trauma and how difficult it was to cope with, however, not all used substances as a way of coping.

### **3.2.2 Theme two: “*Would you want to be in here?*”: Traumatic experience of being in hospital**

All participants described their admission to hospital or their experience as a patient as traumatic. Themes of having a lack of control, experiencing inhumane treatment, incarceration leading to further problems, and concerns regarding the hospital resources were present. To a certain extent these negative experiences of care are reminiscent of the experiences described in asylums. For all participants these negative experiences of hospitalisation were seen as preventing recovery and leading to them feeling worse. Several participants identified some positive aspects which are reflected within the theme of hospital providing a break from life to reflect.

#### **3.2.2.1 “*I’m in a real situation now where I don’t feel I have a huge amount of control*”:**

**Lack of control.** Six participants expressed a lack of control in relation to their admission. This lack of control was defined as being admitted via a MHA (1983, 2007) Section or feeling under external pressure to agree to an admission. This can be linked with the wider societal narrative about people with mental illness needing to be controlled for the safety of society. “The Great Confinement” described by Foucault (1967) viewed people with mental illness as choosing this way to be and therefore requiring punishment and subsequent reward for making different choices. Segregation from society was seen as the only way of achieving these changes and subsequent social order (Porter, 1990). This lack of control experienced by participants may be a reflection of the wider control imposed by society. It appeared to lead to participants feeling ‘out of control’ and the possibility of recovery being permitted only by external sources, in effect when society deemed them safe enough to return. Hospitalisation could be a representation of the oppressive power society has which from the descriptions of participants appears to be a more powerful influence than psychosis.

Mohammed described being convinced by a family member to agree to an admission. There is a sense that he may have regretted agreeing to an admission and this change of mind led to sectioning, which resulted in further restrictions being placed on his freedom leading to even less control:

“... the only reason I came into hospital this time was because my dad was out of the country and my wife convinced me to come here as an informal patient but then I ended up getting sectioned because I absconded.” (Mohammed, Pg 8, Ln 10).

Other participants expressed their concern regarding their lack of control around their discharge. Some participants felt they had no control and described being held against their will, for others such as Sebastian he expressed his concern about being discharged too early. He emphasised his distress and lack of control by using the phrase “being pushed out”. Sebastian had been studying prior to his admission and spoke about needing time in order to reintegrate back into University rather than being discharged and having to wait to hear about the future of his University place. His account highlighted his lack of control over decisions made within hospital and those made about his life by his family, suggesting that it is not only within hospital where he lacked a sense of control. This quote illustrates a sense of feeling lost and a lack of belonging, leaving him feeling unsupported and potentially rejected:

“So I’m in a real situation now where I don’t feel I have a huge amount of control. One I’m being pushed out of this place erm...and then I have family who while I was in here effectively wanting to carry out what the university were doing which was to evacuate my accommodation on campus. That suggests to me that they weren’t even trying to set up a deal if I came out of here earlier I could join earlier than that. So at the moment I don’t feel particularly supported or in control.” (Sebastian, Pg 17, Ln 6).

This powerful representation of feeling excluded from society and from hospital could be interpreted as Sebastian feeling like he has no place in the world, which could be traced back to Dain’s (1980) explanation of society attempting to “rid itself” of mental illness.

**3.2.2.2 “*The worst I have ever been dealt with by anyone in the whole of my past, that was just wrong.*”:** **Inhumane treatment.** Seven participants described experiences of inhumane treatment, leading to a sense of unsafety and a lack of respect for the staff and what the hospital represented. These experiences included treatment experiences as well as the process of being admitted. Paul described his distress and horror at the way he was treated during his admission. The powerful image of his dignity being taken from him as his belt was removed may represent his sense of security being taken from him, leaving him bare and exposed, emphasising the level of vulnerability he may have experienced as a result of being hospitalised:

“The police ended up pulling up and took me to [location]mental health unit, I was a size 32 waist, size 36 jeans and they took my belt and they took my dignity as my trousers fell to the floor, erm it was horrific, and this time round they’ve done the same thing, horrific.” (Paul, Pg 1, Ln 14).

Sebastian described the impact of being medicated without his consent. Sebastian referred to his human rights being denied suggesting he may have experienced staff’s treatment of him to be inhumane. He referenced this event throughout his interview which may indicate his disbelief at how he was treated as well as having difficulty processing this potentially traumatic event:

“They literally took me, 5 of them, I didn’t resist if you like but I didn’t help, they took me round there and jabbed me in my ass...and when I actually walked out of that room I turned to[name], the ward manager and to others who are with him and said I’m just going to leave this in here, that was morally corrupt, deal with that...I never ever had anything like that happen to me before, you know I wasn’t bawling my eyes out but I actually felt that I’d literally had a kind of human right there denied me. So that is the worst I have ever been dealt with by anyone in the whole of my past, that was just wrong.” (Sebastian, Pg 14, Ln 7).

**3.2.2.3 “*Incarcerated, institutionalised, log cabin coglaben hypnogogic fever*”:** **Incarceration creates more problems.** Seven participants described the negative consequences of being “incarcerated”. Participants’ language to describe the hospital

environment provoked the image of being in prison such as “incarceration”, “imprisoned” and “trapped”.

Paul conveyed his perception that his life was ruined once admitted. He described not being able to do anything right and experiencing a constant battle with the staff. He described his non-adherence to his treatment plan due to him experiencing medication as having a negative impact on his functioning, which could be an indication of him feeling that treatment and hospitalisation makes you feel worse. There is a sense that he felt hospital treatment was attempting to strip him of his identity as a businessman which may be linked to stigma he may have experienced as a result of having a diagnosis:

“No matter what happens you’re f\*\*\*\*\* for life once you come in here. The staff have no respect for you at all, they argue and you’re wrong, if you don’t take your tablets you’re wrong, I’ve now stopped taking certain tablets because they make me weak and feeble. I’m not going to take them just because someone says take them for mental health when actually no I’m a businessman, so and so forth, you know.” (Paul, Pg 2, Ln 9).

Several of the participants referred to their identity changing as a result of experiencing psychosis and being hospitalised, particularly in regards to their employment status and the way that others viewed them.

Richard shared a phrase he had invented to describe hospitalisation, focusing on the effects of institutionalisation. He emphasised not being able to escape the confinement of hospital which in turn effects behaviour. It is interesting how he produced what could be considered a diagnosis which may represent how behaviours or experiences are commonly understood within the medical system or may represent him feeling restricted or “trapped” as a result of a diagnosis:

“I made it up. Erm my doctor wrote it down...incarcerated, institutionalised, log cabin coglaben hypnogogic fever...erm it’s just how I was feeling erm and so how you start behaving when you become institutionalised. You feel incarcerated, you feel trapped, you feel you have no freedom, you feel these inside walls and

the garden is all you have in life, that's all that exists, it exists forever." (Richard, Pg 9, Ln 2).

**3.2.2.4 “*They’re overworked and there isn’t genuinely enough staff*”:** Concerns regarding resources. Half of the participants expressed their concerns or frustration regarding a lack of hospital resources or effective care which reflects the current budget cuts within mental health services. Economic downturns due to austerity have been linked with exacerbating and prolonging mental health risks, particularly risk of suicide (Stuckler, Reeves, Loopstra, Karanikolos, & McKee, 2017).

Ben spoke about helping staff with domestic tasks due to the limited number of staff compared with the amount of work there is to undertake. This experience of there not being enough staff may lead patients to feel unsupported and their basic needs left unmet. Ben reflected throughout his interview on his lack of self-worth and how others had not valued his hard work. This experience of feeling unsupported may have further reinforced the narrative he held about himself being unnoticed by others, which may also be a reflection of government’s austerity policy not recognising the impact of cutting mental health budgets:

“I’ve helped erm literally when I’ve seen I know it probably sounds really disgusting but I’ve always washed my hands thoroughly afterwards, erm but erm sort of wiping skid marks, having to flush the toilet so because I’ve noticed the fact that the staff here are all sort of, they’re over worked and there isn’t genuinely enough staff on the wards.” (Ben, Pg 3, Ln 20).

Mohammed described having to exaggerate his presentation in order to access a hospital bed, indicating the potential for many people being unable to access the level of support they need. The presentation that Mohammed created may be a reflection of his desperation to seek the help that he needed and the extent to which he felt out of control. It may also reflect society’s failure to recognise the level of support and investment mental health services need leading to maintaining or even creating mental health difficulties:

“My sister in law said why don’t you lie to the doctor to get yourself a hospital bed otherwise these aren’t going to give you a hospital bed, so I said to the doctor yeah I’ve been killing people in the street, I’ve been killing doctor and I’m going to stab you as well you mother f\*\*\*\*\*. I was like I want to head butt you man and I was just lying, just lying outta my teeth, just b\*\*\*\*\*.” (Mohammed, Pg 8, Ln 12).

This example of presenting as dangerous and potentially ‘more unwell’ than he was may link with Parsons (1951) sick role theory in that Mohammed felt he had to present as ‘more unwell’ in order for him to prove or legitimise his mental health difficulties to gain access to support and to be provided some ‘leeway’ by society. Parsons posits that it is the individual’s responsibility to make ‘getting better’ a priority and to seek out treatment themselves (Varul, 2010). The extreme way in which Mohammed does this may be representative of the pressure society places on the individual to seek help for themselves.

**3.2.2.5 “It takes for me to come somewhere like this and have a break yeah, for me to start thinking about things again.”: Provides a break from life to reflect.** Half of the participants identified some positive aspects about hospital including the experience of being cared for and having a break away from life in order to rest and reflect, which was seen as vital to begin recovery. Ben reflected on the benefits of having some time away from life pressures and having his basic needs met. His reference to having his meals cooked may imply a sense of being cared for and viewing the hospital as a parental, nurturing figure who was able to meet his needs which links to the wider understanding of attachment difficulties linking to the development of psychosis (Read et al., 2005):

“...So it would be nice to have sort of a little bit of a period of time, like I noticed it has helped me in here having meals cooked for me and things done for me.” (Ben, Pg 8, Ln 20).

Tony also spoke about the pleasant experience of being cared for in hospital which may link with his experience of being abandoned by his father. His experience within

hospital may have challenged his internal working model about others being uncaring or unable to meet his needs.

Mohammed was one of the participants who expressed a lot of anger towards hospital staff due to the lack of control over his admission and the lack of care he experienced. As the interview progressed he was able to reflect on the benefits of his admission which included having a break to think about life and appreciate everything. Many participants described the chaos they experienced as a result of psychosis and it seemed that for some hospital interrupted this chaos and gave them a chance to slow down and focus on themselves, supporting them to begin seeing the world and their surroundings again:

“I’m happy to be alive. Now I’m happy because god has given me...he’s given me my phone, this phone in my hand, money, money in my pocket, money in the bank account, two beautiful children, a lovely wife. Go on a holiday and get out of here, go to [location], yeah so I had all of that before but I just didn’t see it. It takes for me to come somewhere like this and have a break yeah, for me to start thinking about things again.” (Mohammed, Pg 22, Ln 14).

### **3.2.3 Theme three: “*I know roughly why I got ill anyway and what caused this*”:**

#### **A journey towards reaching an understanding**

This theme was represented within each participant’s account and encapsulates the unique journey in reaching an understanding of their experiences. For some this appeared to be a developmental process, moving through each of the stages. Along this journey each participant described their experience of being misunderstood and having to prove themselves which was described as challenging but a key part of learning more about themselves.

**3.2.3.1 “*How the hell did I go from there to there?*”: Trying to make sense of the experience.** The initial phase involved trying to make sense of their experience. For several

participants this involved a process of questioning. Sebastian described two weeks prior to his admission presenting at a panel as part of his degree before experiencing a sudden deterioration leading to hospitalisation. He appeared to be questioning the sudden onset of psychosis and the different quality of the experience compared with prior experiences. His repeated questioning may be reflecting his confusion as well as a process of trying to reach an understanding:

“...How the hell did I go from there to there? And if actually I’d been ill before that, quite potentially, how did I manage to stabilise for that? Or was it the fact that in a psychosis, which I do actually believe I can still do some pretty good stuff as long as I’m really focused on that thing and I don’t allow all the other things which I’m connecting up to to get involved. There’s a lot, I think personally to look into for me, led up to this time because it was totally different and erm, and has led to incidences in sectioning, which I err literally cannot afford this to happen anymore. (Sebastian, Pg 16, Ln 21).

Richard spoke about the interconnectedness of his experiences and a process of things coming together in his mind which may be a visual metaphor for the initial phase of understanding. He described a contrasting experience of delusional beliefs as well as realisations which appeared to be overwhelming but at the same time enlightening:

“Erm and everything had some kind of connection, erm everything was being related in some way to everything else, you know the levels, the channels, the sections, the dimensions and everything all merging into one big state of mind. Erm and yeah I was having a lot of delusional beliefs, but also was realising a lot of things in reality, all at the same time, it was too much for me to process.” (Richard, Pg 1, 23).

**3.2.3.2 “There’s a lot of confusion that people think I’ve actually done worse things than I actually have done.”: Being misunderstood.** This theme included disagreeing with diagnosis as well as only being able to relate with those enduring a similar experience. Paul spoke about disagreeing with the diagnosis of bipolar disorder and had instead made sense of his experiences through another diagnostic term:

“I haven’t got psychosis in my opinion so I can’t answer that. **Okay, because you mentioned bipolar before?** That’s what they say, that’s not what I say. **What do**

**you think...?** PTSD, post-traumatic stress disorder, my dad died in front of me of a heart attack when I was 17. That's my main problem cannabis addiction, no one wants to listen to you do they, they just want to say you're bipolar." (Paul, Pg 8, Ln 18).

Paul described a traumatic experience which he felt needed to be accounted for when trying to make sense of his experience. Experiencing trauma was common amongst all participants and links with the literature regarding the role trauma can play in psychosis (Bentall et al., 2012, Read et al., 2009; Varese et al., 2012). This expression of a diagnosis not fitting with an experience is reflected within the BPS (2011) critique of the DSM-V. Paul's understanding of his experiences may be that he witnessed a traumatic and devastating loss which he is naturally having difficulty processing which may have led him to use cannabis as a way of coping. The conceptualisation of his experiences in a diagnosis of bipolar appears to have left Paul feeling misunderstood and frustrated. This may prevent him from accessing support due to his lack of validation within mental health services and may also lead to him not being able to access support for the trauma he has experienced. This experience of being misunderstood appears to present many obstacles to Paul's recovery.

Several participants discussed their difficulties in communicating due to fears of being misunderstood. It appears the barrier to communicating with friends and family is due to the lack of shared experience and them potentially viewing the individual as unwell and relating to them differently. Richard discussed turning to new people to form connections with due to his inability to communicate in pre-existing relationships. He described finding new bonds when he was "in those states" which was how he referred to being unwell. The creation of new bonds created new opportunities to be understood without the threat of being compared to when one was not in one of those "states":

"I mean I find these new true bonds but I find it more difficult to relate to my family and friends. I just don't have the time for friends and family, and it's not in a rude way, it's not because I don't want anything to do with them, it's just I can't

communicate with them. I'm in a different communicative place, I can't, I don't know how to go about communicating with the people I need to communicate with. But I find, I often find new bonds or kinships or soulmates in those states." (Richard, Pg 6, 16).

Sebastian discussed his perception of his father having a limited understanding of mental health which created tension within their relationship. He described his father as being focused on medication being the key to recovery. This appears to be a reflection of the current medicalised model which focuses on medication as a way of reducing symptoms. His father's misunderstanding appears to be frustrating for Sebastian which he described as having a "destructive" impact on their relationship. As part of this misunderstanding Sebastian had been able to reflect on his own understanding of what was helpful, which involved staying connected with the world and maintaining interests:

"...yet he doesn't have a full, grounded, understanding of mental health. It's just about medication and if I try to talk to him about anything else he literally closes down the conversation and he will be like you've got to get your medication and I'm like for God's sake it's supposed to be a balance right? Erm medication takes about one minute of a day, erm...you know you want to stay in touch with the world and talk about things that interest you because that will kind of bring you up from...so...yeah so I've certainly experienced a lot of the relationship erm issues that can happen, especially with bipolar, that can almost be destructive." (Sebastian, Pg 15, Ln 22).

**3.2.3.3 Process of proving yourself to others.** This process included participants proving to others that they were not dangerous, could be trusted, or that they were a good person. It involved others developing an understanding of the participants' experiences by considering the context in which they became unwell. This resulted in acceptance and less judgement, reducing experiences of discrimination and stigma, which supported recovery. Ben described the progress he had made in hospital as a form of evidence that he was safe to enter back into society. He also referred to a potential misconception that he was a "bad person" which may be a reflection of how he was perceived or an internalised perception of how others viewed him, which links with self-stigma and the context of being discriminated

against throughout his life. He led on to reflect upon the impact these misconceptions and life experiences had on his self-esteem, beginning to make connections between his past experiences and current experiences. As a result he appeared to feel empowered to stand up for himself:

“I think that I’ve showed that I’m genuinely not a threat to society if I was to enter back into society I would be fine and I would never really have had, had a really bad heart. I’ve had a lot of hurt and it’s caused me to have low self-esteem and I’ve got to maybe sort of take the right steps but erm yeah I think that I’ve realised that the only way that I can...erm sort of move forward in life is by having some self-respect because if I don’t stand up for myself then no one will, if that makes sense?” (Ben, Pg 2, Ln 18).

Sebastian described his frustration at having to evidence his mental health with the University in order to access appropriate support. The passiveness of the external agencies appeared to motivate him to take action in order to advocate for his position and enhance others’ understanding of mental health:

“I think God damn it this is pretty serious mental health scenario, surely the Uni and the school could do more than just nothing, err more than just erm stay away. I can obviously get letters from Dr [name] I could go and see them in person so they can see what I’m like. (Sebastian, Pg 17, Ln 16).

This process of proving oneself also links with the earlier example of Mohammed presenting as ‘more unwell’ in order to prove to others that he needed support.

**3.2.3.4 “I understand myself a lot more”:** **Reaching an understanding.** The final stage in the journey is reaching an understanding. This is not necessarily a finite process and many participants reported an ongoing experience of learning about themselves. Several participants described processes that had helped them to reach this understanding and others focused on the components that contributed to their understanding. Christopher discussed factors that had supported him to develop ways of coping:

“...well I’ve been taking part in his courses, they’ve been helping me to understand a bit more about how the mind works. Psychology- because that’s

what I'm interested in- how the mind works. It's really interesting how the brain works and the mind operates...it's quite interesting, it has helped me if I'm having negative thoughts and things like that. It has actually helped and given me something different to do." (Christopher, Pg 7, Ln 3).

Other participants also reflected on accessing psychological support as a way of understanding their experiences, such as Mohammed who spoke about reflecting on his substance use with a Psychologist.

Alex described a process of introspection as the way he enhanced his understanding. He highlighted the process of questioning his experiences which links back to the initial phase of reaching an understanding. He appears to perceive this process as internal and looking within to find the answers which may be linked to the idea that only the person experiencing a phenomenon truly understands the internal process:

"I use my own thinking to understand how to deal with it if you know what I mean. Sort of, it's becoming a little bit ingratiating, and you think to yourself is that all there is to it? Who knows? Like that's it, that's an example of me doing it. You become introspective and I turn things in and I look in on myself and I start to project, my illness projects itself, that's how it works." (Alex, Pg 5, Ln 10).

#### **3.2.4 Theme four: Recovery/Rehabilitation/Recuperation: A process of evolution**

All participants described recovery as a process that involved change. "Rehabilitation", "wellness" and "recuperation" were terms used by participants instead of recovery. All participants except Miriam believed recovery was possible, which may have been linked to the chronicity of her experiences. Six participants reported experiencing recovery. Graham and Miriam felt they had never experienced recovery and Alex and Tony described periods of "feeling better" or "having good days" but not experiencing complete recovery.

None of the participants spoke about recovering from the trauma of hospitalisation. It could be that due to participants being interviewed in hospital it may have been too difficult for them to consider recovering whilst still living within the context of the trauma.

