

Factors that promote recovery: The views of service-users experiencing  
psychosis on an acute psychiatric ward

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## Abstract

**Background:** Psychosis was once considered a progressive and untreatable “illness” due to a “diseased brain”. Current thinking suggests childhood adversity along with a combination of psychological, biological and environmental factors influence the development of psychosis experiences, with recovery now considered an achievable aim. Recovery is a multifaceted concept. Research indicates that service-users hold different views about recovery, however research exploring recovery from the viewpoint of those who are currently inpatients is scarce.

**Aims:** The aim of the current study is to explore the views that a group of service-users who are currently inpatients in a psychiatric hospital, hold about what is important to them in recovery.

**Method:** Q-methodology allows the exploration of the distinct viewpoints that are present among a group of people in relation to a subject matter. Thirty-eight participants were recruited across four acute psychiatric wards from a London based psychiatric hospital. Using Q-methodology, participants engaged in a card sort task where they ordered 54 statements relating to recovery from most to least important to them.

**Results:** The analysis revealed four distinct viewpoints held among the group regarding factors that are important to recovery from psychosis. These were: “Stability, independence, and having a roof over your head”, “Hope, optimism, and enhancing wellbeing”, “Emotional change through self-management and social support”, and “Symptom reduction through mental health support”.

**Conclusions:** Service-users who experience psychosis and are currently inpatients, hold different views about what is helpful to them in recovery. Services must be

sensitive to the subjective conceptualisations service-users hold of their experiences and be flexible in tailoring support to meet their needs. The findings from this study suggest that changes are required both within services and at a socio-political level, in order to support people with psychosis toward recovery. Clinical implications and areas for future research are discussed.

### **Statement of terms**

The term “people with psychosis” has been abbreviated throughout this thesis to PWP. In taking a non-medicalised stance to mental health the term “service-user” has been adopted throughout, however in reference to the work of other authors, or in relaying service-user’s personal accounts, this term may be used interchangeably with “patient”. In reference to those service-users who have experience of hospitalisation the term “inpatient” is used.

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## **Chapter 1 Introduction**

### **Overview**

This chapter begins by defining what is meant by the term psychosis. It proceeds in discussing criticisms of schizophrenia as a diagnosis, and the historical development of the concept. The psychiatric model of mental health and criticisms of this model, along with the anti-psychiatry debate are outlined. Following which, alternative models of psychosis, such as the cognitive and traumagenic models are discussed. The chapter moves on to defining what is meant by recovery and outlines the development of the recovery model. Research exploring recovery in relation to psychosis is presented, along with criticisms of the recovery model and alternative explanations of recovery. Following this, the history of psychiatric inpatient settings is outlined and the current picture of psychiatric inpatient care in the UK is presented. The chapter concludes with a literature review evaluating the experience of recovery from psychosis for those who have a history of psychiatric hospitalisation. Finally, the aims and rationale for the study and use of Q-methodology are discussed.

## **Part I Psychosis**

### **1.1 What is Psychosis?**

Psychosis is conceptualised differently depending on the discipline and school of thought one subscribes to. Individuals from different schools of thought tend to disagree about how to understand experiences such as psychosis and therefore what can and should be done to support those who report these experiences.

#### **1.1.1 Psychosis experiences**

The experience of psychosis varies greatly among different people. However, some types of experience are more likely for those who receive labels such as psychosis or

schizophrenia. Individuals may hear voices or noises when there is no one around. Similarly, people may see, smell, feel or taste things that are not there (Cooke, 2017). These experiences are sometimes labelled hallucinations. Other experiences include holding strong beliefs that are not shared by others, and difficulties with thinking or concentration, such that following conversations may become difficult. In addition, people with psychosis (PWP) may experience layers of confusing thoughts and their speech may become difficult to understand by others. Such experiences can be referred to as *positive symptoms*. Additionally, PWP may experience what can be termed *negative symptoms*. These may involve low mood, difficulties with motivation or lack of interest and enjoyment in the things previously enjoyed (Cooke, 2017).