**3.2.4.1 Reclaiming a purpose.** This theme featured in all participants' accounts. Purposes included life goals, roles and responsibilities and making a contribution to society. Several participants spoke about reclaiming their role as a father:

“Being with my kids, playing anything with my kids, noughts and crosses, playing football.” (*Paul begins crying*) (Paul, Pg 8, Ln 4).

Paul began crying as he reflected on spending time with his children. This embodied affect may emphasise the grief he experienced being separated from his children when he becomes moved when recalling a personal memory of playing with them.

Several of the participants spoke about reclaiming focus on their goals. Tony described the impact being unwell had on his progress towards his goals:

“Obviously when you're unwell you sort of lose track of things and when you're better you're sort of heading towards your goal more. Definitely yeah.” (Tony, Pg 6, Ln 21).

Graham spoke about reclaiming some aspects of his personality including his ability to socialise and his confidence, which led to increased contribution. This reference may imply that an internal change may need to take place in order for external change to happen:

“...go back to being the sociable person that I used to be erm yeah, just sort of enjoy being a confident sociable you know person that could probably contribute at some level but I don't want to do that in isolation anymore.” (Graham, Pg 10, Ln 1).

Christopher also mentioned a goal orientated mind-set as being a sign of recovery and linked this to feeling happier and more fulfilled. This could be seen as the external outcome of achievement leading to an internal emotional transformation:

“For me I try and think about what I want to do with my life...I want to be happier you know. I want to set a goal, achieve something and do something with my life. Just get out there you know to feel more fulfilled.” (Christopher, Pg 6, Ln 8).

**3.2.4.2 “A fine life is a fine balance”:** Finding a balance/stability. Half of the participants discussed the ability to find a balance in recovery. This related specifically to mood for some and for others it involved a balanced lifestyle. Sebastian described finding stability in relation to bipolar disorder which may be an indication of the impact that mood swings had on him and his ability to feel in control of his life:

“Erm I think recovery for anyone that’s had err Bipolar or has Bipolar is really erm is stability erm...and the ability to be in control of your future. Erm so...you know as far as what I would consider recovery would be to erm yeah have stability, more stability.” (Sebastian, Pg 18, Ln 4).

All participants diagnosed with bipolar disorder reflected on the experience of mood swings and the difficulty managing them.

Alex used a powerful metaphor to describe the “fine balance” between being well and unwell, indicating that recovery does not mean continuous wellness but an ability to keep moving on in spite of challenges. The use of moving vehicles may be representative of the journey of recovery and moving forward as an indication of progress:

“...but there’s sort of like a balance, a fine balance between being unwell and being well. I mean, it’s like, so like going along, so it’s like a train or a plane, it’s driving in a little bit of wind turbulence, so it rocks from side to side, some days are better than others, some days are worse than others, so forth and vice versa.” (Alex, Pg 8, Ln 13).

Miriam echoed Alex’s view that recovery involves periods of feeling unwell:

“Being more okay but not being okay.” (Miriam, Pg 8, Ln 21).

**3.2.4.3 “Bringing it all back together”:** Re-integrating the self. Six participants described a process in recovery of re-integrating the self. For Christopher this involved integrating his experience of psychosis into his life story and it becoming part of him. It appeared helpful for him to integrate his experience into his conscious self in order to support him if having a similar experience again. This process of integration implies an acceptance of psychosis which is necessary to move forward:

“Erm... basically you could say it’s the story of my life really, it’s part of my life, psychosis yeah. It’s something quite personal you know. It’s part of who you are and your experiences, I guess it’s part of who you are. It’s a chapter of your life about your experiences, where you can say you know this is what I did to maybe come out from it.” (Christopher, Pg 10, Ln 7).

Richard used a vivid image suggesting that experiencing psychosis may result in the self being pulled apart or broken and recovery involves putting the self back together. He suggested that this reintegration leads to no changes due to the outcome being “still the picture you started with”. This could be interpreted as being different from other participants’ views as others suggested that the self changes and therefore the picture would be different to how it started:

“Well it means bringing it all back together. Pick up the pieces you could create a picture puzzle, shuffle them all up, drop loads of them on the floor and you pick them up and put the picture back to how it should be and it’s still the picture you started with.” (Richard, Pg 16, Ln 7).

Sebastian spoke about recovery being health orientated whereas rehabilitation involved focusing on the individual’s life. He spoke about the importance of integrating both recovery and rehabilitation in order to prevent future deterioration. It appeared that his experience of recovery orientated services were to support you to improve mentally and then expected to put your life back together by yourself. His view of rehabilitation involved

reintegrating the self on a biological, psychological and social level, which may be a reflection of his disagreement with the medical model:

“Recovery I kind of see almost as health, erm recovery and stabilisation of your mind if you like, erm rehabilitation is okay that’s critical input erm the problem is if then when you’re considered kind of recovered in the mind you have to then do the work to try to do the rest of the rehabilitation to your job or to your studies or whatever.” (Sebastian, Pg 25, Ln 27).

**3.2.4.4 Being reborn/evolving.** Five participants described the process of recovery as an evolutionary process. Alex used the metaphor of a hibernating hedgehog to symbolise the experience of being unwell which may emphasise how psychosis can weaken and sedate your spirit. Waking up from hibernation may symbolise the process of waking up from illness and beginning to feel alive and connected to your surroundings. Alex also appears to refer to increased insight as part of the ‘waking up’ process. The presence of the hedgehog’s prickles is symbolic in visually representing that the difficult experiences remain part of you and that recovery can be achieved in the presence of these:

“A metaphor for recovery? Err...yeah...yeah a hedgehog...a hedgehog...that’s my little recovery friend (*ppt shows interviewer a necklace he is wearing with a hedgehog pendant*) helps me recover...a hedgehog because hedgehogs hibernate and being mentally ill is like being asleep, but when you’re awake you know why you were ill and all those little prickly experiences when you were mentally ill.” (Alex, Pg 9, Ln 11).

This metaphor and the powerful image of rebirth provided by Graham below appear to be quasi-spiritual in their nature and could be linked with The Human Potential Movement (HPM). This movement links with recovery in that it believes that by developing “human potential” a better quality of life can be achieved involving happiness, creativity and fulfilment (Puttick, 2004). This process of growth and change can lead to achieving self-actualisation (Maslow, 1943) which also links with the struggle to meet basic needs which several participants spoke about in regards to their struggle living with psychosis. Maslow’s Hierachy of Needs (1943) posits that a person’s basic needs need to be met in order to grow

and evolve to a place of self-actualisation. Self-actualisation is reaching a place where an individual has achieved their full potential which could be what Alex and Graham may be referring to when conceptualising recovery using these quasi-spiritual metaphors:

“Yeah an actual fact I saw that this time in stone with Christ crucified but on a on a round, but that’s the first time I’ve seen that.” (Graham, Pg 15, Ln 1).

Graham’s image of recovery could be interpreted as the crucifixion representing the painful struggle of psychosis involving sacrificing parts of the self. The narrative linked with this image of Christ is the rebirth in order to cleanse the world of sins. It could be that Graham saw recovery as starting afresh and beginning life again free from the painful experiences of psychosis.

Christopher described the emotional significance of experiencing psychosis changing him forever. His description could be indicating a personal transformation resulting in him realising his potential which supports the process of recovery. He discussed how difficult it could be to recover when experiencing psychosis for a prolonged period but appeared hopeful that improvement could happen. He also emphasised the importance of embracing moments of feeling positive in order to maintain recovery:

“Experiences of psychosis can only change you...to quite a profound level. While you’re in that state it can be difficult to try and get yourself out, when you spend a particular amount of time in that state it’s hard to say come on now then let’s get out of it, so you need to be okay. The full process of going through that emotionally is significant. When you get out you feel positive and happier, but when you stay in that state for a particular amount of time you start to become ill and your mental state might deteriorate further.” (Christopher, Pg 9, Ln 3).

**3.2.4.5 Accepting the self and others.** Eight participants spoke about recovery involving acceptance, whether that be accepting the self, accepting others, or being more accepting of psychosis. Over half of the participants expressed happiness as being a key component in recovery which is an emotion often linked with acceptance.

Several participants described a process of accepting yourself through forgiveness, loving yourself, and finding peace. Ben referenced being able to forgive in order to move on which could be interpreted as a process of forgiving himself in terms of shame associated with his behaviour when unwell, as well as forgiving others for how they have responded or perceived him when unwell:

“Erm...you know...in a way forgiveness, being able to move on and to find peace with myself erm...yeah.” (Ben, Pg 11, Ln 16).

Christopher described the importance of loving yourself first before loving others, implying that recovery should focus on your own needs as a priority. Self-worth was a concept highlighted by all participants in regards to maintaining their low mood or suicidal tendencies and mentioned by several as a potential barrier to recovery. Increasing self-worth appears to be important as part of recovery:

“Like I said before if you achieve something and love yourself, love yourself before you love others. If you think positive things then positive things happen.” (Christopher, Pg 6, Ln 12).

Alex illustrates the importance of accepting others in order to be in recovery. He acknowledged that we all have to exist alongside each other and that tolerance is key. It may be that this is a subliminal message to those who have not experienced mental illness and an expression that he is still a human being and that others need to be more tolerant of mental health:

“Anyway you have to get on with it and you just have to accept everybody’s, we are all moral beings because we’ve all got the same ideas, we’ve all got the same life, same planet, share the same planet. So just be a bit more tolerant of each other and get on with it from there you know.” (Alex, Pg 11, Ln 17).

**3.2.4.6 “Back to life, back to reality”:** **Getting back on track.** Seven participants described some form of ‘getting back on track’ or back to the life that they were living prior to their admission. Several participants indicated that hospital may be preventing them from recovering. Paul illustrates the need to get on with his life by leaving hospital:

“Let me out of here and I’ll get on with my life, it’s alright.” (Paul, Pg 3, Ln 21).

Miriam also spoke about recovery happening when she was discharged:

“I’m not in hospital, or I see friends and family or I go to my activities. Just look after myself a bit better, I wash, I eat and drink.” (Miriam, Pg 6, Ln 14).

Richard described recovery as:

“Erm... back to life, back to reality.” (Richard, Pg 11, Ln 16).

This may be explaining the return to reality in regards to no longer experiencing delusional thoughts. It may also mean returning to the community and returning to the ‘real world’ as hospital was described by several as being a break from ‘real life.’

Sebastian illustrated the unique and idiosyncratic nature of recovery by considering how life had changed as a result of psychosis and the need for rehabilitation to be focused on getting the person back onto the track they were on prior to being unwell. He may view recovery as a superficial concept and view rehabilitation as a deeper process of understanding the course of an individual’s life, including their aspirations and their sense of purpose in order to recover not just their health, but to recover their soul:

“Yeah I guess erm I guess rehabilitation is a bit deeper than recovery, it’s a bit more erm...I think recovery people would associate more with health erm rehabilitation is okay well there was a track the person was on beforehand, how does that person get back on that track? Otherwise that person’s life has changed a lot and would you call that rehabilitation? For instance for me like if you’re off your course and you’re out of [location] well that to me doesn’t seem like rehabilitation.” (Sebastian, Pg 24, Ln 23).

### **3.2.5 Theme Five: “*You need all the help you can get*”: Facilitators of recovery**

This theme includes the components that participants felt facilitated recovery. These included faith, time, reconnecting with nature and support from others. All participants identified at least one of the following facilitators of recovery.

**3.2.5.1 “It’s God that’s what gets me through this”:** Faith in recovery. Faith was discussed within the majority of participants’ accounts and was described as being a generally positive influence. Many used faith or religion to understand their experiences and four participants spoke about the key role that faith played in recovery. Alex described his faith as a motivator for surviving and seeking guidance when he needed support:

“My faith keeps me going so I just read the bible when I need help.” (Alex, Pg 7, Ln 14).

Graham described his faith as playing an active role in recovery. He described God as being the provider of knowledge and skills to healthcare professionals and advancing technology which make recovery possible. It appeared that without his faith recovery may not have been possible:

“No, no the doctors...the doctors obviously have to be there...but God you know gives the doctors and all the every...if I believe in G...God has been there...since the beginning of time so I believe in Genesis all the books of the bible, and the technology is getting better and better and better. Erm but it’s not just that I believe, I believe God’s involved as well, and that’s my belief.” (Graham, Pg 15, Ln 9).

Mohammed described his faith as being the only thing that got him through his experience of psychosis. The following quote illustrates his frustration that his family did not support him to be discharged and how abandoned he felt by others. It may be that internalising his belief in a higher power helped him to believe in recovery and in himself:

“You’ve missed a major part of my recovery, it’s my religion and my faith. It’s God that’s what gets me through this. It’s the only thing that’s got me through here. My family haven’t got me through here. My wife’s not been to see me that much, she’s not signed my discharge letter, she’s not wrote into the doctors to say I want my husband home or anything like that, she’s just left it be.” (Mohammed, Pg 23, Ln 19).

**3.2.5.2 Importance of time in intervention and recovery.** Time was an important factor for many participants. Several described needing time to recover and it being a lengthy process and others described the importance of time in regards to early intervention.

Mohammed reflected on his father supporting him to take his needs into account when considering discharge. Prior to this admission he spoke about being discharged too early which had a detrimental impact on his mental health. It seemed important for Mohammed to take as long as he needed to recover:

“He said don’t get out if you think it’s too early for you to get out, get out when you think the time is right. If the doctor says you can get out today or wait a couple more days, then wait a couple more days... just tell the doctor, you can be honest with him.” (Mohammed, Pg 21, Ln 13).

Alex considered the importance of time in recovery in a different way. He considered the time he had spent living with psychosis as a supportive factor in recovery. He described a sense of calm coming with age which may be linked to gaining more understanding about his experiences and knowing that he could survive them. Alex also described an increased sense of curiosity and ability to reflect which allowed him to cope in more effective ways:

“Erm yeah, my experience is as you get older, my age and my maturity are helping me feel more relaxed about things. With age comes wisdom and you tend to learn more from about what you knew when you were younger and you look at things and you ask questions about things, rather than rushing head long into new directions to change things to sort yourself into a situation that’s either apparent to you or not apparent to you.” (Alex, Pg 7, Ln 2).

Graham illustrates the importance of early intervention in facilitating recovery and preventing an unmanageable deterioration. He described how early intervention protected against a chaotic experience and avoided the use of ineffective medication. His use of “captured” insinuates that an external force took control of the situation and reinforces the idea that support from others is required to intervene early:

“Erm but I was almost there so I think I was sort of captured quickly enough to be brought in and I think that’s why this time instead of going in to all the chaos and the medication, or the medications improved because I didn’t know you could get Quetiapine slow release for example.” (Graham, Pg 13, Ln 22).

Mohammed and Sebastian also spoke about early intervention making recovery easier.

### 3.2.5.3 “*Seeing nature reminds me of why I’m alive*”: Reconnecting with nature.

Half of the participants cited nature as being part of recovery which may refer to leaving hospital and being back in one’s natural environment as opposed to being in hospital where access to the outside world and nature is restricted. This process of reconnecting with nature was described as not being possible during admission which may indicate that for those five participants that recovery could not begin until discharge. Needing to be discharged from hospital in order to recover was not a theme shared across all of the participants, several felt they had already begun recovering.

Christopher described the positive emotions evoked within him when he was able to be present in nature. He described seeing nature as a reminder of life which may have supported him to keep fighting for his life when experiencing psychosis:

“It just makes you feel good about stuff, nature, flowers and forests and what have you, seeing nature reminds me of why I’m alive you know.” (Christopher, Pg 6, Ln 19).

Paul reflected on the purity and innocence of nature which evokes images of untarnished surroundings which may represent how he felt he was before experiencing psychosis. His description of the addition of buildings removing natural habitats may symbolise his distress at being taken out of his own natural habitat and placed in hospital:

“Nature is the key to recovery, not buildings...it’s untouched, it’s innocent, it’s pure. It’s how things should be not these concrete jungles, taking away the natural habitat, I suppose, it’s the animals that should be there, putting the building there for humans.” (Paul, Pg 11, Ln 8).

Several of the other participants made reference to freedom as being important for recovery but did not explicitly describe reconnecting with nature.

### 3.2.5.4 “*She’s like an anchor, no matter how far I drift, she’s always got me*”:

**Support from others.** Seven participants discussed the importance of having support from

others in order to recover. Healthcare professionals were mentioned as playing a key role for some and for others their family or friends. The general consensus amongst participants was that recovery could not easily be achieved in isolation. Several different ways of being supportive were described. Mohammed described his family supporting him to recognise when he was becoming unwell. This appeared to support him in being independent in asking for help and playing a role in his own recovery. Supporting him to make his own decisions about his health may have supported him to feel more in control and maintain his self-worth in spite of psychosis:

“My family, they notice it straight away before I do. They tell me, once they tell me I call the doctor and say that they have told me to come and see you. I’m a sensible person, I have a lot of insight into my illness.” (Mohammed, Pg 13, Ln 1).

Having insight into illness was not shared by all participants as several mentioned that they would not agree they were unwell when others were suggesting they were.

Alex described how supportive a positive attachment can be in facilitating recovery. He described his relationship with his mother and the sense of security and consistency she provided. His use of the image of a rock portrays a strong, resilient foundation that never breaks potentially describing the secure attachment base his mother provides. He described “drifting” which may represent the process of feeling disconnected from the world and how his mother was pivotal in making him feeling grounded and bringing him back to shore:

“I do find...my mum is like a rock for me, she’s, she never, she’s always there for me. She always helps me out when I need help or she’ll try and knock some sense into me, even, I’m still her little boy even though I’m 50. I’m still, still, it’s still me mum, she’s like an anchor, she always, do you know what I mean, no matter how far I drift, she’s always got me.” (Alex, Pg 2, Ln 25)

Several participants spoke about how relationships with family had kept them on the path to recovery, however, for some, family relationships became strained as a result of hospitalisation.

## **CHAPTER FOUR: DISCUSSION**

This chapter begins by summarising the findings in relation to previous research, clinical policies and psychological theory. The key strengths and limitations of this study are then considered before discussing the clinical implications of the findings and providing recommendations for future research. This chapter concludes with a personal reflective summary.

### **4.1 Study Aims**

Participants' lived experiences of psychosis and their personal views of recovery as a MHI were explored. The aim was to develop an understanding of MHIs' experiences of psychosis and their views and conceptualisations of recovery from psychosis.

### **4.2 Summary of findings**

Five superordinate themes and twenty-four subordinate themes emerged from participants' accounts, reflecting the key research aims. Findings from each superordinate theme and corresponding subordinate themes are presented and discussed in relation to the study aims.

#### **4.2.1 “*My future is just being ripped out in front of me*”: Living with psychosis is a struggle**

All participants described the struggle of living with psychosis and how this impacted on their ability to recover. Suicidal ideation and attempts were described by the majority of participants which supports the literature demonstrating a relationship between psychosis and suicide both in community and MHI populations (Nordentoft, Madsen, & Fedyszyn, 2015; Mork et al., 2012; Stefenson & Titelman, 2016; Talseth, Jacobsson, & Norberg, 2001). The desperation and struggle described by all participants may indicate that suicide was viewed as the only way for the struggle to end. Suicidal ideation has been linked with increased hopelessness (Klonsky et al., 2012), dissociation (Laddis & Dell, 2012) and loneliness (Skodlar, Tomori, & Parnas, 2008) which were difficulties expressed by the majority of participants. Substance misuse and experiences of trauma have also been linked with increased risk of suicide which were two common factors discussed by the sample (Hor & Taylor, 2010; Roy, Carli, & Sarchiapone, 2011).

The subordinate theme of a “struggle to survive” encapsulated the day-to-day difficulties participants experienced such as struggling to meet their basic needs, struggling with traumatic histories, and struggling financially. All of these factors were described as preventing recovery which is replicated within the current literature (Noiseux & Ricard, 2008; Ramsay et al., 2011; Yarborough et al., 2016). Some research points towards individuals considering factors such as financial difficulty and poor diet to be the cause of psychotic symptoms (Greenfeld, Strauss, Bowers, & Mandelkern, 1989). This view was explicitly expressed by one participant who described his financial situation making it difficult to meet his basic needs, which led to him becoming mentally unwell. The failure to meet one’s basic needs such as adequate sleep and nutrition have been linked with affecting

an individual's recovery potential (Draine, Salzer, Culhane, & Hadley, 2002a) and was echoed by several of the participants. This theme reflects the importance of considering the context in which difficulties develop as opposed to focusing on a diagnosis (BPS, 2011). This is supported by some of the existing literature highlighting service users' views on diagnosis as compounding feelings of hopelessness and disempowerment, increasing feelings of shame, fear and invalidation (Boyle & Johnstone, 2014; Pitt et al., 2009; Schulze & Angermeyer, 2003). Of course, it could be argued that the experience of psychosis itself elicits the same feelings of shame, hopelessness and disempowerment, regardless of the experienced being 'labelled'.

A diagnosis of psychosis was not viewed as helpful by any of the participants, whereas current research has highlighted diagnosis can be viewed as helpful due to it providing relief and validation to suffering and access to support (Boyle & Johnstone, 2014; Pitt et al., 2009). These differing stances have been described by Leeming, Boyle, and MacDonald (2009) as diagnosis representing both "salvation and damnation". This damnation has been highlighted within mental health services, particularly MHI settings, where patients are given the message that they are out of control and unmanageable without detainment and medication, whilst being asked to take responsibility for their behaviour, explain their behaviour, and being expected to get better (Johnstone, 2000). It may be that the lack of control experienced by the participants and the restrictive nature of the MHI settings made all participants view diagnosis as unhelpful, which suggests the individual context should be considered when evaluating the usefulness of diagnosis.

The financial struggles expressed by participants reflect the experience of living within a society influenced by austerity policies, which several described as exacerbating

their mental health difficulties, increasing their dependence, and leading to difficulty coping. If these contextual difficulties were not addressed, it appeared as though several participants felt recovery would not be possible for them, which reflects the current literature describing the barriers to recovery as including unemployment, financial difficulties and housing issues (Bassett, Lloyd, & Bassett, 2001; Killapsy et al., 2014; Law & Morrison, 2014). People experiencing psychosis have been found to be more likely to have dropped out from education, experience unemployment, as well as experiencing poverty, debt and social exclusion, which were difficulties experienced by all of the participants (Marwaha et al., 2007; Meltzer et al., 2007). NICE (2014) published a document highlighting service users' experiences within adult mental health services and recommended the use of quality of life assessment measures to be included within psychiatric assessments to support professionals to understand the service user in relation to their current context. The PTMF provides an alternative to diagnosis by considering an individual's presentation within their social and relational environments and a move away from focusing on the malfunctioning of an individual (Johnstone et al., 2018). However, this alternative has been critiqued in regards to it being a way of Psychologists asserting their power and voice about how to categorise mental illness using psychological language and disempowering individuals by continuously defining their experiences for them (Scheherazade, 2018).

All participants described living through traumatic experiences which is representative of the literature implying a link between trauma and the development of psychosis (Bentall et al., 2012; Kilcommons & Morrison, 2005; Read et al., 2009). Several participants appeared to make sense of their symptoms in relation to the trauma they had experienced and spoke of how misleading a diagnosis of a form of psychosis was, as it failed to acknowledge the impact of traumatic events which is representative of some of the critique

around the medical conceptualisation of psychosis (Cooke, 2014; Insel, 2013). Participants described experiences of sexual abuse, physical abuse and neglect. Traumatic experiences included physical assault, family members and friends committing suicide, and the loss of significant attachment figures. Several described being hospitalised and diagnosed with psychosis as a result of these traumatic experiences. Participants who reported experiencing childhood abuse described experiencing positive symptoms such as hallucinations and delusions which supports the existing literature (Janssen et al., 2004; Kilcommons & Morrison, 2005; Ukok & Bikmaz, 2007). Relapse and rehospitalisation has also been linked with traumatic or adverse experiences in childhood which mirrors the participants in this sample who have all experienced multiple hospitalisations and some form of trauma (Doering et al., 1998). This could be a result of none of the participants receiving therapeutic intervention to support the processing of trauma, implying that relapse could be a result of not treating the trauma itself.

Another struggle described was the internal struggle with the self which was linked with the changing identity of becoming a MHI and the loss of self-esteem linked with hospitalisation and shame around diagnosis. Pitt et al. (2009) found that when service users spoke about their diagnosis they were not able to fully separate the diagnosis from themselves as an individual, which they suggested leaves the individual unable to protect their self-concept and fully separate their identity from an illness identity. This was not something that was found within this study as the majority of participants struggled to relate to their diagnosis and instead rejected it. This could be a result of them being a MHI when being interviewed and experiencing repeated readmissions to hospital. Rejecting diagnosis could be a way of protecting against the potential stigma that comes with being hospitalised as a result of psychosis (Corrigan, 2004). This struggle with the self often led to hopelessness

and a view that recovery was impossible. Existing literature posits that hope is needed to start and maintain the process of recovery so this feeling of hopelessness preventing recovery is supported (Kelly & Gamble, 2005; Leamy et al., 2011; Wilken, 2007; Wood & Alsawy, 2017).

Receiving a diagnosis has already been linked with reduced self-esteem and a change in identity which is representative of this sample's internal struggle (Corrigan, 2004; Pitt et al., 2009). In regards to hospitalisation, existing literature has also emphasised the change of identity involved in becoming a MHI and the struggle to be viewed as an individual as opposed to being defined by one's behaviour (Jones & Crossley, 2008; Lilja & Hellzen, 2008), which was a struggle also expressed by participants. This subtheme highlighted the struggle of being 'labelled' and hospitalised as a result of the medical system and how incongruent this is with recovery.

All participants described experiences of stigma preventing their recovery which is reflected in existing literature (Link et al., 2001; Wood & Alsawy, 2017). Stigma was described as impacting goals, employment opportunities, relationships and motivation to accept support which are all areas commonly described as being affected by stigma (Barut et al., 2016; Corrigan et al., 2006; Thornicroft, 2006). The stigma surrounding the particular diagnosis of psychosis appeared relevant within the sample with many reflecting on the failure of people to understand them as a result of viewing them in light of a diagnosis rather than understanding them in relation to their experiences and the context in which difficulties developed.

Struggling to accept help or actively rejecting help dominated several participants' narratives and reflected the hopelessness they felt in regards to being supported, which for some reflected their previous negative experiences of services. All of the participants had been hospitalised before as a result of psychosis. This feeling of hopelessness linked with increased suicidality and lack of belief in recovery. Many described rejecting help as a result of them feeling they did not need hospitalisation. Some appeared to maintain this belief throughout their interview and others reflected that they realised they needed support, but time was needed to reach this realisation. Denial has been described as a defence mechanism employed to defend against the threat of psychosis as a result of a poorly developed sense of self (Drayton, Birchwood, & Trower, 1998). This description fits with the experiences of participants who appeared to struggle with their sense of self and appeared to lack insight regarding the level of support they required. Tait et al. (2004) found that individuals employing a 'sealing over' recovery style were less engaged with services. This 'sealing over' recovery style involves patients not thinking about their psychotic experiences during recovery and not attempting to make sense of their symptoms and viewing illness in a negative light (McGlashan, 1987). This may be an explanation as to why several participants felt they did not need hospitalisation. Another explanation could be that participants did not actually require hospitalisation and required a sense of inclusion and support, as opposed to exclusion and incarceration. This is a view that has been expressed before in relation to the existence of MHI settings. The Basaglia Law directed the reform of psychiatric services in Italy, recommending the treatment of mental health within community settings that met individual's needs as opposed to excluding them from society without their consent (Foot, 2014). Rejecting help has also been linked with the fear of stigma. Existing literature has highlighted that people reject diagnosis or reject mental health treatment as a way of avoiding

the harm of stigma (Corrigan, 2004). All participants described experiencing stigma which may explain some of their reluctance to seek or accept help.

Reference was made to struggling with substances by the majority of participants. Substance use was associated with onset, maintenance or exacerbation of symptoms and as a way of coping. All participants who mentioned substance use identified it as a barrier to recovery. Previous studies have also linked substance use with preventing recovery (Tucker, 2009; Wood & Alsawy, 2017). Persistent substance misuse has been linked to increased risk of readmission to hospital and increased likelihood of presenting with psychotic symptoms (Sorbara, Liraud, Assens, Abalan, & Verdoux, 2003). This also links with the literature around increased misuse of substances as a way of coping with trauma resulting in higher rates of relapse in psychosis and rehospitalisation (Doering et al., 1998; Mueser et al., 1998).

#### **4.2.2 “*Would you want to be in here?*”: Traumatic experience of being in hospital**

All participants described some aspect of their hospital experience as traumatic. Experiencing MHI care as traumatic is not a novel finding and links with existing literature on MHI care (Barker, 2002; Ford et al., 1998; Jones & Crossley, 2008). A lack of control in regards to admission and the treatment provided dominated participants’ narratives which again reflects the existing literature around experiencing coercion within MHI services (Gilburt et al., 2008; Wertheimer, 1993). Participants’ dissatisfaction with the care they received as a MHI is also reflected within the 2016 Adult Inpatient Survey which found that MHIs reported a poorer experience of care across multiple areas (CQC, 2017). Specific points raised within this survey were mirrored within this study’s sample of not being as involved in decisions regarding their treatment as they wanted to be, not getting enough

emotional support from staff, and not getting enough support from professionals to manage their condition and to recover (CQC, 2017).

It appeared to be a difficult task for participants to recover whilst in a MHI setting and the descriptions and experiences of MHI care provided by participants revealed a setting not conducive with recovery. If recovery began whilst a MHI this appeared to be in spite of the MHI setting as opposed to being a result of the service provided. Hospitalisation for the majority of participants appeared to be a representation of the oppressive power society has over an individual, which for them appeared to be a more powerful influence than psychosis. The findings from this study suggest a disconnect between how services and society view recovery compared with how MHIs' view recovery. MHI services are portrayed as being recovery focused in line with service users' descriptions of recovery, however, participants described MHI services as a barrier to recovery. This disconnect between participants' experience of MHI care, and the view held by services that they are providing recovery orientated care is reflected in the lack of research into how effective MHI care is (Bowers et al., 2009; Muijen, 2002).

Inhumane treatment was an experience highlighted by several participants particularly in reference to being admitted to hospital against their will. This process was described as inhumane, disrespectful and resulting in a loss of dignity. Forced treatment such as being medicated without consent was another concern raised, which several participants linked to a loss of their human rights, which is common within the MHI literature (Gilburt et al., 2008). The failure to establish a positive therapeutic relationship with staff was another difficulty expressed by participants which resulted in them limiting their communication, withdrawing and refusing treatment. This experience of feeling disconnected from staff and in many cases

unheard, misunderstood, and angry appeared to be detrimental to participants beginning recovery. Many mental health staff have reported experiencing burnout and emotional exhaustion (Morse et al., 2012). Higher rates of burnout and stress have been linked with MHI staff due to the challenging situations they regularly face and the often intense nature of staff- patient interactions (Jenkins & Elliott, 2004). This could explain the disconnect from staff that participants experienced, combined with the fact that MHI settings are significantly under resourced.

The subordinate theme of “*incarcerated, institutionalised, log cabin coglaben hypnongogic fever: incarceration creates more problems*” reflects participants’ views that hospitalisation is detrimental to recovery and their personal well-being. The loss of support and comfort from family was highlighted as part of being hospitalised as well as the result of being identified and related to as a MHI rather than being viewed as an individual. The existing recovery literature highlights the need to reclaim or rediscover one’s identity or sense of self (Kelly & Gamble, 2005; Leamy et al., 2011; Wood & Alsawy, 2017). Both the experience of psychosis and the process of hospitalisation were described by participants as causing them to lose their identity, indicating both these experiences as being incongruent with recovery. The stigma around being hospitalised was also raised in regards to the negative impact on employment and relationships post discharge which is commonly experienced by service users (Angermeyer & Matschinger, 2003; Link et al., 1999; Noiseux & Ricard, 2008; Wood & Alsawy, 2017). It was described by several participants as an experience that could not be removed from their life and would always be viewed as a negative event that others would be judgemental of. The experiences of participants were reflective of conditions described within asylums which have been historically criticised due to their restrictive, inhumane and abusive treatment (Adame, 2011; Burstow, 2004; Deegan,

1996). Participants' accounts appeared to reflect the historical accounts of institutionalisation which were linked with causing iatrogenic harm (Everett, 1994; Unzicker, 1989).

Under resourced mental health services are an ongoing concern and this was reflected within participants' accounts. MHI settings as described by the participants reflect a society that fails to provide adequate support for those experiencing mental health difficulties. Economic downturns have been linked with exacerbating and prolonging mental health risks, particularly risk of suicide (Stuckler et al., 2017). Limited support and under resourced care continues to reinforce the idea that recovery is not possible within MHI settings, and to a certain extent the current society. Lack of resources and staffing meant that participants' basic needs were not being met which is one of the factors implicated in facilitating recovery (Forchuk et al., 2003; Noiseux & Ricard, 2008; Yarborough et al., 2016). The current MHI environment and lack of support from society appears to reinforce some of the participants' internal working models that the world and others cannot be trusted, are uncaring, and cannot help. This context leaves the process of recovery up to the individual which can be an impossible task and is a reflection of how the 'sick role' is played out in society (Parsons, 1951). Parsons posits that it is the individual's responsibility to make 'getting better' a priority and to seek out treatment themselves (Varul, 2010). The findings showed that some participants had to prove how unwell they were in order to get support, which is not conducive to recovery. These findings continue to reinforce how services and society are emphasising the need to recover but not providing the context for recovery to be possible, suggesting that the concept of recovery they are presenting may be important to society as opposed to the individuals experiencing psychosis.

Some positive aspects to MHI care were expressed including having a secure base where several basic needs were met, as well as providing time away from everyday life to reflect and rest, which has been a benefit of MHI care recognised previously (Lilja & Hellzen, 2008). These positive aspects were not expressed by the whole sample and did not appear to make up for the traumatic experiences as a result of MHI care.

Due to the challenges faced by MHIs which have been continuously reported over the last 20 years there has been a continued drive to improve MHI settings. The Accreditation for Inpatient Mental Health Services (AIMS) was established in 2006 in response to this drive for improvement. Criteria established to meet accreditation and to provide high quality and safe care included adequate staffing levels, adherence to specific admission processes, including patients in the planning of their care, adequate discharge planning, supporting patients to maintain their dignity, and being respectful towards patients (RCoP, 2014). All of these areas were highlighted as areas of concern for participants who reported feeling they lost their dignity and were not treated with respect as a result of staff not adhering to policies. The findings of this study suggests that the challenges faced by MHIs continue to exist within MHI settings and do not provide an adequate environment to support recovery.

#### **4.2.3 “I know roughly why I got ill anyway and what caused this”: A journey towards reaching an understanding**

This theme reflects the idea that recovery is a process that involves moving through stages, similar to the conceptualisation of recovery proposed by Andresen et al. (2003). The initial stage described by participants was attempting to make sense of their experiences. This stage involved questioning their experiences and was marked by feelings of confusion and being overwhelmed. The cognitive conceptualisation of psychosis reflects this attempt to

'make sense' by searching for an explanation of the cause of psychotic experiences (Garety et al., 2001), as well as highlighting the importance that others can have in supporting individuals to begin this process. White et al. (2000) explained that isolation does not provide an individual with alternative explanations to their experiences and can therefore result in delusional beliefs developing. This suggests that recovery may not be able to begin in isolation. The reality presented by multiple participants was that they struggled to identify people who could support them with this understanding. This is due to the detrimental impact their experiences or hospitalisation had on their relationships, which suggests it may not have been possible for them to begin recovering. Existing literature has supported the idea of size of support network and the individual's sense of how supported they feel as predictors of recovery outcomes (Corrigan & Phelan, 2004; Hendryx, Green, & Perrin, 2009). Individuals experiencing psychosis have been shown to have smaller social networks and have relationships of a poorer quality (Palumbo et al., 2015).

The next phase of being misunderstood mirrors many individuals' experiences of receiving a diagnosis of psychosis. A common theme amongst participants was their diagnosis failing to recognise the traumatic events within their life which is shared by several of the critics of recovery (Cushman, 1995; Recovery in the Bin, 2018). A formal diagnosis results in an intervention plan being based upon the NICE guidance for the given condition which can result in particular life experiences failing to be addressed (Gee et al., 2003; Johnstone, 2017; Krupa et al., 2010). Diagnosis could therefore be considered by participants as a barrier to recovery as it prevents them from being understood, engaging therapeutically and being offered the appropriate support. If an individual with psychosis has experienced numerous interpersonal traumas and continues to be misunderstood by their social network then this may likely increase isolative experiences. This is supported within the attachment

and psychosis literature which suggests that avoidance and interpersonal difficulties in psychosis can be conceptualised as attachment strategies that were developed as adaptive responses (Berry et al., 2007; Mallinckrodt, 2000).

The third stage of proving yourself to others is interesting in regards to recovery as it poses the question of who is recovery for? Historical debates have suggested that the medical conceptualisation of recovery in terms of symptom reduction or remission and the need for hospitalisation to support recovery may be a form of social control and a way of ‘ridding’ society of mentally ill people (Cohen, 1985; Dain, 1980; Foucault, 1967; Porter, 1990). This subordinate theme may be a reflection of the pressure and expectation felt by the individual to get better and prove that they are safe to be in society and able to contribute. Within this study this process was presented as being part of recovery, however, it could also be considered a barrier to recovery if an individual is unable to prove themselves as a result of stigma, lack of opportunity, or limited personal resources. The difference between how MHIs and mental health services conceptualise psychosis contributes to this as services conceptualise psychosis according to the DSM-V criteria, whereas service users have reported conceptualising their experiences in line with psychological theories and within a spiritual context. These conflicting conceptualisations fail to promote a shared understanding.

The final phase in the process of recovery was described as reaching an understanding which involved learning about oneself. This process of learning is frequently referenced within existing recovery literature (Watson, 1994; Whitwell, 1999). This process appeared to be aided by introspection as well as psychological support. Several participants explicitly spoke about psychologically informed groups or individual work that had helped them to understand their experiences. Wilken (2007) identified in his review of recovery literature

that developing psychological skills to perceive life and one's identity in a new way supported recovery. Positive support from services was also identified by Wood and Alsawy (2017) as facilitating recovery from psychosis. The form of support described by participants appeared to involve identifying factors that contributed to the current difficulties, whilst considering their experiences, which echoes the paradigm shift recommended by the BPS (2011) and is reflective of the move towards psychological formulation as a way of conceptualising experiences (Johnstone, 2017).

#### **4.2.4 Recovery/Rehabilitation/Recuperation: A process of evolution**

Nine participants reported that recovery from psychosis was possible. The remaining participant felt that recovery was possible for others but not for herself. This particular participant had experienced in excess of ten hospitalisations between the ages of 18 and 26 years old which may explain her pessimism regarding recovery. Evidence suggests that specific factors increase the likelihood of relapse which include suicide attempts, previous hospitalisations, social adjustment, and psychopathology which were all present within this participant's narrative (Doering et al., 1998).

Six participants reported experiencing recovery, two reported they had never experienced it and the remaining two felt that they had short phases of feeling better or having better days but had not experienced complete recovery, which highlights the different individual perspectives of recovery. Three of the participants made it explicit that they had recovered despite remaining in hospital and that they were ready to be discharged. One of these participants felt they did not require hospitalisation in the first place, one described seeking admission as a way of supporting him to stop smoking cannabis and felt he had recovered as a result of stopping smoking. The third participant who reported being

recovered acknowledged that his hospitalisation had provided some time to take a rest from his hectic life which he felt had contributed to him becoming unwell.