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

The dominant practice of psychiatry subscribes to a biomedical model of understanding mental health and employs an illness framework where mental health experiences are conceptualised as “illnesses” which can be identified, diagnosed, and treated – often with medication. Psychiatry employs a categorical diagnostic system, whereby people are categorized in to what are considered discrete categories of experience, based on symptoms (e.g. depression, schizophrenia etc.). From a medical perspective, psychosis is understood as an umbrella term referring to a cluster of mental health “disorders” thought to share similarities in symptomatology. The Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-V; American Psychiatric Association, 2013) specifies that “abnormalities” in one or more of the following areas are characteristic of psychosis: delusions, hallucinations, disorganised thinking or speech, grossly disorganised or abnormal motor behaviour and the presence of negative symptoms (such as low mood or lack of goal directed

behaviour). Diagnoses such as schizophrenia and schizoaffective disorder, among others, fall under this category.

### **1.1.3 Challenges to medical conceptualisations of psychosis**

The biomedical model and the practice of psychiatry have dominated the field of mental health for some time. Psychiatrists are medically trained, and taught to recognise abnormality, delineate cause, and treat with medication (Rogers, 2010). It is therefore of no surprise that the medical and psychiatric view of mental health is rife with discourses of illness, deficiency, biological or genetic causation, and abnormality. Even less surprising therefore is the often, yet somewhat disappointingly, unaccompanied model of treatment: medication. However, medical conceptualisations of mental health experiences as illnesses are not shared by all. Criticism of this model has come from varying sources and alternative models of understanding are proposed.

### **1.1.4 Anti-psychiatry debate**

Over recent years the anti-psychiatry debate has gathered some considerable force and anti-psychiatry movements such as *Mad Studies* (LeFrançois, Menzies, & Reaume, 2013) and anti-diagnosis service-user groups such as *Recovery in The Bin* have gained a louder voice in mainstream discourse, at least within these arenas. These groups argue against medical conceptualisations of mental health and practices of psychiatry which are viewed as damaging (Double, 2002).

### **1.1.5 Reliability and validity of schizophrenia diagnosis**

The conceptualisation of schizophrenia as a diagnosis remains highly contested, and disagreements date back to the mid 1960's. Researchers have suggested that the inability to discover a unitary biological cause for schizophrenia is mirrored in the

heterogeneity of the disorder and as a result questions have been raised as to the reliability and validity of such a diagnosis (Read, Bentall, & Fosse, 2009). Reliability in terms of diagnosis, refers to the consistency with which an individual receives the same diagnosis regardless of the person or context in which they are diagnosed.

Validity when applied to diagnosis, refers to how accurately the label can explain or describe an individual's presentation, prognosis, aetiology, and treatment (Aboraya, Rankin, France, El-Missiry, & John, 2006). Early studies examining consistency between clinicians in diagnosing schizophrenia yielded agreement rates of 33%-50% (Ash, 1949; Hunt, Wittson, & Hunt, 1951). Over subsequent years alterations to the way that schizophrenia is defined and classified have led to more recent studies producing 'good' reliability estimates, however the question of validity remains (Guloksuz & van Os, 2018; Read, 2013a; Regier et al. 2013). The variability in presentation among those who receive labels such as schizophrenia and the cross over in symptoms shared with other diagnoses, coupled with the lack of evidence of a group factor to explain the categorization, suggests that current diagnostic conceptualisations of schizophrenia are problematic (Guertin, 1952; Read, 2013a). Questions have also been raised as to how useful a categorical system is in supporting those who receive labels (Read, 2013a).

### **1.1.6 Cultural relativism**

The DSM-V (APA, 2013) suggests experiences such as hallucinations and delusions are relevant to a diagnostic assessment if they are not shared by those of a similar culture. Research indicates significant differences in how these experiences are understood across cultures (Al-Issa, 1995; Ndeti & Vadher, 1984; Sartorius et al., 1986). Cultural awareness in diagnosis is therefore important, however this raises

questions pertaining the validity of such diagnoses and highlights issues raised by the anti-psychiatry debate.

### **1.1.7 Social construction of diagnosis**

From a social constructionist standpoint, both diagnosis and illness are considered to be products of social process which are culturally and historically bound (McCann, 2016). This logic contrasts with the epistemological underpinnings of the medical model which posits that schizophrenia exists as an objective reality which can be located within individuals and therefore observed, named, and treated (Maddux, 2008). From a social constructionist vantage, cultural relativism in diagnosis is easily understood, providing an alternative understanding to labels such as schizophrenia.

### **1.1.8 Service-user critiques of mental illness**

From a service-user perspective, it is recognised that although some people find it useful to understand their mental health experiences in terms of an illness, for many being seen as ill or labelled as 'schizophrenic' delivers more harm than good (Cooke, 2017). Service-users have spoken about experiences of stigma related to having a mental health diagnosis and the damaging impact of common public perceptions of mental illness as being linked with dangerousness and unpredictability (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007).

### **1.1.9 The medical model and stigma**

The experience of stigma is commonly reported by PWP (Brohan, Elgie, Sartorius, Thornicroft, & GAMIAN-Europe Study Group, 2010; Vass et al., 2015; Wood, Byrne, Burke, Enache, & Morrison, 2017). Stigmatizing attitudes are associated with the desire from the public to keep social distance, and the adoption of illness labels

among service-users has been linked with experiences of self-stigma (Kvaale, Haslam, & Gottdiener, 2013; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Livingston & Boyd, 2010; Speerforck, Schomerus, Pruess, & Angermeyer, 2014). Additionally, medical conceptualisations of mental health experiences are suggested to produce more stigma and negative attitudes than when mental health is considered from a psychosocial perspective (Longdon & Read, 2017; Read, Haslam, & Magliano, 2013; Read, Haslam, Sayce, & Davies, 2006; Walker & Read, 2002).

#### **1.1.10 Psychosocial conceptualisations of psychosis**

Those coming from a psychosocial standpoint argue that conceptualisations of mental health experiences as illnesses are both reductionist and damaging (Read, Mosher, & Bentall, 2013). Instead, the unusual experiences and distress that PWP experience can be understood as a reaction to adversity and difficult life experiences. It is argued that medical conceptualisations of psychosis, which favour a process of labelling and subscribing medication, side-line the complex reality of people's lives; discouraging efforts to understand what has happened to these individuals and what can be done to help (Read, Mosher, & Bentall, 2013).

#### **1.1.11 The Continuum Model of psychosis experiences**

In contrast, suggestions have been made that psychosis experiences (like other mental health experiences) vary along a continuum, with many being reported to varying degrees by those who are not deemed to be "psychotic" or "mentally ill" (Cooke, 2017). Research suggests that psychosis-like experiences vary in frequency and severity among the general population, with a meta-analysis indicating prevalence rates of around 5% (Bebbington et al., 2013; van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). This suggests that the presence of psychosis-like

experiences is not indicative of a “mental illness” but instead constitute normal experiences that vary in severity and frequency among the general population.

Continuum models of psychosis suggest that experiences such as paranoia or delusions build on common cognitive and emotional experiences such as social anxiety, wariness, and mistrust (Bebbington et al., 2013). A meta-analysis examining the continuum model found evidence for a “Psychosis Proneness-Persistence-Impairment Model” (Os et al., 2009). They suggest that it is the severity of disturbance that these experiences cause, coupled with the individual’s ability to cope, that indicates clinical need, rather than the mere presence of these experiences. Sub-clinical psychosis experiences are thought to be broadly prevalent, with the majority disappearing over time, where both genetic and environmental factors are considered to influence whether these experiences persist or develop to cause impairment (van Os et al. 2009).