The subordinate theme of reclaiming a purpose mirrors the existing literature around re-engaging with life goals, roles and responsibilities as signs of recovery (Noiseux & Ricard, 2008; Ramsay et al., 2011; Yarborough et al., 2016). For the participants in this study these external transformations resulted in internal transformations such as feeling happier, more fulfilled and feeling more confident. Positive internal states have also been identified within previous studies on recovery from psychosis (Yarborough et al., 2016).

Part of the process of recovery was described as finding a balance which involved a balance in regards to mood and emotional regulation or a more balanced lifestyle. All participants diagnosed with bipolar disorder reflected on the experience of mood swings and the difficulty managing them, which may be linked to the symptoms related to this diagnosis which involves experiencing periods of mania or elation followed by depression or a lowering in mood (APA, 2013). This balance was also defined by participants as the presence of symptoms but the ability to manage them, which fits with current service users' conceptualisations of recovery (Anthony, 1993; Forchuk et al., 2003; Pitt et al., 2007; Wilken, 2007; Wood et al., 2010) and reinforces the incongruence with the medicalised conceptualisation which focuses on pervasive reductions or complete removal of symptomology (Slade et al., 2008).

The process of reintegrating the self and accepting psychosis as part of the self mirrors Wood and Alsawy's (2017) findings. Participants described psychosis as breaking apart the self and recovery involved putting these pieces back together. For most this resulted in a

changed self which reflects the findings of existing research stating that a person is unable to return to a former state (Watson, 1994; Whitwell, 1999). Unlike existing literature, the majority of participants felt that experiencing psychosis had not made them into a better, more enriched person and instead they focused on the losses they had incurred as a result of psychosis and hospitalisation, such as relationships, employment, and self-esteem. The losses described as a result of psychosis are consistent with existing research (Barut et al., 2016; Forchuk et al., 2003; Noiseux & Ricard, 2008; Wood et al., 2013; Yarborough et al., 2016).

Several participants used powerful metaphors to describe recovery as a process of being reborn or evolving which mirrors the recovery literature around the self-transforming and growth or change in the process of recovery (Andresen et al., 2003; Kelly & Gamble, 2015; Leamy et al., 2011). Several of the participants' descriptions of recovery were interpreted as leading to self-actualisation, where an individual can reach their full potential (Maslow, 1943). The experience of psychosis has been linked with preventing self-actualisation as a result of impairing one's ability to meet lower levels of needs such as impairing one's motivation to look after oneself, delusions leading to an inability to feel safe and difficulty trusting others, and hearing voices that are critical and attacking one's self-esteem (Ellerby, 2016).

The subordinate theme of accepting the self and others encapsulated participants' explanations that recovery involved accepting the self, others, or being more accepting of psychosis. Several participants described happiness, forgiveness and loving oneself as key components in finding peace and achieving acceptance. Acceptance of the self and others has been highlighted within existing research as indicating recovery (Barut et al., 2016; Forchuk et al., 2003; Noiseux & Ricard, 2008; Yarborough et al., 2016). Increasing one's self-esteem

was highlighted as vital to recovery which was a construct identified as being damaged by psychosis and the resulting consequences of stigma, loss and hospitalisation. The role of self-esteem in the development and maintenance of psychosis has been evidenced previously (Laithwaite et al., 2007). Previous research has also indicated that individuals who achieved symptomatic recovery from psychosis can continue to experience low self-esteem which affects their quality of life and increases the likelihood of depression (Gureje, Harvey, & Herrman, 2004). Therefore highlighting the importance of improving self-esteem in order to achieve a better quality of life, which is something all participants reported valuing, as well as highlighting how reductionist symptomatic recovery can be.

Getting back on track or getting back to the life that participants were living prior to their admission was described as being part of recovery by the majority. Several reported needing to leave hospital in order for recovery to begin which could be interpreted as MHI settings being a barrier to recovery, which supports the existing literature on patients' negative experiences of MHI settings (Barker, 2002; CQC, 2017; DoH, 2002; Ford et al., 1998) and the failure to implement recovery-oriented practices due to the focus being on stabilisation and symptom relief (Waldemar, Arnfred, Petersen, & Korsbek, 2016).

#### **4.2.5 “*You need all the help you can get*”: Facilitators of recovery**

This theme encapsulated the dominant factors that participants considered to be vital in facilitating recovery. These factors included faith, time, support from others and reconnecting with nature. Having a form of faith appeared to support the belief that recovery was possible. Multiple studies have emphasised the importance of faith and spirituality in recovery from psychosis (Kelly & Gamble, 2005; Leamy et al., 2011; Wood & Alsawy,

2017). It was clear that faith could be practised and maintained in any environment and for many was described as facilitating recovery in spite of the MHI setting.

Time was discussed in regards to the importance of early intervention and how this could prevent hospitalisation and support quicker recovery, which has been evidenced within existing literature and policies (Killackey & Yung, 2007; NHS England, 2016). Other participants considered time in regards to duration of experience and how living with psychosis for years supported one to understand themselves better, know what they were dealing with and what they needed. This was not a shared experience by all participants as others felt that ongoing relapses and hospital admissions had made them lose belief that recovery was possible. Timing in regards to discharge was discussed by participants and was deemed to be vital in regards to whether recovery could be facilitated. Some discussed the importance of not staying in hospital for too long and others expressed concerns regarding premature discharge which often led to relapse. These opposing views highlight the need for personalised care and flexibility in regards to MHI care which does not appear to be an approach participants experienced, despite being recommended within MHI policies (NHS England, 2016; NICE, 2014; RCoP, 2014). This links with the critique of recovery not being a one size fits all approach and services branding themselves as being recovery orientated but failing to adapt to personal needs (Harper & Speed, 2012; Slade et al., 2014).

The identification of reconnecting with nature appeared to be linked to the need for freedom and to begin recovery outside of a MHI setting, as well as being physically present with nature and appreciating its beauty. Needing to be discharged from hospital in order to recover was not a theme shared by all participants, several felt they had already begun recovering despite being in a MHI setting. Lack of freedom has been linked to exacerbating

distress, which fits with the findings here of freedom facilitating an improvement (Gilburt et al., 2008). Experiencing nature via sight, being present in nature or being actively involved with nature has been found to be beneficial to mental health, although not specifically linked with psychosis (Pretty, 2004).

Support from others was described by multiple participants as being vital for recovery. Having a support network has been identified previously as supporting recovery (Jose et al., 2015; Wilken, 2007; Wood & Alsawy, 2017), as well as feeling connected (Leamy et al., 2011). Descriptions of secure attachment relationships were described as supporting recovery, which not all participants had access to. Secure attachments have been identified as supporting recovery due to them resulting in increased resilience and the ability to regulate emotions (Rutten et al., 2013).

Relationships were also identified as preventing recovery or making recovery more difficult which links in with systemic conceptualisations of psychosis and the acknowledgement of the impact of relational exchanges (Bateson et al., 1956; Gibney, 2006). Several participants described exchanges with family that could be viewed as involving high levels of EE, which has been linked to maintaining psychosis and increasing the likelihood of relapse (Amaresha & Venkatasubramanian, 2012; Bebbington & Kuipers, 1994; Brown et al., 1972). Hoffman (1982) provides further evidence for relational factors contributing to psychosis. She suggested that it is not the system that causes the symptoms, but the presence of symptoms that contributes to the system responding in a way that maintains or exacerbates symptomology, suggesting there may be more complex interactions at play in the development of psychosis rather than a person experiencing it in isolation. This evidence is interesting because it undermines the idea that recovery is something a single person can 'do'

in the absence of wider systemic change. Viewed this way recovery appears to be less a psychological process than an interpersonal one. Identifying the impact of relationships on psychosis highlights the need to consider systemic influences in recovery due to the fact we do not exist in isolation and therefore the possibility of recovery needs to be considered in the context of relationships.

### **4.3 Methodological Strengths**

The majority of the research on recovery from psychosis remains situated within community samples and this is the first study to the researcher's knowledge to focus on recovery from psychosis within a solely MHI population. A particular strength is that the findings suggest that MHIs' conceptualisations of recovery are distinct from community samples. The findings offer a novel insight and presents an argument for a reconsideration of using empty signifiers to attempt to define a unique experience. A breadth of experiences are presented which support further understanding of MHIs' experiences of psychosis and brings the effectiveness of current MHI care into question in regards to their purpose of promoting recovery. This novel insight suggests areas for future research and argues for a revolution in regards to how to conceptualise recovery and support individuals receiving MHI care. This study could therefore be considered to meet Yardley's (2000) quality criteria of impact and importance.

The research methods utilised were the most appropriate to achieve the research aims and were applied in a robust and transparent manner. Several quality assurance measures were applied including the researcher transcribing all ten interviews and checking several of the transcriptions for accuracy as recommended (MacLean, Meyer, & Estable, 2004). However, due to time constraints not all transcriptions could be checked. All transcriptions

involved notation of nonverbal behaviours which has been recommended for increasing reliability and validity (Easton, McCornish, & Greenberg, 2000; Seale & Silverman, 1997). After conducting two interviews, the interview transcript and initial analysis of one interview was checked by research supervisors to improve confirmability. This was to ensure that similar interpretations would be reached if other researchers analysed the data (Shenton, 2004).

The use of a reflective diary throughout the research process also aided transparency and enhanced credibility (Lincoln & Guba, 1985). This supported the researcher's reflexivity which has been presented within the methods chapter and supported the management of biases. Rigour of the data analysis process was aided by the researcher attending an IPA training course where they received feedback from experienced IPA researchers regarding the quality and appropriateness of the interview schedule. The interview schedule was developed from a previously used tool for researching recovery from psychosis which supported the relevance of the schedule in regards to the population. The service user feedback was valuable in modifying the interview schedule and obtaining recommendations to enhance rapport between the researcher and participants, as well as acknowledging the growing recognition of the importance of service user involvement in research (Neil et al., 2009; Thornicroft & Tansella, 2005).

The researcher recruited from three different geographical locations to facilitate recruitment and obtain a sample with varied demographic characteristics. The sample varied in regards to age range, formal diagnosis, number of hospital admissions and current length of stay, despite not varying in regards to gender and ethnicity.

## 4.4 Limitations

### 4.4.1 Sampling issues

According to an interpretivist paradigm, no assumptions are made in regards to generalising the findings of qualitative research. However, the recruitment procedure utilised may have failed to capture more typical experiences within MHI settings. The majority of participants were relatively stable in their mental health and were adequately engaged with staff in order to be approached regarding the study. From a clinical perspective it could be argued that it would have been more valuable to understand recovery from those who find it harder to engage as this inadvertent exclusion of those who have difficulty engaging may be replicating individuals' experiences of exclusion, which has been linked with preventing recovery. Recruitment may have been more successful if all patients who met the criteria were approached individually by various members of staff on multiple occasions to provide multiple opportunities to engage. Negative relationships with MHI staff were expressed by several participants and being approached by staff to engage may have prevented some patients from participating which could have been rectified if the researcher approached patients rather than staff. However, practical and time constraints meant this was not achievable.

The sample size achieved was within recommended parameters (Smith et al., 1999; Turpin et al., 1997) and ten participants were recruited. However, in relation to the total number of patients within the services, proportionately few volunteered to participate, which suggests there is scope for improvement in regards to recruitment. Two additional patients agreed to participate, however, when the researcher met with them both patients declined due to not feeling comfortable with the interview being audio-recorded and felt that the recording may be used against them later on. This response could be linked to feelings of paranoia

around others but may also have been a reflection of the discrimination they may have experienced and a fear this would happen again. Therefore, to a certain extent, this study did not actively facilitate the inclusion of all patients who may have experienced discrimination which reinforces the ongoing exclusion individuals experiencing psychosis might face. Although the researcher emphasised the purpose of recording and how they would be used, individuals may have had concerns about their identities being revealed which may be a reflection of the powerful influence discrimination and stigma have over individuals' decision making.

#### **4.4.2 Participant demographics**

Eight participants described themselves as White British which shows little variation in ethnicity across the sample. This was surprising given that one of the hospitals was located in an area where one might expect more ethnic diversity. The sample consisted of one female participant and nine male participants. The initial aim was to recruit a sample in keeping with Aleman et al. (2007) reported gender ratio of 0.41:1 women to men. Therefore, the sample could be considered not to be representative of the population of people experiencing psychosis. However, incidence and prevalence rates for psychosis have frequently been disputed with some studies indicating a higher incidence in men (Aleman et al., 2007; Castle et al., 1993; Lewene et al., 1984) and others indicating no gender differences (McGrath et al., 2008; Perala et al., 2007).

The upper age limit of 65 years old was selected to reflect the way services are currently set up, however, this did mean that MHIs living with psychosis over the age of 65 did not have the opportunity to participate which may have resulted in a skewed perspective. It may be that individuals living with psychosis over the age of 65 have different experiences

of being a MHI as they may possibly have experienced care from MHI settings prior to community teams being developed and may have been able to provide their experiences of MHI care across their lifetime, which could have provided a different outlook on current MHI care compared with how it used to be. Excluding this population may have resulted in a more reductionist view of recovery.

#### **4.4.3 Analysis**

The main themes identified within the results are one interpretation of the data provided by participants. Other researchers analysing the data from different backgrounds, theoretical positions etc may have interpreted the results in a different way. This does not necessarily take away from the coherence of the interpretation as multiple interpretations of the same data are possible (Jordan, Eccleston, & Osborn, 2007).

#### **4.5 Clinical Implications**

The findings have shown that the majority of participants found their admission to hospital traumatic due to their confusion surrounding their admission and the way they were treated by staff. These findings suggest that the admission process to MHI settings needs to be carefully considered to support individuals to maintain their dignity, feel safe, and understand the reasons for their admission. The AIMS criteria provides recommendations ensuring safe and effective admission to hospital involving orientation to the staff and ward as soon as possible, providing refreshments on admission, reading patients their rights if detained and ensuring they are provided information about the MHI setting and their admission in an accessible format (RCoP, 2014). Not all MHI settings are currently accredited via the AIMS criteria and one recommendation could be to ensure consistent accreditation across all MHI settings to ensure consistent quality of care for all.

Trauma was highlighted as being experienced by all participants and indicates that trauma should be discussed as part of the assessment when individuals are admitted to MHI settings. Including discussions about trauma within the initial assessment may support the individual to begin to understand their difficulties in regards to the context in which they developed as well as supporting the MHI staff team to see beyond diagnosis. Enquiring about trauma is already a statutory responsibility for clinicians, however, evidence suggests this is often missed within assessments due to clinician's biases regarding the etiology of schizophrenia, which may inhibit them obtaining trauma histories from people with psychosis (Read & Ross, 2003). Due to the importance of systemic factors in the maintenance of psychosis as well as the view that recovery cannot be 'done' by the individual in isolation, it may be beneficial for all MHIs to be offered a family therapy assessment as part of routine treatment in order to highlight the role family and networks can play in recovery, as well as removing the onus and responsibility to recover from the individual.

The lack of resources and consequences of budget cuts within MHI settings has been highlighted as an ongoing concern (CQC, 2017; NHS, 2016) and is an issue that continues to need to be raised in regards to the impact it has on individuals' ability to recover. This study has highlighted several areas of under resourcing which participants linked to having a negative experience of MHI care and therefore considered MHI care to be a barrier to recovery. Staffing levels, staff training in mental health and access to acute beds are all areas that need to be addressed.

Promotion of psychological services within MHI settings is needed to support the process of MHIs developing an understanding of their experiences, which is helpful and meaningful to them, and promotes alternative ways of conceptualising experiences as well as

satisfying current recommendations for MHI care (RCoP, 2014). Psychoeducation groups and coping skills-based groups were reported by participants as being helpful. This recommendation would also support the preparation phase of Andresen et al's. (2003) recovery model by supporting patients to learn about mental illness and the skills needed to recover.

This study has also supported the need to focus on early intervention as a way to promote recovery and prevent hospitalisation which has been highlighted by existing policies such as 'The Five Year Forward View' (NHS England, 2016). This recommendation needs to be taken forward within community settings who are currently responsible for providing early intervention services.

Care planning and discharge planning are both areas that have already been highlighted as needing improvement within MHI settings (CQC, 2017; NHS England, 2016; RCoP, 2014). MHI settings should incorporate what participants have highlighted as facilitating recovery into care planning including a patient's support network. Occupational Therapy could support patients to identify ways of increasing their support network such as accessing peer support groups such as the HVG. Widening an individual's support network should be initiated during admission to ensure they are not left unsupported when they are discharged. Facilitating opportunities to engage with their religion or culture should also be incorporated into MHI schedules such as access to places of worship, interacting with religious figures and being supported to celebrate any religious festivals or engage with traditions whilst a MHI. It would therefore be important to gather information from individuals on their arrival regarding their cultural and religious needs and incorporate these factors into conceptualising their experiences. Reconnecting with nature was also reported as supporting recovery and should be incorporated into the daily ward schedule for those that

want to. For patients who have restricted access to the community this should be incorporated into activities on the ward such as indoor gardening activities.

As a result of this study concluding that the word recovery appears to be an empty signifier for the participants interviewed, it may be useful to stop using the word recovery to describe how services are set up and instead develop services in accordance with meeting MHIs' needs by getting to know each patient as an individual, developing a formulation that the individual believes reflects their experiences as opposed to only viewing each patient in line with their diagnosis. This could result in removing the pressure of a patient trying to reach a state that is defined as helpful by others who have not lived through their experience. This recommendation supports the premise of the Tidal Model of Recovery which advocates the identification of what the patient feels they need and listening to how they think these needs could be met (Barker, 2003). It is understood that it would be difficult to promote an approach within a MHI setting that is not focused on risk and symptoms but more alternative frameworks of understanding and responding to patients should be considered.

#### **4.6 Future Research**

Based upon the limitations with this study it may be beneficial for future research to focus on exploring MHIs' experiences of positive care within MHI settings. This could possibly lead to supporting the development of MHI settings that are in line with patients' needs as opposed to developing them to be 'recovery' focused which this study, to a certain extent, has highlighted as being unhelpful. Future research may also benefit from including a more diverse sample in regards to gender and ethnicity within MHI settings and to attempt to engage with patients that typically disengage.

Further exploration of specific themes identified in this study may be useful such as the subordinate themes of “process of proving yourself to others” and “*seeing nature reminds me of why I’m alive: reconnecting with nature*”. In regards to the first subordinate theme, this raised the question of who is recovery for? This may be an interesting piece of research to carry out with MHIs experiencing psychosis in order to ascertain their views on who recovery is for and whether recovery as defined by services is something they actually want. It would be beneficial to explore the idea of reconnecting with nature as part of recovery as this has not been specifically highlighted by individuals experiencing psychosis before. Exploring this within both MHI and community populations would help understand whether this is specific to MHIs due to their freedom being restricted.

The ability and value of engaging MHIs within applied research has been demonstrated within this study. It would be beneficial to continue to involve MHIs in research that is meaningful to them and the facilitation of focus groups to identify areas of research that MHIs deem important may be a way of achieving this.

#### **4.7 Conclusions**

The aims of this study were to understand MHIs’ lived experience of psychosis and their views on recovery from psychosis. Participants identified living with psychosis as a struggle due to internal struggles, struggles to survive, struggles with substances, experiences of stigma and struggling to accept help. Recovery was identified as being a process involving stages of making sense of experiences, being misunderstood, proving oneself to others and reaching an understanding. Recovery was indicated as a result of reclaiming a purpose, finding a balance, reintegrating the self, evolving, acceptance and getting back on track.

Participants also identified several factors they considered to be facilitators of recovery which included time, faith, support from others and reconnecting with nature.