#### **1.1.12 Dimensional Model of psychosis**

Dimensional models of mental health are built around a similar premise. These models suggest that individuals vary on a continuum-like structure across a number of dimensions. For example, models have been suggested where individuals differ on five key symptom dimensions, these are: mania, reality distortion, negative, depressive, and disorganization, where symptom severity varies from a clinical range to what would be considered “normal” in the general population (Demjaha et al., 2009; van Os & Kapur, 2009). Arguments for these models protest that the current system provides little use in the prediction of clinical course or need, and evidence suggests that dimensional models may be more effective (Peralta, Cuesta, Giraldo, Cardenas, & Gonzalez, 2002; van Os et al., 1996).

### **1.1.13 Power Threat Meaning Framework**

A more recent advance to understanding mental health experiences comes from The Power Threat Meaning framework (PTM; Johnstone & Boyle, 2018). The PTM was developed in collaboration between professionals and service-users as an alternative framework to understanding distress (Johnstone & Boyle, 2018). This framework is built on the assumption that mental health experiences are caused by life experiences, and it attempts to draw together different models rather than subscribing to one approach. A core tenant of the framework is that “threat responses” (viewed as symptoms under the medical model) were once meaningful and adaptive to survival and can be understood when taken in the context of a person’s life experiences. This framework has however come under significant criticism from various sources who question its applicability, and claim it merely replaces psychiatric diagnosis with psychological concepts, whilst failing to provide any useful means to address social justice issues (Recoveryinthebin, 2018a, 2018b).

## **1.2 The history of psychosis and schizophrenia**

The dominance of medical conceptualisations of psychosis can be understood with reference to the historical development of the diagnosis of schizophrenia. The current diagnostic system draws heavily from the work of Emil Kraepelin and Eugen Bleuler. The concept of schizophrenia was first described by Emil Kraepelin in the 19<sup>th</sup> century. From his longitudinal studies, Kraepelin observed common patterns of symptomology and course, which had been observed by other physicians at the time, but not yet integrated into a unitary category. He drew together these varying pictures of symptomology and termed it “dementia praecox” (Kraepelin, 1919). Building on this, Kraepelin identified nine types of dementia praecox which demonstrated varying

patterns of symptoms and deterioration (Kraepelin & Walter, 1915). At the time of his work, Kraepelin recognised the variation in presentations among individuals diagnosed under this category, and nearing the end of his work he alluded to the possibility that his categorisations may have been incorrect (Read, 2013b).

Building on the work of Kraepelin, Eugen Bleuler (1857-1939) renamed the disorder “schizophrenia” (etymologically Greek meaning, “splitting of the mind”) and incorporated additional forms that did not result in the same level of deterioration as previously described by Kraepelin (Read, 2013b). Bleuler felt that schizophrenia was not an illness, but better described a group of illnesses, and was the first to make the distinction between positive and negative categories of symptoms which are still utilised today (Jablensky, 2010; Read, Perry, Moskowitz, & Connolly, 2001).

In contrast to the work of Kraepelin and Bleuler, Karl Jaspers explored a phenomenological approach to psychosis and suggested that the experience of psychosis stemmed from real life experiences that were “non-understandable” (Jaspers, 1913). His work took a more person-centred stance which focused on processes of meaning making and self-interpretation (Stanghellini, Bolton, & Fulford, 2013). This person-centred view of psychosis however was somewhat side-lined due to the dominance of the medical model and biological explanations of psychosis.

Over the decades that followed, clinicians continued to expand and re-define the varying pictures of the psychosis, with later conceptualisations suggesting a spectrum disorder or classifying it as either Type I or Type II (Baron & Risch, 1987; Chapman & Chapman, 1980; Crow, 1980). These theories were driven by ideas of underlying

biological and genetic factors along with research suggesting that relatives of those who experience psychosis have an increased likelihood of developing mental health issues themselves (Kallmann, 1938).

Since this period, a large proportion of schizophrenia research has followed in this same vein, exploring genetic components, the role of chemical imbalances and neurotransmitters, and genome-wide association research (Cooke, 2017).

Schizophrenia is arguably considered the most heritable or biologically based of the mental health diagnoses and this no doubt results from the historical development of the concept (Read et al., 2001).

### **1.3 Who experiences psychosis?**

Approximately 10% of people report the experience of hearing a voice when there is no one there at some point during their lifetime (Johns et al., 2014). However, voice hearing is not limited to psychosis and is reported in other severe mental health diagnoses such as borderline personality disorder, bipolar, depression and dissociative disorders (Goodwin & Jamison, 2007; Lattuada, Serretti, Cusin, Gasperini, & Smeraldi, 1999; Ross, Norton, & Wozney, 1989; Slotema et al., 2012). Individuals may hear one voice or many, and often the identity of the voice is known to the individual experiencing it (Bentall, 2013). What has been found to be most important is the individual's attitude towards the voice (Bentall, 2013).

About 1 in 100 people in the UK population will be diagnosed with psychosis during their life time. (Cooke, 2017). The duration of psychosis experiences varies, and is dependent on a multitude of factors. It is suggested that about half will recover completely in terms of symptom remission, while a small number are reported to be likely to continue to experience difficulties and may need on-going support from

services (Cooke, 2017; Slade, Amering, & Oades, 2008). However, despite the continuation of psychosis experiences many people can live fulfilling lives (Cooke, 2017).

### **1.3.1 Age and gender differences**

The average age of on-set for men is suggested to be between 18-24 years, and for women between 25-30 years (Read & Beavan, 2013). Research often indicates a higher incidence of psychosis in men, however some research has indicated similar rates between the sexes (Bogren, Mattisson, Isberg, Munk-Jørgensen, & Nettelbladt, 2010; Kirkbride et al., 2006, 2012). The course of incidence of psychosis has been found to decline in both sexes from mid-twenties, with women experiencing a secondary peak after midlife (Kirkbride et al., 2012). Additionally its suggested that men tend to experience more cognitive deficit and have a worse prognosis in terms of response to medication, symptom remission, and impact on social functioning, again there are numerous explanations for these reported differences (Sajatovic, Jenkins, Strauss, Butt, & Carpenter-Song, 2005; Schön, 2013; Read & Beavan, 2013).

### **1.3.2 Poverty and social inequality**

It is now a well-established finding that people who experience poverty and social inequality are more likely to be diagnosed with schizophrenia (Harrison, Gunnell, Glazebrook, Page, & Kwiecinski, 2001; Read, 2010). A combination of factors such as discrimination, lack of power and access to resources, along with issues around social status, play a causal role in this link (Read, Johnstone, & Taitimu, 2013). This association is even more pronounced for relative poverty, that is, rates of mental health difficulties are higher in societies with a greater disparity between the rich and the poor, when compared with an equally poor society (Wilkinson & Pickett, 2010).

However, critics of this study have contested their methodology in regards to the measurement of inequality, the studies and countries included, and the interpretation and reporting of findings, suggesting their account of relative poverty and mental health is misleading (Saunders, 2011; Simic, 2012).

### **1.3.3 Urbanicity**

Studies have consistently found a correlation between urban living and psychosis, with the risk of developing psychosis increasing with years spent living in an urban area (Lewis, David, Andréasson, & Allebeck, 1992; Pedersen & Mortensen, 2001). The impact of which is reported to be stronger than having a mother with psychosis (Mortensen et al., 1999). The mediating factors in this relationship are linked with poverty, crime, stress, isolation, overcrowding and pollution (Sharpley, Hutchinson, Murray, & McKenzie, 2001)

### **1.3.4 Ethnicity**

Another commonly reported finding is the increased rates of schizophrenia in ethnic minorities when compared with members of the dominant culture (Fernando, 2003; Kirkbride et al., 2012; Read, 2004). A study in Britain found diagnoses of schizophrenia were nine times higher for Black African populations compared with White British (Fearon et al., 2006). Opinions differ in explaining these differences, with proponents of the medical model suggesting a biological basis. However, it is thought that these differences again come down to issues of social inequality, discrimination and poverty, along with biases in treatment and diagnostic practices (Read, Johnstone, & Taitimu, 2013). What appears most important is having the experience of being a minority, as there is no evidence to suggest higher rates of schizophrenia in dominant black populations. (Kirkbride et al., 2012).