This study also supported the emergence of several findings not directly related to the aims but important to understand in regards to MHIs' views on recovery. The experience of being a MHI and the experience of hospitalisation was a dominant discourse throughout interviews. This study highlighted that for the participants interviewed, MHI settings are not settings where everyone can be in recovery or approaching recovery, however the concept of recovery is conceptualised. For some, recovery appeared to be an 'empty signifier' that is meaningless to them and is a word used by services that does not necessarily correspond with some of their experiences of MHI settings. The general consensus for the participants who felt they were recovered or had improved was linked to factors separate from the MHI setting such as maintaining their spirituality or faith, being visited and supported by family or due to them not misusing substances. For others, the MHI setting was viewed as contributing to recovery by providing some time to reflect and rest, meeting basic needs of providing shelter and nutrition or providing access to psychological services to increase their understanding of their experiences. The overall conceptualisation of MHI care was one of a traumatising environment that is not conducive to recovery. This study highlights that for these participants recovery within MHI settings is in scant supply and appears to be more rhetoric than reality.

These findings have therefore highlighted several areas in which MHI settings could change in order to provide a more helpful and less harmful experience for MHIs. This study has also highlighted a disconnect between how recovery is conceptualised and the actual experience of MHIs.

#### **4.8 Reflective account**

Conducting this research has been enlightening, inspiring and thought provoking whilst also being frustrating, challenging and emotionally draining. On reflection, as a novice qualitative researcher, I think I was unprepared for how invested one can become in striving for individual perspectives to be accurately portrayed and interpreted. This became clear to me during the analysis where I became overwhelmed by the amount of data and my initial inability to condense the number of themes. I felt that condensing emergent themes into subthemes would possibly replicate the experience of participants being unheard and my fear was that I was reducing significant experiences into generalised themes, increasing the likelihood that participants would be misunderstood. This anxiety re-emerged when I began writing my results section and struggled with the restricted word count and the need to reduce the number of quotations I included, again this felt like I was restricting participants' voices. This experience supported me to feel more empathic towards services by experiencing how difficult it is to ensure equal attention is paid to individuals' experiences and how difficult decisions have to be made as a result of frameworks imposed.

The powerful expressions of the dissatisfaction and trauma experienced left me feeling more frustrated and hopeless than I had expected. Within my experience working in MHI settings I was aware that there is a high level of dissatisfaction regarding lack of resources and level of care but the reported trauma experienced as a result of these settings left me shocked. In spite of this I have felt reassured by the significant impact supporting individuals to be heard can have and how a positive connection can still be developed in MHI settings. I feel this is an important message for services and staff working in MHI settings to hold on to when faced with continued resource cuts.

Completing this research has made me curious about the unspoken expectations placed on MHIs to recover, despite society and services providing many barriers that appear impossible to overcome. I used to perceive recovery to be a positive word that would be received by service users in a motivating and helpful way, but I have now come to wonder how helpful it is to use a word that appears meaningless and to a certain extent detrimental. I reflected that this push towards adhering to these expectations seems unrealistic, insensitive and uncompassionate given the context in which we now live and the continued adversity individuals with mental health difficulties face. I hope this study will encourage more curiosity regarding the concept of recovery and support services and professionals to begin to highlight the need for flexibility in supporting individuals in what they deem to be helpful for them rather than reinforcing a system that oppresses subjective views.

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## Appendix A

### Systematic Review: Mental Health Inpatients' Views of Recovery from Psychosis

Search Number	Search Terms	CINAHL Complete Search run: 17/01/2018 All years (Results)	PsycINFO Search run: 17/01/2018 All years (Results)	PsycARTICLES Search run: 17/01/2018 All years (Results)	MEDLINE Search run: 17/01/2018 All years (Results)
1	“Psychosis” OR “Psychotic*” OR “Schizo*” OR “Hallucination*” OR “Delusion*” OR “Voice*” OR “Bipolar*” OR “Paranoi*”	188, 919	179, 441	36, 268	411, 505
2	“Recover*”	184, 335	55, 892	20, 835	878, 732
3	“Patient*” OR “Inpatient*” OR “Acute*”	1, 844, 625	578, 399	50, 686	6, 206, 531
4	“Qualitative*” OR “Interview*”	390, 461	425, 750	53, 325	698, 586
5	#1 AND #2 AND #3 AND #4	10, 276	862	4, 551	15, 173

*Combined results (duplicates removed) = 25, 803*

Search Limiters and Expanders	Justification
1. English Language	1. Translation unavailable
2. Journal articles	2. Accessible empirical evidence wanted
3. Search within full-text	3. Identify full range of available research
Inclusion Criteria	Justification
1. Focus on service-user experience	1. Focus of review
2. Qualitative methodology	2. Obtain rich accounts of lived experiences
3. Mental health inpatient context	3. Focus of review
4. Adult population (aged 18 years and older)	4. Focus of review- ethical approval only obtained for an adult population
5. Formal diagnosis of psychosis	5. Focus of review
6. Empirical research (interview, case studies or focus groups)	6. First hands account wanted
7. Focus on experience of recovery and conceptualisation	7. Focus of review

Table 1: Systematic review search strategy: mental health inpatients' views of recovery from psychosis

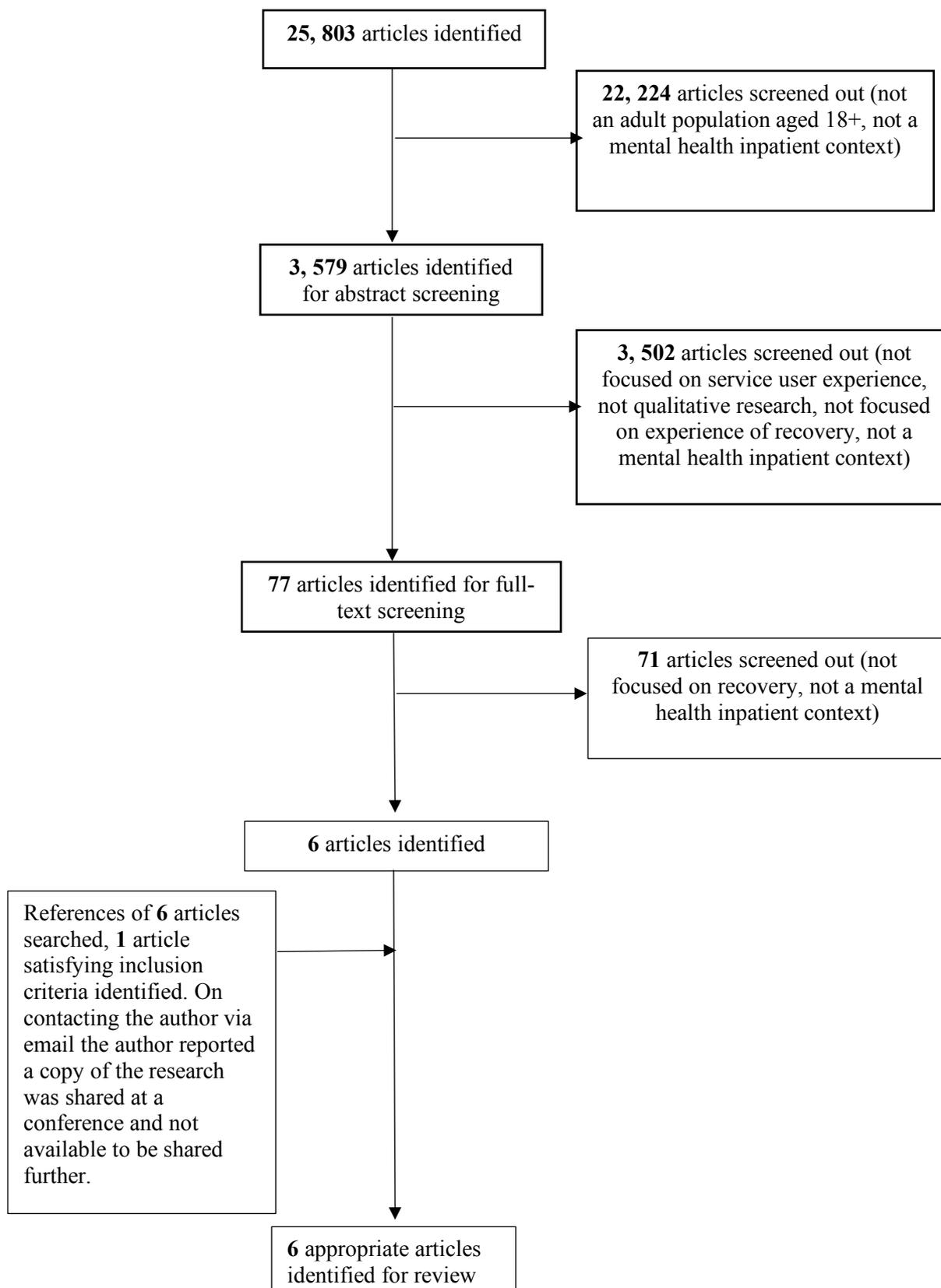


Figure A: Flowchart of included studies for systematic review.

**Appendix B**

## Methodological Quality Appraisal of Systematic Review: Mental Health Inpatients' Views of Recovery from Psychosis

Table 2

*CASP quality appraisal of reviewed articles regarding mental health inpatients' views of recovery from psychosis (N= 6)*

Reviewed Article	Clear statement of aims?	Qualitative methodology appropriate?	Appropriate research design?	Appropriate recruitment strategy?	Appropriate data collection?	Relationship between researcher and participant adequately considered?	Ethical issues considered?	Rigorous data analysis?	Clear statement of findings?	How valuable is the research?*
Wood, Price and Morrison (2013)	2	2	2	2	2	1	1	2	2	Findings are related to previous research, theory and practice. Clinical implications and limitations are presented. Further research identified.
Noiseux and Ricard (2008)	2	2	2	2	2	1	2	2	2	Findings are related to previous research, theory, policy and practice. Clinical implications and limitations are discussed. Further research identified.
Yarborough, Yarborough, Janoff and Green (2016)	2	2	2	2	2	1	2	2	2	Findings are related to previous research, theory, policy and practice. Clinical implications and limitations are thoroughly discussed. Further research areas are not identified.

Forchuk, Jewell, Tweedell and Steinnagel (2003)	2	2	1	2	2	1	1	1	1	Findings are related to previous research, but this is very limited. There is no reference to theory or policies when discussing the findings. Limitations and further research areas are not identified. Clinical implications are discussed briefly and appear quite general.
Barut, Dietrich, Zaroni and Rinder (2016)	2	2	1	2	2	1	2	2	2	Findings were not discussed in relation to theory, policy or practice. There was minimal reference to the findings in relation to previous research. Limitations are explicitly discussed. Clinical implications are not discussed. Further research areas are explicitly discussed.
Ramsay, Broussard, Goulding, Cristofaro, Hall, Kaslow, Killackey, Penn and Compton (2011)	2	2	1	2	2	1	2	1	2	Findings were discussed in relation to previous research, policy, theory and practice. Limitations are explicitly discussed. Further research areas are discussed, though rather limited. Clinical implications are discussed.

*Note.* \* contribution of the study to existing knowledge, consideration of findings in relation to current practice, policy, or literature base, areas identified for further research, transferability of findings discussed; 2 = yes; 1 = can't tell; 0 = no

## Appendix C

## Systematic Review: Reviewed articles

Table 3

*Characteristics of synthesised articles exploring mental health inpatients' views on recovery from psychosis (N= 6)*

Authors	Aims	Sample	Methods and Analysis	Demographics	Service Context
Noiseux & Ricard (2008)	To put forward a theory for the recovery of people experiencing schizophrenia to explain how recovery is viewed and described by people experiencing schizophrenia, those close to them and health professionals working with them.	N= 41 16 service users, 5 family members, 20 health professionals	Semi-structured interviews and field notes. Grounded Theory	Service Users: Male 8/16, average age 35 years, majority unmarried. Schizophrenia 16/16. Family members: Female 5/5, average age 46 years. Mothers 3/5, sister 1/5, spouse 1/5. Health professionals: Psychiatrists 3/20, Nurses 8/20, Educators 9/20.	Recruited from a community setting, a self-help group setting and a hospital psychiatry centre
Wood, Price, Morrison & Haddock (2013)	To explore what factors are important to individuals in recovery from psychosis.	N= 40 service users	Q-sort developed from existing literature and semi-structured interviews. Q-methodology	Male 25/40, age 36.97(SD: 12.01) Delusions 32/40, Hallucinations 27/40 White 35/40, Black 3/40, Asian 1/40, Other 1/40.	Recruited from early intervention services, community mental health teams, assertive outreach teams and inpatient wards.
Yarborough, Yarborough, Janoff & Green (2016)	To gain a better understanding of recovery from mental health from mental health consumers points of view. To identify opportunities for improvement to practices to align services with the goals of consumers.	N= 177 service users	Semi-structured interviews. Modified grounded theory approach.	Male 85/177 White 167/177, Black 10/177, American Indian or Alaska Native 5/177, Asian or Pacific Islander 3/177, Hispanic 1/177, Mixed racial heritage 8/177 Schizophrenia or schizoaffective disorder 75/177, Bipolar disorder 84/177, Affective psychosis 18/177	Recruited from members of an integrated health plan providing inpatient and outpatient medical, mental health and addiction services.

Forchuk, Jewell, Tweedell & Steinnagel (2003)	To explore individual's views of the process of recovery or non-recovery over the initial year of treatment with risperidone or clozapine. To describe this subjective experience in order to better meet their needs by improving support and care.	N= 10 service users	Semi-structured interviews. Ethnographic method of data analysis.	Male 7/10, Age range 26-51 years. White 10/10 (Italian 3/10, Dutch 2/10, English 1/10, Irish 1/10, Israeli 1/10, Mixed 2/10) Taking clozapine 7/10; taking risperidone 3/10	Recruited from a tertiary care psychiatric hospital and a general hospital. Both hospitals had inpatient and outpatient treatment for schizophrenia.
Barut, Dietrich, Zaroni & Ridner (2016)	To explore belonging and hope in people living with chronic schizophrenia spectrum disorders. To gain an insight into patients' perceptions of treatment.	N= 20 service users	Semi-structured interviews. Qualitative enquiry using a phenomenological approach	Male 13/20, Age 40.2 years(SD:13.8) Black 6/20, White 14/20	Recruited from a psychiatric hospital that is part of a tertiary teaching medical centre.
Ramsay, Broussard, Goulding, Cristofaro, Hall, Kaslow, Killackey, Penn & Compton (2011)	To provide a summary of the life and treatment goals for individuals currently hospitalised for treatment for first-episode non-affective psychosis.	N= 100 service users	Brief structured interview. Qualitative method not explicitly identified.	Male 74/100, Age: 24.3 years(SD:5.1) Black or African American 89/100 Schizophrenia 56/100, psychotic disorder not otherwise specified 17/100, schizoaffective disorder 14/100, schizophreniform disorder 8/100, delusional disorder 3/100, brief psychotic disorder 2/100.	Recruited from a university-affiliated public-sector hospital and a suburban county psychiatric crisis centre.

## Appendix D

### Interview schedule

#### **Recovery from psychosis: a mental health inpatient perspective**

#### **Interview topic guide**

##### **1. Introduction section to promote engagement and make the individual feel comfortable.**

- Describe that we are trying to understand individual's experience of psychosis who are currently within a mental health inpatient setting and their understanding, views/experiences of recovery.
- Conducting interviews to find out peoples experiences of psychosis and recovery in order to generate themes to provide a conceptualisation of recovery. We want you to have control over the interview, so we do have some questions that will hopefully cover your experiences but if there is anything else you want to talk about you are welcome to add it in.
- This interview will last about 45 – 60 minutes long and you have the right to withdraw at any point.
- This interview is completely confidential and any information given will only be known by our research team. The only exception to this is if we felt that you or others could be in danger from what you told us. Is this OK with you?
- If you want us to tell your key worker or any other clinical ward staff about anything said in the interview please let us know.
- For research purposes, we may use unidentifiable statements taken from these interviews to put in our report.
- During the interview, if you feel upset we can stop and chat and that there is support available from the clinical ward staff if needed
- Is this all fine with you? Is the plan of the interview ok with you?

##### **2. General information about experiences**

Will be focusing on eliciting information regarding the individuals' personal experience of psychosis and the impact it has on them.

- First contact with mental health services (explore this with the individual to orient them to the topic of discussing experiences).
- Description of experience when feeling unwell (focusing on last time they felt at their worst)
  - What effect does being unwell have on:
    - Relationships
    - Community engagement
    - Employment
    - Well being
    - Health
    - Behaviour
    - Emotions
    - Sense of self (how you feel about yourself)

- When you are not at your worst what is different about:
  - Relationships
  - Community engagement
  - Employment
  - Well-being
  - Health
  - Behaviour
  - Emotions
  - Sense of self (how you feel about yourself)

### **3. Concept of recovery**

Will be trying to unpick whether the individual has a sense of what recovery means for them and whether it is something they think exists.

- What does recovery from psychosis mean to you? If the person appears not to have a conceptualisation of recovery then interviewer can offer some current conceptualisations from the recovery literature.
- Explore whether the individual believes recovery is possible and their thoughts behind their belief.
- Explore with the individual whether their view on recovery has changed over time. If it has changed why? What factors have contributed to their views?

### **4. Experience of recovery (if the person has provided a conceptualisation and believes recovery is possible then explore the following areas...)**

- Have you ever experienced recovery? Gather information regarding when this was, how they knew they were in recovery focusing on previous areas of relationships, community engagement, well-being, health, behaviour, emotions, sense of self).

### **5. Debrief**

- Thank them for taking part in the study
- 'Is there anything else you want to talk about?
- 'Did anything come up that upset you? Do you want to talk about it?'
- Make sure they are feeling OK and offer some therapeutic support.
- Remind them they can talk to ward staff about the interview experience afterwards if they wish to.

## Appendix E

### Participant Information Sheet

## Recovery from psychosis: a mental health inpatient perspective.

### Invitation and brief summary

- You have been invited to take part in a research study. Taking part in this study is entirely up to you. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you.
- This information sheet will help you to decide whether or not you would like to take part and you can ask any questions that you may have about the research. Please feel free to talk to others about the study if you wish.
- This study has been reviewed by an NHS ethics committee (IRAS ID: 216011) to ensure that the rights, safety, dignity and well-being of everyone that takes part in this study are protected.

### Who is conducting the study?

#### Chief Investigator:

Laura Emrich- Trainee Clinical Psychologist, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, Email: [REDACTED]

#### Supervised by:

Dr [REDACTED] – Lecturer in Clinical Psychology / Clinical Tutor, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, Tel: [REDACTED], Email: [REDACTED]

Dr [REDACTED] - Lecturer in Clinical Psychology/ Clinical Tutor, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, Tel: [REDACTED], Email: [REDACTED]

### What is the purpose of this study?

- A lot of research has been conducted on individual's views about recovery from psychosis. Most of the existing research involves individuals living in the community and there is currently no research in this area specifically on individuals receiving mental health inpatient care.
- This research will therefore help us to learn more about individuals currently in inpatient care and their views on recovery from psychosis and whether their views differ from those living in the community.
- The outcome of the research will be to understand what recovery from psychosis means for individuals in inpatient services and will support inpatient services to adapt the way they deliver services and how they train staff to support individuals in their recovery.

### Who is excluded from participating in this study?

You cannot take part in this study if:

- You are a non-english speaker.
- You lack the capacity to provide informed consent.

- You are currently experiencing severe thought disorder.
- The cause of your psychotic experiences are due to an acquired brain injury or substance misuse.
- You are already participating in another research project.

### **What would taking part involve?**

If you agree to take part in this study you will be involved in the following process:

- You will be interviewed in a private area on the unit about your views on recovery by the chief investigator. This interview will be audio recorded so the chief investigator and academic supervisor can listen back to the interview later on in order to analyse the data. The interview will take approximately 45-60 minutes and you will be allowed breaks throughout the process if needed. At the end of the interview 10 minutes will be spent discussing how you found the process and addressing any concerns that yourself or the chief investigator may have. The interview schedule was developed with the help of service users.
- Approximately 10-12 people will be interviewed for this study and your participation is confidential.
- The audio recording of the interview will be transcribed by the chief investigator and then analysed.
- After the data has been analysed and written up you will be contacted via letter (if you consent to this) to see whether you would like to meet with the chief investigator for the findings of the study to be fed back. There is also the option to receive this information in writing rather than attending a meeting.