These findings suggest that psychosocial factors such as inequality and discrimination play a role in the development of psychosis. This adds further weight to the consideration of alternative models to understanding psychosis, which emphasise the role of environmental, psychological and social influences in addition to biological factors.

## **1.4 Models of psychosis**

Despite, the long history of understanding psychosis as resulting primarily from biological factors, there are now many alternative models of understanding the development of psychosis. A critical review of how psychosis is thought to develop from different models of explanation will allow an in-depth understanding of the aetiology of psychosis.

### **1.4.1 Biomedical model of psychosis**

#### **Genetics**

Research has suggested a genetic basis to psychosis, with the tendency for psychosis experiences to run in families (McGuffin, Asherson, Owen, & Farmer, 1994).

However, it is argued that the effect size may be much smaller than initially assumed (Torrey, 1992). Further, suggestions have been made that genetic predispositions for mental health are not disorder specific, but instead are for a general “mental health” predisposition, e.g. tendency towards emotionality (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013; Hamshere et al., 2013; Lichtenstein et al., 2009). However, this research has been the subject of much debate due to questions relating to methodology and difficulties with replication of findings (Crow, 2008).

Further research suggests that it is the combined influence of genes and the environment, rather than either in isolation that is important when considering the

development of psychosis (Van Os, Rutten, & Poulton, 2008). A systemic review found evidence for both genetic and environmental factors and suggested that genetic risk factors lead to an increased sensitivity to environmental stressors (Svrakic, Zorumski, Svrakic, Zwir, & Cloninger, 2013). The study of epigenetics suggest that certain genes can be “turned on or off” in response to the environment, therefore the inheritance of such a gene is insufficient to cause schizophrenia without the presence of additional environmental factors (Champagne & Curley, 2009; Read, Bentall, & Fosse, 2009). What remains clear is that separating genetics from environmental factors is a complex task, therefore currently no definitive conclusions are drawn.

#### **1.4.2 The Stress-Vulnerability Model**

The Stress-Vulnerability model of schizophrenia proposed by Zubin and Springer (1977) suggests a bio-psycho-social integration of risk factors that in combination, may increase the likelihood of developing psychosis. This model however was inaccurately adopted to mean that there is a biological vulnerability and that psychological or social factors could trigger the onset of this underlying biological predisposition (Read, Fink, Rudegeair, Felitti, & Whitfield, 2008). Despite this misinterpretation, what Zubin and Springer (1977) actually suggested was that the vulnerability could exist in any three of these domains, not just the biological.

This bias towards a medicalised view of mental health has been replicated within the research community, with an undue amount of attention over the subsequent years being paid to biological factors (Read et al., 2008). Over the past decade this restricted view has shifted, with an increasing amount of research considering the social and environmental determinants of mental health. Resulting from this is the

recognition of the role that psychological, social and environmental factors play in the development of psychosis experiences.

### **1.4.3 Childhood adversity and psychosis**

Childhood adversity has been implicated as a causal factor in the development of mental health difficulties (Mullen, Martin, Anderson, Romans, & Herbison, 1993; Read, 1998; Read, Agar, Barker-Collo, Davies, & Moskowitz, 2001). This too is true of psychosis. A meta-analysis found those who experienced childhood trauma were 2.8 times more likely to experience psychosis (Varese et al., 2012). Research indicates a dose response, with the likelihood of experiencing psychosis increasing as the number or severity of abuse experiences increases (Janssen et al., 2004; Varese et al., 2012). Shevlin, Dorahy, and Adamson (2007) reported that those who experienced one form of abuse were 1.7 times more likely to experience psychosis, this rose to 18 times more likely for three types of abuse, and 193 times more likely for five adverse events. Research considering childhood adversity and psychosis has found 42% of women and 28% of men diagnosed with psychosis had experienced sexual abuse, similar rates have also been reported for experiences of physical and emotional abuse, neglect, bullying and parental loss (Morgan & Fisher, 2007; Read, 2013c). Additionally, for large proportions of individuals, the content of experiences such as hallucinations are linked with the trauma experience (Hardy et al., 2005; Honig et al., 1998). In their influential review, Read, van Os, Morrison and Ross (2005) concluded that “Child abuse is a causal factor for psychosis and schizophrenia”. This remains contested by some subscribers to the biological model, who argue that the childhood trauma model of psychosis is synonymous with the “parent blaming” of the 1960s (McGuffin, 2006). Additionally, critics of this view contest the number of studies indicating a causal role and suggest that methodological

limitations have led to overinterpretation of findings, indicating that more research in this area is needed (Morgan & Fisher, 2007).

Numerous mechanisms have been suggested to explain the causal link between childhood adversity and psychosis. Research has provided an explanation for the role of cognitive processes, dissociation, psychodynamic defences, attachment, coping responses and social withdrawal in the development of psychosis resulting from such experiences (Read, 2013c).

#### **1.4.4 Traumagenic Neurodevelopmental Model**

It is now understood that the experience of trauma itself can alter the function or structure of the brain, which may well account for the brain differences observed in people who have a diagnosis of psychosis (Read et al. 2001). For years the discovery of these differences was incorrectly assumed to be the cause of mental health difficulties, with little attention paid to the circumstances in which they arose.

The Traumagenic Neurodevelopmental Model of Psychosis (Read et al. 2001) suggests that the experience of early trauma leads to neurodevelopmental changes in the brain which lead to the sensitivity to stress often reported in schizophrenia. They report that the structural and functional brain abnormalities discovered in those who experience psychosis when compared with “healthy” controls correspond to those present among children who have been traumatized and those who have not. They conclude that changes in areas of the brain that regulate responses to stress, characteristically found in psychosis, are the result of trauma rather than a biological inheritance.

### **1.4.5 Psychodynamic Model of psychosis**

The psychodynamic approach to understanding psychosis is centred on gaining an understanding of the meaning of psychosis experiences in the context of the individual's life (Koehler, Silver, & Karon, 2013). Building on Klein's model of internal object relations (Klein, 1948) Kleinian psychoanalysts believe psychosis results from a "defence against overwhelming annihilation and persecutory anxiety" (Koehler, Silver & Karon, 2013). Koehler, Silver and Karon (2013) stress the importance of gaining an understanding of both the conscious and unconscious meanings PWP give to their experiences in the context of their life history. They explain that despite the heterogeneity of presentations in psychosis, the underlying common thread is the protection of oneself from unbearable experiences. They suggest the defences used by PWP, protect them through altering their experience of reality.

From a psychoanalytic perspective, psychosis is understood as a reaction to the stress of a person's life. The conscious and unconscious meanings ascribed to experiences shape the magnitude of stress produced, which is buffered by the quality of support received from others. The individual's internal world, shaped by their early experiences, determines how one relates to themselves and others and thus influences the meanings ascribed to experiences. These personal meanings further shape the way one experiences others and the world around them, and thus defences against these experiences form. Through this view, seemingly meaningless psychosis symptoms are viewed as meaningful responses to intolerable experiences. At the heart of the psychodynamic understanding of psychosis is an appreciation of the centrality of an individual's early experiences and life history (Koehler, Silver, & Karon, 2013).

#### **1.4.6 Cognitive Model of psychosis**

Garety, Kuipers, Fowler, Freeman, and Bebbington (2001) suggest a cognitive model of positive symptoms. This model posits that adverse events or experiences lead to a disruption in cognitive processing, whereby the impact of memory processes linked with previous input on perceptual experience are weakened. This is coupled with memory intrusions of unintended material, leading to a sense of unfamiliarity of cognitive and mental processes, which subsequently impact on emotional experience. It is suggested that these disturbances lead to experiences such as racing thoughts, thoughts experienced as voices, and thoughts appearing to be broadcast. Freeman, Garety, Kuipers, Fowler, and Bebbington (2002) suggest that in the process of searching for meaning, an individual's conclusions are influenced by pre-existing beliefs and anxiety which are likely influenced by early experiences, along with cognitive biases.