### **What are the possible benefits of taking part?**

- To thank you for taking part and to acknowledge the time taken you will receive £10 in the form of a retail voucher.
- The outcome of the research is not yet known but it is thought that future individuals accessing inpatient services will benefit from you participating in this research due to service providers and staff being more aware of what is important for patients in their recovery.
- The research findings will be communicated to various inpatient services and the local NHS to guide them in developing more recovery focused services based on the views provided by the individuals participating in the study.

### **What are the possible disadvantages and risks of taking part?**

- There is the possibility that some participants may find the material covered in the interview sensitive, as you will be asked about your personal experiences and views regarding psychosis. The interview will also involve talking about recovery which might bring up a variety of emotions for individuals. This is why some time is allowed at the end of the interview for the chief investigator and yourself to discuss how you felt about the interview and to address any concerns.
- Following on from the interview the inpatient staff will be available to talk to about the research if you feel you need any support and the staff can contact the chief investigator on your behalf if needed.

### **What happens if something goes wrong?**

- This project does not have any medical interventions such as asking you to take a new medication. You will only be asked to complete an interview with the chief investigator. There is no 'right and wrong', the study is about finding out the things that are important to you. As such there is nothing about the study that should impact on your current health.
- It is necessary for us to point out that if you were to feel that taking part in this research project caused you upset or harm, there are unfortunately no special compensation arrangements. However if you were harmed due to someone's negligence (for example, if the chief investigator did not do their job as they should), then you may have grounds for a legal action, but you may have to pay for this.

### **What if there is a problem?**

- If you have a concern about any aspect of the study, you should ask to speak to the chief investigator who will do their best to answer your questions. Laura Emrich (chief investigator) can be contacted via email on [REDACTED]

### **Formal Complaints**

- If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Planning Manager, Research Office, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, by emailing [REDACTED]

### **Independent Advice**

- If you would like independent advice about taking part in research please contact: Patient Advice and Liaison Service (PALS), [REDACTED] Foundation Trust, Trust Headquarters, [REDACTED]

### **Further information**

- Your decision to participate or to not participate in this study will in no way effect your care or treatment plan.
- You can decide to withdraw from the study at any point by telling the chief investigator. If you withdraw from the study any recorded material will be destroyed immediately.
- Your identity will be kept confidential throughout the research process. The audio recorded interview will only be listened to by the chief investigator and their academic supervisor and will be stored on a secure University computer on University premises for 5 years, after which the recording will be destroyed.
- The reason for keeping the recordings for 5 years is due to the fact that sometimes when research is published other researchers request access to the research data for additional research in the area. This would mean the recording of your interview would potentially be listened to by other researchers, however they would not be given any personal details about you.
- The aim is to submit the research for publication and your participation will remain confidential. Direct quotes from interviews will be included in the write up of the research and it is therefore important to point out that it might be possible to identify participants from these quotes. The only personal information included in the study

will be participants' demographic information such as their age, gender, length of stay and formal diagnosis.

- If you wish to participate in this study, then you will be given a copy of a consent form which you will be asked to sign and you will also be provided with a copy of this information sheet to take away with you. You will not be able to participate in this research if you are already participating in another research study.
- The researcher is employed by [REDACTED] NHS Foundation Trust and is completing this study as part of their Clinical Doctorate in Psychology at the University of Essex. If you need to speak with someone regarding this research, please discuss this with the ward staff who will contact the chief investigator directly for comment or if you agree for the chief investigator to contact you then you can complete the slip below.

-----  
I agree for my name and contact number to be provided to the chief investigator so they can contact me directly to answer any questions I have about this study.

Name.....

Telephone Contact Number.....

Signed.....

Date.....

## Appendix F

### Reflective Journal Extracts

#### **Initial observations from transcript 2**

Ppt seemed to want to hurry through the consent process and get to the interview. It felt like the ppt wanted a space to air his views about hospital care due to him feeling like he had been mistreated and not listened to. I wondered about whether the participant had considered the research and his reasons for participating or whether he needed the time to be listened to by an external person.

The ppt appeared quite angry and I noticed during the interview that I did shy away quite a bit from prompting for more information or going deeper due to not wanting the ppt to think I wasn't listening. Part of me was worried that he would experience the interview as another form of mistreatment. I found myself thinking a lot about not wanting to provoke his anger or upset him further which I think prevented reaching as much depth as I would have liked. On reading back through the transcript I realised that I had maybe been more empathic than in other interviews and at times I had responded by implying how the ppt must have felt etc, which is something I tried very hard not to do in other interviews. I think I may have been doing this to try and compensate for his experiences of mental health services and trying to give him a "good" experience.

There was a real sense of things being done to him- police abuse, wife leaving him etc, staff abuse. I found it quite difficult to build a rapport with him as I was fearful of being another "abuser" or someone who listened to his story and then abandoned him.

Playing the recording back it felt like the ppt didn't think he was unwell and didn't think he needed hospital treatment. At times I felt he was trying to separate himself from other patients in regards to class etc. I felt that the ppt thought quite negatively about people experiencing mental health and that he did not fit with this category or the "stigma". At these points I was thinking to myself about how unwell I thought this person actually was and how he may possibly have been using the interview process as a way of convincing me, himself and others that he was well and ready to leave.

On playing the recording back I realised that I deviated a lot from the main topics on the schedule and at times the interview felt like a therapeutic session in regards to me trying to empathise and formulate the difficulties.

It was interesting when the ppt stated that the worst time was when he was released from hospital as I assumed this would have been a positive for him given the fact he spoke strongly about mistreatment in hospital. At times it felt like the ppt was contradicting himself- no one to help him but also stating that he didn't want help etc. Felt like it would be hard as a professional or loved one to know what to do that would be right and accepting by him. May have also been a reflection of his confused state and trying to adjust back into the community. On playing it back it was evident that the ppt would begin answering the question before I had finished asking or take a guess at what I was trying to ask. This was quite irritating for me at times as I felt he wasn't interested in the questions and it also made it difficult for me to remain on track. However this did provide me with the information that was meaningful to him which is actually the purpose. It seemed like it was difficult for him to focus on himself at times and there was a sense that he was quite defensive at times when asked about his difficulties.

I felt at times that the ppt was in denial about their difficulties and the role he played such as drinking too much red bull. It was almost as though he was framing it as a very positive thing in terms of building businesses, which I know can be a common way of viewing "mania". It felt like the ppt was painting the image that he was in control of creating mania

or not which does not appear to fit with him being in hospital. I started to gain insight into how difficult it must be to not want to be manic if you do build businesses etc and feel that you are in control as this does provide a sense of safety.

When the ppt began showing me pictures of things he had made it felt like he was trying to evidence the fact that he was well and able. I also wondered whether this was him trying to deflect me from asking further questions around being unwell? There was also a sense of him needing to be acknowledged as it felt like there wasn't really much in his life that he is praised for. It seemed really important for him to let me know that he is skilled and capable and for me not to view him as a mental health patient or an unwell person.

When the nurse interrupted to tell the ppt that his care co-ordinator was here he didn't seem annoyed, which I expected him to be as I felt annoyed for being interrupted myself and felt the staff had not listened to me when I had told them it was a confidential interview and had placed a sign on the door. Instead the ppt began smiling and laughing stating that he was always in demand. The way he interacted with staff also did not fit with our previous conversations of them mistreating him and him becoming quite angry during the interview when talking about staff. It felt like he wanted to portray that he was reasonable, well etc despite experiencing a lot of negative thoughts and feelings about hospital and the treatment he had received.

Is bipolar more acceptable than psychosis?

Is PTSD more acceptable than psychosis?

### **Initial observations from interview 3**

When listening back to the recording I remembered this interview well as it was a particularly noisy and eventful time on the ward. I remember spending hours transcribing this interview due to the background noise and how quiet the participant spoke.

The interview felt quite awkward at times due to the participant struggling to make eye contact, speaking very quietly and appearing to be quite interested in me ( a lot of this was when completing the demographic sheet and after the actual interview). I remember questioning myself during the interview about how much personal information I should have divulged, however I was keen to build a rapport with the participant as he did appear quite anxious.

The interview was very hard to follow, not just when listening back but also during the actual process. The participant tended to go into a lot of detail which sometimes did not seem relevant to the question. It was clear that the participant had experienced some very difficult events and the interview may have possibly been a way for him to air these experiences. The participant spoke a lot about racism on the ward and I wondered whether he felt comfortable due to me being white as I was aware that he was one of very few white patients on the ward. I also wondered how being exposed to this kind of treatment from others impacted his ability to recover.

I found it interesting that the participant described their first experience of mental health services as their first inpatient admission and not the prior contact with community services. I wondered whether for him the hospitalisations were at the fore front of his memory due to potential trauma experienced in these admissions or whether being admitted was a sign that you were unwell as opposed to being well if you could manage in the community.

At points during the interview the participant became very distracted by what was going on outside and began to talk about situations related to the patients he could hear outside. I wondered whether hospital provided the participant with enough space to recover and to think about himself rather than be distracted by others and their behaviour.

When the interview moved on to talk about feeling unwell I remember becoming quite confused at this point as it seemed like the participant was contradicting himself. He was talking about not having psychosis but earlier on had actually used the word psychosis to

describe his symptoms etc. It seemed like later on he was describing the act of becoming angry as being a symptom of psychosis as well as an individual characteristic. When listening back to the interview I wondered whether the participant was experiencing some difficulties with concentration and processing my questions as a lot of his answers seemed quite confused.

I noticed that the participant actually used the term recovery in his narrative before I had mentioned the word or moved on to questions in that area. To me this indicated that this was a concept he was already familiar with and held a meaning for him.

I felt quite surprised listening back to how positive the participant felt about his future in terms of accessing employment etc and generally the positive outlook he had on life. I interviewed someone prior to this participant in the same hospital and their outlook on recovery was similar however they presented in very different ways. This participant described some really traumatic experiences but I did not sense any anger or resentment regarding this.

It was interesting later on when the participant began talking in depth about people's voices and how powerful they can be. When playing this back I started to think about the participant's experience of hearing voices and wondering whether he now saw voices as powerful due to his experiences and whether he was unconsciously trying to express this experience in this narrative about voices.

#### **Initial observations of interview 5**

When listening back to this interview I felt myself being surprised at the amount of detail the participant provided regarding his experiences. It felt like he had spent some time trying to make sense of his experiences and his report of them was very fluid and fluent. I found myself thinking about other interviews where it was quite confusing when the participant was trying to express or verbalise their experience whereas this participant appeared very coherent and knowledgeable. I was also aware of the language he was using, incorporating a lot of medicalised language but also using many philosophical terms. I did think the latter may have been a reflection of his beliefs about existence etc.

There were points during the interview when the participant was describing quite traumatic experiences such as multiple losses, very vivid dreams of being attacked by a monster etc and when listening back I didn't feel any emotional connection from him to these events. It was as though he was describing them very matter of factedly and that he had shared these experiences many times before and potentially not had any form of reaction or interest from others. Something that really stood out for me when listening back was how he spoke about the difficulty in identifying what was myth or fact, what was real or a delusion and this was the first time I had really thought about how confusing and distressing experiences of hallucinations and delusions might be, in that it must be so difficult to know what is real and what is not. I also started to think about how some beliefs that people may have might appear delusional to some but completely realistic to others so is the environment, culture etc that you are in that decides whether you are "ill" or not?

When reading back through the transcript I noticed that I was deviating more from the interview schedule than in other interviews which I think was to do with the language and metaphors the participant was using and me wanting to ensure I was understanding things correctly. When listening back I really felt that I was definitely not in the expert position and that the participant was teaching me a lot about life and experiences of mental health. In other interviews I noticed that participants were seeking reassurance about answering correctly etc whereas I felt this participant was very comfortable in explaining his experiences and beliefs

and responding to questions. There was a certain confidence about this participant which I found myself linking to his level of knowledge about the world and psychosis.

As the interview continued I began to think about how people's beliefs whether that be religious, beliefs about the world and the purpose of existence etc I thought about how difficult it might be to distinguish between someone having delusional beliefs as opposed to someone believing in something different from you that doesn't make sense to you. This whole concept is very confusing and complicated to me. I began to think about what it might be like to be a patient in a mental health hospital and being supported or helped by staff from different cultures, religious backgrounds etc and how this could lead to greater levels of distress and feelings of isolation.

Overall I noticed when listening back that I felt I appeared more interested in this participant which may have been linked to how easy conversation was with him and his ability to express himself. I noticed there were several points in the interview where we shared laughter which was something I found very difficult in other interviews. This may have been linked to the fact that this participant was due to be discharged and he may have been closer to recovery compared with other participants? I was also aware that this participant identified several aspects of being unwell that were quite positive such as becoming aware of more aspects of reality which stayed with him when well.

#### **Initial observations from interview 7**

When I first met this participant he appeared very keen to take part and agreed to meet later on that day to complete the interview. When we actually started to engage in the process of completing the consent forms and starting the interview it felt like the participant became rather nervous. Even before the interview had begun he started to tell me stories about recent events in his life, such as one of his friends being assaulted and spoke about being surprised that I did not have more empathy for the stories he had told. I explained to him about my role as a researcher and he appeared to accept this and every time he spoke about something that evoked emotion he referred back to and acknowledged that I was not really there to provide empathy. I remember feeling rather on edge in the room and this was not due to me perceiving the participant as threatening but instead I felt the participant was slightly uncomfortable being in the room with just me who he did not know and I felt he was very concerned with appearing stupid or saying something wrong. There were several occasions during the interview where he referred to his fiancée and spoke about how he used to find it very uncomfortable to look or interact with other women and I wondered whether this contributed to some of the discomfort he felt.

I remember prior to starting the interview he was worried about his memory and the fact that he tended to forget what the initial question was during interactions. He did seek a lot of reassurance during the interview around whether he was answering the question or whether he had gone off track and I felt like this also added to his anxiety and potential irritability during the interview. Prior to the interview whilst completing the consent forms etc he asked about my qualifications and experiences working in mental health and he appeared quite surprised and I wondered whether this had made him feel under pressure to display his competence and do a good interview.

When listening back to the interview it did seem like he was justifying a lot of his behaviours and experiences which led me to think he may have felt quite embarrassed or ashamed of some of the things he did or believed. He spoke about taking a lot of drugs but also being heavily medicated in hospital and kept stating that lots of his behaviours and experiences were common within mental health. In terms of his unwell periods involving increased

attention on religion he explained this as at times being a joke which others did not perceive as a joke or the fact that he had been very interested in religion as a topic at school. I remember thinking during the interview that the participant was quite difficult to read in terms of how he was feeling. He was rather matter of fact when he spoke about quite traumatic events such as a girlfriend dying and then would hold his head in his hands at other points of the interview when I didn't feel there had been anything poignant spoken about. When reflecting on this I wondered whether he had repressed a lot of his painful memories and that was why he appeared quite cold or distant when describing certain events. I also wondered whether reflecting on his life may have been very difficult for him at times and may have brought some unprocessed feelings to the service leading to him appearing distressed at times when I felt the content was not particularly distressing. It was interesting as he referred to me as being quite cold when I spoke about being in a researcher role rather than a psychologist role and I actually found him to be quite cold and difficult to connect with during the interview.

At points during the interview the participant appeared to struggle to understand what I was asking which led to him becoming slightly frustrated. For some questions to do with how being unwell feels he said he couldn't think of any feelings but then answered this within the next question. I felt that at times he was holding back from answering due to getting caught up in wanting to be right and wanting to give an accurate answer which did make the interview process quite difficult at times.

I remember feeling quite confused at times due to the participant often giving long explanations that didn't appear relevant to the question and then I found it difficult to re-orientate the interview back to the direction where I was trying to head. I think this was a reflection of the participant feeling confused and was actually a really useful insight into how confusing and disorientating his experiences may have been. I also questioned whether he was presenting as having thought disorder.

This participant was also the only participant who did not wish to receive the voucher for taking part and I wondered whether this was him feeling embarrassed about taking a form of payment for the time we spent together and what they may have symbolised for him.

### **Initial observations of interview 10**

I remember when gaining consent from this participant that I was struck by how young he was compared with most of the other people I had interviewed. I remember immediately thinking that he may have a more optimistic and positive view of recovery due to his age and the likelihood that he would have had fewer admissions and lived with mental health difficulties for less time. When gaining consent he appeared very motivated when he found it was for part of my University qualification and he spoke to me about the research he had been doing for his degree. When completing the consent and discussing the research he appeared quite anxious about being able to answer questions due to him feeling that he had a poor memory. I wondered whether part of this was his anxiety about giving me a good interview for my degree but also whether he was concerned how I would perceive him as it felt like he really wanted me to think highly of him and there felt like there was an element of him wanting to prove his ability and knowledge to me.

When listening to the recording I became aware that it felt like he was processing some of his experiences whilst answering the question as he was very reflective, paused quite a lot and there seemed to be a process of making sense of things as he explored them out loud.

At points during the interview I felt like the participant was "down playing" some of the events that had occurred due to wanting to be seen in a more positive light. He mentioned the fact that he was brought in on a 136 which implies he was brought in by the police but did not expand further on this. He also spoke honestly about him feeling like others perceived

him as being and doing a lot worse things than he had done. I wondered whether maybe he had been misperceived by others, whether there was some shame linked to being unwell and whether there was some part of him that was seeking acceptance from me. There was also a part of me that felt he was trying to prove to me that he was no longer a threat as he did explicitly refer to this at points. Later on he spoke about how he had been helping staff with their duties and at times it felt like he wanted to be seen as different from the other patients, again I was unsure whether this may be linked to a sense of shame or a need to present himself as well.

When listening back I felt quite conflicted as to how well I thought he was. He seemed very articulate and coherent however still appeared to hold some beliefs around people watching him and him possibly being on tv etc and that's why people have been noticing him. He also spoke about his mother possibly framing him. I found his presentation very confusing due to him appearing very well and not presenting as a lot of other people had during the interviews such as angry, actively responding to voices, overwhelmed etc.

As I continued to listen to the interview I found it hard to connect with any emotion, he was describing self-loathing, serious suicide attempts, trauma etc and he just seemed so disconnected from it all, it all felt very matter of fact. This led me to feel quite disconnected and I noticed that when I was listening back I was struggling to concentrate on what he was saying and was finding it hard to maintain my interest. My immediate response was thinking about how he had experienced a lot of trauma and that this disconnect may have been a sign that this was still unprocessed or was a way of protecting himself.

I noticed later on that when I explicitly spoke about feelings it felt like the participant intellectualised a lot and would talk about thoughts or actions of others rather than really connecting with particular emotions. I didn't feel like he was deliberately avoiding discussing emotions it more felt like he was so disconnected from his feelings that he was not even able to name them or express them in any way to me. I also think this was one of the reasons I found the interview quite difficult to stay engaged with.

## Appendix G

### HRA Approval Letter



Health Research Authority

Miss Laura Emrich  
School of Health and Human Sciences  
University of Essex  
Wivenhoe Park, Colchester  
CO4 3SQ

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

20 April 2017

Dear Miss Emrich

#### Letter of **HRA Approval**

**Study title:** Recovery from psychosis: a mental health inpatient perspective  
**IRAS project ID:** 216011  
**REC reference:** 17/EE/0113  
**Sponsor:** University of Essex

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	216011
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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	216011
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procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **216011**. Please quote this on all correspondence.

Yours sincerely

██████████

Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: ██████████, *Sponsor Representative, University of Essex*

██████████, *Lead NHS R&D Contact, ██████████*  
*NHS Foundation Trust*

██████████, *Academic Supervisor, University of Essex*

## Appendix H

### Trust Research Governance Approval Letter

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

11<sup>th</sup> May 2017

Dear Laura Emrich,

Letter of access for research

As an existing NHS honorary clinical contract you do not require an additional honorary research contract with the [REDACTED] NHS Foundation Trust. We are satisfied that such checks as are necessary have been carried out by your employer. This letter confirms your right of access to conduct research through the [REDACTED] NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 11/05/2017 and ends on 02/04/2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct activities associated with such projects as you have received authorisation confirmed in writing from the Research and Development Director of the [REDACTED] NHS Foundation Trust. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to the [REDACTED] NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this Trust, in particular that of an employee.

While undertaking research through the [REDACTED] NHS Foundation Trust, you will remain accountable to your employer [REDACTED] NHS Foundation Trust but you are required to follow the reasonable instructions of your nominated manager [REDACTED] in this Trust or those given on her behalf in relation to the terms of this right of access.

You must act in accordance with the [REDACTED] NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer [REDACTED] Partnership NHS Foundation Trust is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

You are required to co-operate with the [REDACTED] NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998.

Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The [REDACTED] NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the [REDACTED] NHS Foundation Trust in connection with any

such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Please also ensure that while on the premises you wear your NHS ID badge at all times, or are able to prove your identity if challenged. Please note that this Trust accepts no responsibility for damage to or loss of personal property.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform the Research and Development Department and your nominated manager in [REDACTED] NHS Foundation Trust.

Yours sincerely

[REDACTED]

Research and Development Deputy Director, [REDACTED]

**Appendix I**

Participant Consent Form

Participant Identification Number:

**CONSENT FORM**

**Title of Study:** Recovery from psychosis: a mental health inpatient perspective

**Name of Chief Investigator:** Laura Emrich

Please initial box

- 1. I confirm that I have read the information sheet dated 18.04.17 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my care, treatment plan or legal rights being affected.
- 3. I agree for the interview to be audio- recorded by the chief investigator. I am aware that this recording will be listened to by the chief investigator and academic supervisors. I am aware this recording will be kept on a secure University computer on University premises and will be destroyed after 5 years.
- 4. I agree to my General Practitioner being informed of my participation in this study.
- 5. I understand that relevant sections of data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 6. I consent to direct quotes being used from the recording of my interview (optional).
- 7. I agree to be contacted later on to be offered the opportunity to attend a feedback meeting about the findings of the study (optional).
- 8. I agree to participate in this study

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix J

Example of coding and analysis

Interview 5 on 01.08.17 at 1.36pm

Duration: 28 minutes, 16 seconds and 16 minutes, 34 seconds (44 minutes, 32 seconds)

The first bit is just to think a bit about your first contact with mental health services in regards to psychosis and could you tell me a little bit about that? So how you came into services and what it was like?

Okay well there's a bit of a story behind it. Err I lost my mother and my grandfather in close succession and I was taking a lot of drugs at that time, my mother was ill with cancer (okay). And that was two sort of real sort of daggers in the heart that really sort of unsettled me and I was also unwell. I was too unwell to be at University and they had to ask me to leave the course and they said I could come back when I was feeling more well. So that was 3 sort of blows and then sort of the next year, 2013 I broke up with my girlfriend. She turned round and said she didn't want to be waiting for me... or anyone else, she said she wanted to go back home and finish her degree (mmhmm). So that was pretty hard another punch... err so then I was homeless in .....when she left (right) and after that I stayed with a dear friend, err and I thought look I can't take all this pressure and I thought all I wanted to do was to get myself off the drugs and sort myself out. I went cold turkey (mmm) and because I'd been smoking cannabis since I was 13 (right) I couldn't sleep... for like a week at a time (mmm). Err so it was literally around that time that I went cold turkey erm... where I fell into sort of really, really heavy sort of delusional, erm sort of paranoid, err paranoid delusions..... paranoid, delusional (right). Erm... then a psychosis based sort of illness erm that was triggered by all of those things that I mentioned. I'd gone cold turkey to sort of but err but I'd also reached a place, manged to reach a place in my unconscious memory, memories of stuff, abuse in the past (mmm) you know with all this stuff going on at once it was like all these different areas of perspective mind, kind of all merged and clashed into one big, sort of hyper, sort of erratic, delusional, pan delusional and realistic erm... sort of psychedelic state of mind where nothing looked the same anymore, perception was completely changed (mmhmm), my memory wasn't retaining in the same way, my beliefs about what was going on, that I was in death camps with people with special abilities, I thought I was Jesus at one point (mmhmm). Err and I could see the flowers spirit auras, which is a real aspect of the reality of life, not just delusion (right). Erm... every meal was like the last supper. You know erm I was very, very, what's the word? I was in a state of disarray for a start, so I was very erm, very, very nervous that I was going to get killed (right) and that I was in a death camp. Even here I thought it was a death camp for abilities. Erm and everything had some kind of connection, erm everything was being related in some way to everything else, you know the levels, the channels, the sections (mmm), the dimensions and everything all merging into one big state of mind. Erm and yeah I was having a lot of delusional beliefs, but also was realising a lot of things in reality, all at the same time, it was too much for me to process (mmm, yeah).

So that was your first contact with mental health services?

Emergent Themes

Significant Losses  
Substance Misuse  
Repeated rejection

Loss of Identity

Physical pain

Repressed trauma

Delusions

Paranoia

Integrating perspectives

Perceived Threat to survival

Overwhelming ~~pressure~~ experience

Trauma  
Multiple bereavements  
Substance misuse  
Family illness  
Further losses  
Feeling unsettled  
Homeless  
Too much pressure  
Loss of identity  
↳ as a student  
↳ as a boyfriend  
Rejection - uni  
- girlfriend  
Loss of stability + security  
Loss of place in the world?  
actual act of withdrawal  
"cold turkey" - desperate for things to be different? Had to do something drastic - give it all up.  
"dagger to the heart"  
"another punch"  
painful experiences?  
hurt → physical pain  
Lack of sleep  
Paranoia  
Delusional  
Repressed memories of trauma and abuse came to the surface.  
Was this psychedelic state of mind a response to going 'cold turkey' or part of experience of psychosis?  
Merged mind - integration of separate parts?  
Everything changed  
Poor memory  
Death/danger felt imminent?  
Everything merging - reality with delusions.  
Learning a lot about reality  
↳ Too much to process  
↳ Too many demands on the mind.  
\* Scared regarding survival. Is illness a threat to survival?

Emergent Themes

Mmm

What services did you receive at that time?

Erm well I went to ..... Hospital, I was only there for a night and then I went to ..... or it might have been the other way round actually, no that was right, that was right. Was it? I think I went to ..... for one day and then went to ....., I think that's right. Erm and then after a week of not sleeping, or even more than a week, I don't know how long it was, erm my sister and dad came to visit me and they brought me here (mmm, okay).

And you spoke before about experiencing things from an even younger age but that kind of wasn't picked up or you?

(The ppt had mentioned this when filling out the demographic sheet prior to the recording being started.)

Yeah, I used to have lots of erm sort of sleepless nights, nightmares and very strange dreams. I used to wave to the milkman every morning. Erm I used to have really severe hypnogogic nightmares as well.

What does that mean?

Erm hypnogogia is a state in sleep that can occur in REM state sleep err that's when rapid eye movement (yeah) is making the shapes of the patterns that you're seeing inside your brain but your body's paralysed and your body doesn't move like it would do if it wasn't paralysed in a hypnogogic state.

Right okay.

Erm but hypnogogia for me is a paralysed dream awake state. So I'm aware that I'm lucidly dreaming (mmhmm) but I'm not erm, although I'm lucidly dreaming, I'm not in control of the dream and my body's paralysed. I can remember one of the dreams in particular where I was just, it's almost like an out of body experience (mmhmm). I can see myself in bed, but I wasn't looking through my eyes, I was looking through my soul (okay), I was above my body. I can see, I can see it was a third of my head was on the pillow here (mmhmm) and it was like my soul was sort of here looking into the room (yeah). And I could see this dark figure, sort of it stood up at first and it sort of came through the light of the bedroom door, it was just ajar, erm and it came through and was sort of holding onto the edge of the doorframe, sort of creeping through the light (yep) and went into the darkness, and it was like crawling around, it was moving so slowly as well, extremely slowly (mmm). And it was all hairy and just like a dark shadow, mass, mesh, mess of just darkness, and at one point it seemed to disappear from the view of my bed and that's because it went beneath my bed (right) and I was thinking it had disappeared right in front of me (mmm) and it was like, slowly crawling up to my feet, up to my legs, passed my mid-section and got on to my chest and tried to suffocate me, I

traumatic experience? ← Difficulty remembering hospitalisation process  
 V. sudden or shocking? Admitted to a few different hospitals  
 Confusing experience?

Lack of sleep  
 Family members involved in process.

scary/unsettling - History of poor / disturbed sleep - Nightmares  
 Ppt uses quite medicalised / scientific language - Is this due to being in medical environments - is this how he understands experiences?

Body's paralysed - is this a metaphor for his experience of mental illness? Feels paralysed by his mind?

Feels out of control but can't do anything about it - powerless!  
 Out of body experience

Mental illness affects the soul? You can see what's going on but can't do anything - Is psychosis the dark figure? A mass of darkness that is suffocating you. It creeps up on you.

Sleep difficulties

Hospitalisation can be confusing.

Feeling unsettled.

Mental illness can be paralysing.

Powerless

Psychosis controls you.

A suffocating experience.

Emergent Themes

just managed to wake myself up somehow, I don't know how (mmm). That is, apparently I've heard there is a real, there is a real myth behind that dream, lots of people have experienced that dream.

Okay what's the myth?

Well that, that, there is a mythical creature that attacks you in your sleep (mmhmm), I've forgotten what the name of it is. I did come across it in my research of mythical creatures. And this is where I think there's a dividing line erm because for me to dream that, you know I suppose in an archetypal way to do with personalities there could be a chance that people would have the same dream, of a similar kind of being of just like darkness (mhm), suffocating them, but I think it's a little bit too coincidental to be honest. And I think myths are created through, well it's in the word isn't it myth? (mmm). I think they're created because some people do have experiences like that, and some people do have experiences like that because it's real (mmm) and some people have experiences like that because they are just hallucinating or just dreaming (yeah). Err... and I think that's why it's impossible to tell sometimes.

So what are those experiences like? So you've described this kind of...

Disturbing.

Yeah.

Unsettling. .....I was literally being suffocated (mmm). If you stop breathing in your sleep and you can't breathe anymore then you die (mmm).

And are they kind of dreams that you still have had sort of when you've grown up, or was that just when you were younger?

Yeah. I've had dreams like that since then. But around the age of .... Sort of mid-teens, I had a similar kind of dream but this one was in daylight, I knew it was daylight without my eyes being open (mmm), seeing myself in my room. Again I wasn't really in my body, but my body got thrown by this dark spirit across the room and I woke up on the floor in my duvet, in a pile of mess on the other side of the room (mmmm). I had lots of experiences like that.

Okay so would these be experiences that you have when you are feeling particularly unwell or do they just happen..... at other times?

No..... it could be anytime (yeah).

Okay.

lots of people have experienced mental illness?

Uncertain of how he regained control.

Searching for understanding/knowledge.

Is he trying to express how difficult it is to differentiate between reality + hallucinations/delusions?

Is he expressing how some people do not think psychosis/HH is real - it's a myth, it's all in your head?

Hallucinations are disturbing.

Near death experience?

Is psychosis like being in a nightmare?

↳ No escape until you wake up? Until you recover?

Out of body experience

Attacked by a dark spirit.

Wake up in a pile of mess.

experience of mental health

Difficulty recognising reality

Suffocated by darkness

Trapped in a nightmare

Out of body experience

Emergent Themes

They are not necessarily when I'm having an episode or whatever you call it.

**What do you, do you have another name for it? If you don't like to call it an episode?**

Well I call it a series.

**A series?**

A feature length series.

**Okay a feature length series, okay.**

**So when you're experiencing a feature length series, what kind of things would you notice are different?**

Erm well at the time you don't notice that anything's different (ah okay). It just feels like non-reality becomes reality and reality becomes reality and it all merges into one (mmhmm).

**And looking back on the feature length series, do you notice when you look back on it that things are different?**

Oh yeah, definitely. My key worker told me some stuff today that I didn't want to wash inside the shower I only wanted to wash in the rain because I didn't want to ruin my own scent (ah okay). So it's a bit crazy isn't it? (*ppt begins laughing*).

**So what other things erm when you look back on those times, what other things have you been aware, well now, that you kind of experienced, you did or you felt?**

Erm... some of the things is taking a double meaning or a metaphorical meaning in some of the simplest things in life or even the TV or what someone say. There's always with me, there's always some kind of hidden meaning behind everything.

**Could you give me an example maybe of one of them?**

Yeah... one that I can think of on the TV erm.... when Australia put an extra star on their flag, there's a 6<sup>th</sup> star (mmhmm) instead of 5. Now I thought that was to do with the sixth sense, that's why they added it because as a nation they had accepted that telepathy was real (right). Yeah but god knows why they actually put the star, the extra star on probably for some real historical reason, but you know just little things like that. Everything is a message or a sign, you know it's like erm but then when I realise that certain other things were real like signs from birds, you know that's the sort of thing that helped calm me.

feature length series implies a longer period of time than an episode.

↳ not a short one-off but a repeating on-going experience; but there are usually breaks in a series → are these breaks recovery?

confusing experience merging - blurry?

Lack of insight when unwell.

Non-reality merges with reality.

Others are aware things are different.

Acknowledgement that his behaviour was different.

'crazy'

Different perceptions → Does being unwell mean you have a different outlook on life?

Analysing everything can lead to increasing knowledge and help to calm. Appears to be a helpful part to psychosis and searching for meaning.

Enduring experience

Lack of insight

Change in perspective

A search for meaning.

Emergent Themes

Can you tell me a bit about that, the signs from the birds?

Erm yeah sometimes, erm no I shouldn't say actually. I can't say.

Reluctance to talk openly about certain aspects  
↳ paranoia?  
→ concerned about judgement?

Sleep difficulties

No that's fine. Erm in terms of kind of you've spoken a bit about sleep, in terms of your sort of physical wellbeing what impact does having a kind of one of these feature length series have on your physical health?

Lack of sleep

Well I'd go for days without sleeping or I would just have very, very little sleep, like 2 hours a night (mmhmm) in that kind of state but I would still have so much natural energy. So I managed to keep, on the move, on the go all the time (mmm). I would only stop now and then for a cat nap.

Lots of natural energy.

Relentless

Did you ever actually feel tired even though you're not actually having sleep or ....?

No.

No, okay.

That's why they put me on so much clonazepam.

Running on empty?  
- relentless

Busy 'on the go'  
↳ leading to burn out?  
↳ Is his mind also on the go?

Okay about....

I seemed like a danger to myself and others.

Use of 'they'  
- implying them vs him, a divide?

Wording suggests he was 'put on' medication - did he have a say?

Perceived threat to society

Okay. Can you tell me a bit about that if you don't mind?

Others thought he was a danger but he didn't? Different perceptions.

Fight for survival

Yeah well because erm it felt very much like I was in the animal kingdom, being in that garden. You know we are (mmhmm) that literally is what it is, but it felt a lot more archaic than it really was at times. Of course, people and animals can have that effect anyway naturally (mmhmm). Erm I really felt like it was in some sort of prehistoric time, I suppose we are in some ways, the nature of nature has not changed its nature throughout nature's existence (yeah). So that's a quote for the day isn't it?

Animal kingdom - basic natural instincts, survival of the fittest - fight for survival, perceive others as a threat to survival?

So sleep is something that kind of you don't get a lot of...

I can't remember now, what did I just say? Nature's nature has not changed in nature, naturally throughout the course and the history of nature, that's a better version.

Nature has been constant through the time - the need for survival. Motivation to exist.

Lot of natures.

Emergent Themes

Need for nourishment

Using substances to cope

Difficulty maintaining existing relationships

Finding new connections through shared experience

Difficulty communicating

Mmmm.

Erm in terms of sort of your diet or your drug and alcohol use, is there anything that changes there?

Erm... yeah I become ravenous... absolutely ravenous.

And does that lead to putting weight on or not?

Not really because I'm burning and metabolising so much energy (yeah). I've still, you know I've got a lot of core muscle and I'm still really slim (mmm). I've been eating a lot since I've been here.

And is it particular foods or is it just anything?

Erm...yeah it's particular foods. In fact, I've become a lot more particular about my food.... when erm I'm having a feature length series.

In terms of drug and alcohol use, does that change at all?

Errr yeah I find it hard to cope so I do draw back to the drugs and alcohol (mmm) not alcohol. I don't like alcohol.

So when you say the drugs is that kind of the smoking weed or is there other things?

Ah yeah, weed, I'm not usually thinking about weed, but spice (okay) synthetic (yep).

And erm so it sort of impact's on your physical health and it impacts on your sleep, what about your relationships and your interactions with other people?

Oh definitely yeah. I mean I find these new true bonds but I find it more difficult to relate to my family and friends (mmm). I just don't have the time for friends and family, and it's not in a rude way, it's not because I don't want anything to do with them, it's just I can't communicate with them (okay). I'm in a different communicative place, I can't, I don't know how to go about communicating with the people I need to communicate with. But I find, I often find new bonds or kinships or soulmates in those states.

And where would you find those new like kingships or bonds?

Kinships (kinships).

Being unwell uses a lot of fuel?

urge to fulfill needs increases

Really hungry when unwell - huge appetite

Burning energy -> sounds exhausting, no break or rest.

Eating lots - nourishing self - meeting basic needs or comfort eating?

Substance use as a way of coping.

A way of caring for himself?

No preconceived judgement from others?

Is this because he can be who he wants to be?

Connecting with new people is easier.

do they expect a certain type/level of communication? Difficulty relating to family + friends.

Communication becomes time consuming + hard

-> sharing experiences creating a new self?

'kinships' - sharing of characteristics - can relate more to those who have experienced psychosis?

Emergent Themes

Feeling segregated

Erm well usually unfortunately I'm banged up in these places (ppt laughs momentarily) (mmm). Err this is not the best place to meet people really.

So do you, do you form relationships with the other people here when you're...

Imbalance of power within the hospital system

Well it becomes like a hierarchy, that's what I was saying about the archaichness of the garden (yeah). It becomes a hierarchy and so different bonds are created through the hierarchy.

Can you explain that a bit to me?

Like roles. Yeah it's to do with rituals and roles, erm in social anthropology they call it communities (mmhmm). So our behaviour really hasn't changed that much since our ancestors really, I don't think. Yeah we are still the same.....

So how does the hierarchy work in here?

Erm it's still much the same as when I was ill really. When I was ill I ...some people are fighters, some people are not, some people are philosophers, some people are not.

And what are you, how would you describe you?

Guard, den, garden, guard, den, art, zen.

What does that mean?

Erm well I'm a guard of the garden and of nature and of the birds, protector of the birds and the trees. I'm a bit of a hard zen. Zen relating to the Chinese word zen, zen as in peaceful (yeah), very meditative. I do yoga, thai chi and martial arts (mmhmm).

Are those all things that you still do when you're experiencing a feature length series?

That kind of thing kind of disappears, usually, I can't focus on all the activities in my life at once (yeah). I usually stick to one thing, and this time it was listening to music. Finding songs that had real poignant times, meanings, at certain points of time (mmhmm) and meetings with others. Every other person with different kind of eyes and different kind of hair and different kind of skins are sub species of humans as well (okay.)

Is that something that you think about a lot then?

Not particularly no.

Maintaining a purpose.

Protecting the peace

Difficult to focus

Focused on making connections.

Imprisoned  
→ Segregated from others  
'banged up' - prison, form of punishment?  
Hospital can be isolating.

Does the hierarchy include staff?  
'hierarchy' - suggests power and status exists within hospitals.  
bond depending on 'rank'. How does this work?  
Hospital can be a community.

Talking about being ill in the past tense. What is he now?  
Everyone has a role/purpose within the community they exist in, even hospital.

You still have a purpose when ill.  
Does your role change when you're ill? He thinks no.

Role is to protect nature.  
Engages in peaceful activities.

Difficulty focusing  
Life is overwhelming.  
Having a sole focus  
Searching for meaning and connections. → Is this a way of coping? Or does this contribute to being unwell?

Emergent Themes

Increased unconscious awareness

You spoke about having lots of things going on...

I'm aware of it. Yeah I'm aware of it, I don't necessarily think about it much. I'm more aware of some of those things that I don't think about so much in my series.

An erm in terms of when you're not in hospital, kind of thinking about your local community, do you engage much with your local community?

No.

No, okay.

I do within the hospital, but the outside world, I have very little engagement with.

Okay so when you're in hospital and you're still in one of your feature length episodes how would you engage with the community?

Do you mean the actual community outside of the hospital?

In the hospital.

The community in the hospital? Erm... I'm not sure really, I don't know how I interact with people really, erm...

Do you find it sort of easy or hard to interact with others?

No I find it a lot easier (mmhmm). Because I understand people more when they are in that state.

Ah okay. And what sort of emotions would you use to describe when you're in a feature length episode... series, sorry I used the word that you don't like (both ppt and interviewer began laughing).

It's too late now. (ppt said this whilst laughing). Erm... distress, alarm, disarray... distress, disalarm, no, distress, alarm, disarray... I don't know what else I felt really.

It's okay.

Disturbed, a lot of negative d words isn't it? Distraught, really impassioned and empowered, enthusiastic, enlightened... (long pause) but also incarcerated, institutionalised, log cabin coglaben hypnogogic fever.

Hospital is a separation from the real community

Connecting through experience

Alarming chaos

Learning through experience

Having awareness without much thought - is this a bit of a contradiction? How can you be aware without thinking about it? natural innate awareness? unconscious awareness? Hospital is a separate community. Inside vs. outside world suggests a separation of experience.

Use of the phrase 'actual community' - so the hospital is a community but not the real or proper community?

Confusion around how he relates to others.

Easier to connect with unwell people.

Use of the word 'state' - suggests something temporary that can change? Suggests a mess?

Alarm: fear, anxiety, danger, panic  
Distress: fear, pain, suffering  
Disarray: confusion, chaos

Negative experience.

Some positive aspects empowered + enlightened

Is this due to new knowledge + perspectives? illness provides knowledge - process of learning

Emergent Themes

Institutionalisation

I haven't heard of that before? What's that?

I made it up (oh, okay). Erm my doctor wrote it down...Incarcerated, institutionalised, log cabin coglaben hypnagogic fever (okay).

I think I can understand where you're coming from but could you kind of describe it to me, what were you thinking when you sort of made that up?

Confinement creates symptoms

Erm it's just how I was feeling erm and so how you start behaving when you become institutionalised. You feel incarcerated (mmhmm), you feel trapped, you feel you have no freedom, you feel these inside walls and the garden is all you have in life (mmm) that's all that exists, it exists forever.

Hopelessness around freedom

If you weren't in hospital, so you were sort of living where you normally live erm but you were having one of your feature length series, would you still experience those feelings of being trapped and incarcerated or is it just because you're in here?

Erm.. I would tend to sort of withdraw (mhmm), not going outside as much (yeah) but I would still make it outside (okay).

And what would you do when you're outside?

Reconnecting with nature

Spend time with nature to be honest or I don't know just see the sky at night (mmhmm). Hear the birds, see the birds and hear the birds (mmm).

I might be interpreting something here but birds seem to be quite important to you?

Yeah, a lot. I have conditional and unconditional love for all birds.

Has that always been the way? This feeling towards birds?

Yeah

Yeah.

Does the intensity.....

Since a very early age.

Does the intensity of that feeling change when your kind of mood changes?

hypnagogic - hallucinations, lucid dreaming, threshold to consciousness

Imprisoned, confined

'cabin fever' - symptoms resulting from long term confinement inside

Hospital / confinement causes these symptoms?

Trapped, freedom removed

↳ hopelessness around getting out?

Hospital increases withdrawal

Spending time with nature is helpful

Re-connecting with nature through the senses

Unconditional love  
↳ he gives this but does he receive this from others? Bit of a contradiction on conditional + unconditional love?

Does he experience love with conditions? Unconditional love when well, conditional love when unwell

His love for nature started from a young age

Emergent Themes

Yeah.

Could you tell me a bit about that?

I shouldn't, I'm not really supposed to talk about the birds to be honest.

Okay. That's okay. That's fine. In terms of when you're experiencing one of these feature length series, how do you feel about yourself, how do you view yourself?

I become quite selfless. I feel like I'm having an out of body experience.

An out of body experience did you say?

Yep.

Yeah. Could you describe that a bit more for me?

Erm I feel detached from the reality of my actual body (mhmhm). Dissociated from the reality of what myself is capable of but at the same time it's more like forgetting certain parts but remembering other parts of myself and what I'm capable of (mhmhm).

And how do you think others view you?

Doesn't bother me (ppt begins laughing).

Okay. It's not something you think about?

No.

So we've spoken a lot about some of the kind of the difficult times and the experiences, is there anything about a feature length series that we haven't spoken about that you would want to say?

Erm... yeah.... The clouds (mhmhm) and the weather (yeah) and the situation and what I am doing and what magic I try to wield becomes all very integrated as well.

Did you say what magic you try to wield or did I hear that...

Yeah I did say that.

Reluctant to discuss/  
- paranoia? disclose  
- afraid of judgement?

Out of body  
experience - Not in  
control of his behaviour?  
A form of dissociating?  
'selfless' - more concerned  
with others needs - lack of  
care or concern regarding  
his needs?

Detachment from  
body, Dissociated  
from self - a form  
of rejecting oneself  
when unwell? A defense?  
A response to the trauma  
of being unwell?  
Searching for the 'good'  
or 'well' parts of himself.  
Rejection of the 'ill' self.

Integration of  
self with nature.  
Everything comes  
together. Is this a  
positive aspect of illness?

Being unwell  
is traumatic

Rejecting parts  
of the self

Reintegrating  
with the  
outside world

Emergent Themes

Faith can be powerful

Questioning your identity

Influential forces

Returning to reality

What do you mean by that?

Well I pray to the holy ghost (mmhmm) erm I believe that I do have sort of certain abilities and in a way I worship the birds (yep) erm and I have influence over the weather and theres an old philosophy that was recently passed on to me, not personally obviously erm. Am I the movement of the leaves in the trees, or the wind that blows the leaves within the trees or am I the tree.

And what does that mean to you?

(ppt begins laughing)

Because I suppose we can all interpret it differently can't we?

Yeah. It means that you can influence a tree, but so can a force that you can't influence can influence a tree, a tree can influence both those forces (mmhmm).

Do you mind if we have a break please? Yeah of course. I'm keen to carry on.

(At this point the recording is stopped and the ppt takes a 10 minute break to have a cigarette in the garden).

Okay so we'd mainly been talking about the impact that a feature length series has on you in terms of sort of emotions, relationships, things like that. So now I want you to think about when you're not having a feature length series, is there anything, is there a word or a phrase that you would use to describe times when you're not experiencing that?

Erm... back to life, back to reality.

Back to life, back to reality? Yeah. Okay.

It's a song (ppt says smiling).

I won't sing it (interviewer said smiling). I'm an awful singer.

So when you're back to life and back to reality...

All ladies say that for some reason.

What that they are bad singers?

Faith in yourself and another is important

Does religion provide power?

Belief / spirituality  
He practices by praying  
Influential  
He believes he is powerful? Has an element of control.

Is he questioning his identity, his role in the world?  
Knowledge being passed on.

Nature is more powerful than the human race?

Could this be a metaphor for psychosis having an influence ('the force')?  
Mental illness can influence the course of nature.

Getting back to everyday life.

Is hospital part of reality? Does life stop when you're in hospital?

Is reality getting out of hospital or is reality having no more delusions etc?  
'reality' - the real world

Emergent Themes

Focused on the future

Renewing relationships

Reconnecting with others

Physical health is a priority

Achieving Inner peace

Yeah.

Well it's a talent isn't it? We can't all be good at singing.

Erm what do you notice that's different about life?

Just that I feel a lot more focused. So I can see long term goals and short term goals again (mmhmm). Erm... yeah the word focus is a big point really...yeah I feel focused (okay). In control of life.

And what about relationships with other people?

Erm they sort of start, restart a fresh to be honest (mmhmm) or carry on as they were.

So why do you think some of them start a fresh and some carry on from where they were?

It's a good question, I hadn't thought about that erm I can go for so long without communicating with certain people and sometimes I maintain contact with certain people.

Right okay. And is there any erm... are there some relationships that don't start afresh or don't go back to how they were?

Erm... no actually.

Okay. And what about kind of, we spoke last time about your sort of wellbeing and your physical health. Erm when you get back to life, what's different about that?

Erm... well there's not much difference really because when I'm in one of those feature length series I still maintain my fitness (mmhmm). In fact I concentrate more on fitness actually in a series (okay).

And erm in terms of the emotions you had lots of words to describe kind of how you feel when you're in a feature length series, erm what words would you use to describe kind of how you feel when you get back to life?

Peace, relaxed, relieved.

You like to do things with all the same letter, don't you?

Yeah I'm a poet by the way (ahhh okay).

And in terms of sort of your behaviour erm do you notice anything different about your behaviour?

Focused

Identifying goals

↳ suggests more hopeful for the future

↳ Increased motivation

Sense of control

→ more stability?

Renewed relationships

← Starting over

Continued relationships

Reconnecting and maintaining

No loss of relationships

Contradiction from earlier as he said he engaged less with yoga etc.\*

At peace - Inner peace

Creativity

→ Physical health as a priority

\* Does he perceive fitness as important and therefore wants me to know this is something he maintains. Or is this the one activity he can focus on?

redefining relationships

Emergent Themes

Yeah it's more settled, I think so.

And what about some of the beliefs that you hold, are any of them different?

Recover reality

Erm... no to be honest... no. I still maintain the same beliefs (mmhmm) but there are some beliefs that are misconceptions at times so I sort of recuperate to reality and my perception (mmhmm) and beliefs.

And you, when we were filling out the form earlier you said erm, I'm not going to be able to say it but about your religion, you used the word poly..

Polytheistic

Polytheistic.

Erm does that change, or how you, I don't know if you kind of practice that but does that change when you're getting back to life?

Re-establishing beliefs

Erm... it tends to take a bit more of a back seat (mmhmm) it's not as poignant. But it does again, I recuperate, I re-establish what I've come to the belief of.

Okay and do you do sort of anything, you'll have to forgive me because I'd never heard of it before, but so do you practice it in a certain way or is it...

Not really it's so I may change faith and beliefs in certain deities.

Okay.

Conflicted mind

I don't pray as much as I should erm but the thing is is that the religions I believe in are conflicting. You can't be a, for example you can't be for example an isralite and an isralite (mhmm) so erm but personally I can't, I find difficulties with the rules of religion (yep). Erm...

Did you say find difficulty with ....

Yeah I have issues with the way they persecute and treat women.

Okay.

more settled mind too.  
← More settled behaviour - more stable, in control.

Maintain beliefs  
← "Recuperate to reality"  
↳ recover reality  
↳ lose reality when unwell.

open to different perspectives  
← open minded regarding beliefs  
belief in multiple deities (gods)

Faith takes a temporary back seat during recovery.  
Re-establishing self + belief system

Does this change in line with illness?  
← Faith is dynamic, changeable.

Conflicting beliefs  
↳ Is this what happens when he is unwell too?

Reality vs delusions.  
↳ a conflicted mind.  
Disagree with persecution

Emergent Themes

Faith is a constant

I find it very difficult, the way they sacrifice and torture as well (mmm) erm but I don't lose my religion in a series, that's for sure.

Religion remains present when unwell.  
↳ It is a constant.  
→ Faith is constant.

Regaining self belief

Is there something different about it because you said when you get back to life it kind of takes a bit of a back seat?

Yeah... I just... I guess yeah I don't rely on the help of the sages, I rely on myself (mhmm).

self belief ← regains faith in self rather than focusing on other faith.

Sorry, is that when you're in a feature length series?

No that's when I'm back to life.

Yep. Okay you rely on yourself.

← Became self reliant  
↳ accept responsibility for self.  
'sages' - wise person.

Healing the self

This is my birthstone agate (okay). Erm and there are other stones, like gemstones (mmm).

relevance of birthstones having healing properties  
↳ self-healing?

Are those things important to you? Like your birthstone and the meaning of those things?

Yeah.

Yeah.

Yeah.

Okay and how do you feel about yourself when you get back to life and back to reality?

Paradoxical journey

← Journey involving a struggle / conflicting

Paradoxical Journey.

Well sometimes I feel less motivated (okay). Erm...

need to take time for self - prioritise self-care.

← less motivated when well.

Prioritise self-care.

Can you tell me a bit more about that, sort of feeling less motivated?

Yeah... I kind of feel like I've been through a hell of a lot, heaven a lot as well at the same time, and just feel like I need a rest after all of that to be honest (yeah). And that can mean that I'm sleeping more, less motivated. Erm sometimes it's like the comedown period after the series (mmm) because there's so much hyper and excitement at the same time and it's like... it's a reflection period, a sort of calming down period (yeah).

Good and evil Ups and downs heaven and hell

Need time to rest and recover.

Sleeping is part of recovery.

Finding a balance.

Okay is there anything else that you want to say about erm about when you do get back to life and back to reality, is there anything you think we haven't spoken about that's important?

'comedown period'

← low mood? - being unwell can be exhausting.

like being on drugs? ← reaching an equilibrium again - rediscovering & finding a balance.

Emergent Themes

Increased alertness

Erm... well it's really more on the ball and having my beliefs about what I believed in anyway. More on the ball and more focused.

Remembering existing beliefs

Okay and so the word recovery, when I say kind of recovery from psychosis, what do you think about or what does that mean for you?

More responsive and focused. Increased alertness

Transformation of the self

Erm... I mentioned this earlier, when I recover from a psychosis, in a way I don't ever recover because part of me changes and that stays the same. And the part of me that changes, my perception and beliefs... perception, memory and beliefs (mmhmm).  
Erm.. and I see things in a more heightened way, my <sup>delusions</sup> imagination gets carried away and my delusions can cause cosmic mystery and there is also new reality to be found. I found those realities in people (mmhmm).

Psychosis changes you. → You can never return to how you were? The self changes.

Reality becomes amplified

So you've said that....

But I don't keep the delusions so.

You don't keep the delusions?

No I keep the realities.

So you said something about erm, I've forgotten already but you said something about recovery and it not, sometimes you, it's kind of an ongoing thing or you don't necessarily recover because part of you changes?

New identity? Transformation? Recovery involves a new self. New realities exist ← Life becomes amplified

Beliefs + perceptions change. - things are amplified.

Experience of delusions changing perception of reality when recovered  
↳ do some delusions remain in recovery in the form of a new reality?

Process of learning

Yeah. Erm no it's just certain things that I learn in the series that do carry on into recovery (mmhmm).

And would you have a different phrase, rather than recovery that means more to you, or sort of fits more with your experiences?

(A car alarm begins to go off outside that you can hear in the interview room).

Is that a car alarm?

It sounds like it yeah.

Erm sorry can you repeat the question please?

Yeah.

Learning experience  
- Are there some positives involved in experiencing psychosis?  
- a process that carries on into recovery.

Emergent Themes

Difficult to find peace

Recuperation

Illness can break you apart

Completing the puzzle

Shedding parts of yourself

Process of growth

Returning to your natural being

It's quite noisy out there as well.

It is isn't it.

Is there a word that fits better with your experiences, so rather than using the word recovery, is there another word that you have in mind?

Recuperation (mmhmm).

And what does recuperation mean to you?

Well it means bringing it all back together. Pick up the pieces you could create a picture puzzle, shuffle them all up, drop loads of them on the floor and you pick them up and put the picture back to how it should be and it's still the picture you started with.

If I was, I think you're going to be quite good at this, but if I asked you to think of an image or a metaphor for recuperation, you've kind of described the puzzle but is there anything that comes to mind?

Erm, yeah a tree, a tree that blooms in the spring and the summer and it sheds ...A tree with a snake around it.

A tree with a snake around it?

Yeah, the tree of life, the tree of knowledge.

Like Adam and Eve, the tree in the garden of Eden?

Yeah.

Why does that....

The snake is not the serpent or beast, it's not that snake... it's a peaceful snake, a wise snake.

And why does that image come to your mind when you think of recuperation?

I don't know, you just asked me to come up with one.

Okay I was just wondering if, because you were quite specific about what tree it was and what snake it was? So I was just curious...

Ward environment can be noisy  
 - difficult to think?  
 - reflection of what is going on in his head  
 too? Unable to escape the noise!

← Unable to find peace?

recuperation - recovery from illness or regaining of something. Regaining the self? Regaining your life?

Illness is messy, breaks you but you can fix it? Contradiction to earlier as he said that illness changes parts of you so therefore the picture would be different?

→ Shed leaves in winter - is this illness - you become bare - lose your identity. A snake also sheds its skin? Losing part of your self + regrowing.

Recuperating - regrowth + returning to your natural being

Snake resembles good qualities 'peace' 'wise'

Emergent Themes

Out of reach of psychosis

Recuperation is a dynamic process.

Integrated self concept leads to recuperation

Erm the tree of knowledge and the tree of life (mhhh) and there's a snake coiling round it, coiling its tail, it's just out of the human arms reach and its head is resting on top of the, it's in the top branches...

Is there a reason why it is out of human reach?

Erm because it can't be caught, it can't be captured.

Okay...and in terms of kind of recuperation do you think that's something you've experienced?

Yeah, I think I'm recuperating now (mmm).

And do you think you've experienced it before?

Yeah.

Has your idea of what recuperation is, has that changed over time or has it remained the same?

Erm... I think it's remained the same, I'm not 100 % sure.

And do you think there's any kind of belief systems that you have that might have helped you to form your idea of recuperation?

Right...

I know that's kind of a difficult question.

Could you repeat it please?

Yep so I suppose it there any beliefs that you hold or any belief systems that you have that might have contributed to your idea of what recuperation is?

Yeah the basis of what I am, how I am and who I am.

Can you tell me a bit more about that belief system if you don't mind?

Yeah that's fine. Erm it's just understanding my sort of current state of mood and mind emotions and how I feel regularly (mmhhh), you know how my mind works.

When recuperating you take the new knowledge into life.

Snake resembles something good that can't be caught.

Is the snake out of reach of illness? Can't be caught again by psychosis?

Uncertain about his view of recuperation.

→ suggests it is not a stable construct.

Does it change everytime you experience it?

Dynamic?

Your life, upbringing, morals etc shape how you view recuperation.

Understanding the self - If you understand yourself then you can recuperate?

self concept ←

Emergent Themes

Are you aware of how your mind works?

Yeah.

Yeah. Have you got any words that you would use to describe or help other people understand how your mind works?

Erm... no.

Okay, going back to this idea of recuperation how do you know that you're recuperating now, what's sort of letting you know that?

Well just my behaviour, my state of mind, erm the way I think and feel. I do what I want to do or don't do what I don't. Erm just, even how I metabolise in my body. Erm... I don't know I can just feel it in my soul. I know when I'm well but I don't always recognise at the time when I recuperate.

And on this theme of recuperation do you think there's anything that we haven't spoken about in terms of helping other people understand your view of recuperation? Is there anything that you think would be helpful?

I think sleeping pattern and the body's circadian rhythms are a big thing erm because when you go through a feature length series it's really racing and it's producing and computing a lot of information at the same time (yeah). I mean once you get through that phase of when you're re-remembering, relearning and recreating something new all the time and you're having an out of body experience at the same time, once that all calms down and you sort of learn and your memory is back to a sort of stable position.

Okay that's all of my questions, so is there anything that you think or hoped that we would have spoken about that you'd like to?

No I think it was a very good interview.

difficult for others to understand psychosis

Difficult to articulate to others how your mind works.

Being in control of your behaviour/decisions/actions

Recuperation is not always obvious at the time

Internal + external changes

Body is overloaded + working hard when unwell

Various phases Multiple processes happening at once

Process of slowing down, reflecting and stabilising

Overwhelming

Rehabilitation of the body + mind

Regaining control over self

The body is overwhelmed

Rehabilitation of the body + mind

Process of reflecting and stabilising