Research has found evidence for the role of cognitive biases in psychosis experiences. PWP are more likely to jump to conclusions and attribute negative events to external causes (particularly to other people) than those not reporting these experiences (Bentall, 2013; Bentall, Kinderman, & Kaney, 1994; Huq, Garety, & Hemsley, 1988; Wallcraft & Bryant, 2003). Research has also found that individuals lose "Theory of Mind" during psychosis and are therefore less able to guess the mental state of others (Bentall, 2009; Sarfati, Hardy-Baylé, Besche, & Widlöcher, 1997). Furthermore, the experience of auditory or visual hallucinations has been suggested to be linked with poor source monitoring where individuals misattribute their own inner voice to an external source, and discrimination difficulties where individuals fail to discriminate between visual and mental imagery (Bentall, 2013).

### 1.4.7 Systemic theories of psychosis

The role of the family in relation to the experience of psychosis has predominantly focused around the concept of high “expressed emotion” and the link with relapse (Read & Seymor, 2013). Expressed emotion refers to the family’s attitude and response to a person who experiences psychosis and is thought to comprise three components; hostility, criticism, and emotional over involvement (Vaughn & Leff, 1976). A review by Kavanagh (1992) reported relapse rates of 48% in families considered to be high in expressed emotion, and 21% for those low in expressed emotion. The impact of which, is thought to be around an increased level of stress experienced by the PWP and the increased processing of negative information (Cutting, Aakre, & Docherty, 2006; Rylands, McKie, Elliott, Deakin, & Tarrier, 2011). Less research has considered the role of high expressed emotion in the development of psychosis, however a causal role has been suggested (Goldstein, 1987).

Other systemic theories of schizophrenia come from Bateson, Jackson, Haley, and Weakland (1956). Bateson et al. (1956) came up with the Double-Bind theory of schizophrenia and suggested that schizophrenia was caused by the repeated experience of receiving conflicting messages from the same caregiving figure. Schizophrenia is suggested to develop as a response to Double-Bind experiences where there is no means for the individual to escape or question the Double-Bind. Since its development however, Bateson’s theory has been criticised as lacking evidence and being unresearchable (Abeles, 1976; Olson, 1969).

Additional systemic theories have focused on patterns of *Affective Style* and *Communication Deviance* (Read & Seymour, 2013). Affective Style refers to interactional styles centred around guilt induction, intrusiveness, and criticism,

whereas Communication Deviance refers to interactional styles where the establishment of shared meaning is difficult or impossible. Both have been implicated in relapse in psychosis (Diamond & Doane, 1994; Velligan, Miller, Eckert, Funderburg, & True, 1996). The UCLA Family Project found that individuals who came from a family with a negative Affective Style or a family that was high in Communication Deviance were more likely to have a diagnosis of schizophrenia at the 15 year follow up (Goldstein, 1987). Although there has been much debate over whether these family patterns are causal or consequential of psychosis, it is clear that family interactions have a role to play in psychosis (Read & Seymour, 2013).

#### **1.4.8 Summary of models of psychosis**

Despite the continued tendency for psychosis to be thought about as an illness and discussed in conjunction with terms such as “brain disease” or “neurological disorder”, exploration of alternative models of psychosis suggests many other contributing factors (Chua & McKenna, 1995; Crow et al., 1979). The continuation of misconceptions of psychosis as being progressive, non-remitting, and due to a biologically “diseased” brain, no doubt stem from the historical development of the concept (Kraepelin, 1919). However, in terms of the biological basis for psychosis, there has been much debate over the extent to which genes or neuro-circuitry play a role and the evidence suggests that the influence of environmental factors is of equal importance (Read et al., 2009; Svrakic et al., 2013). Exploration of the current models of understanding psychosis development suggest a role for environmental, psychological, systemic and biological factors. A common thread across many of these models is the experience of adverse life events or trauma and following which many other factors may be implicated in the maintenance and development of psychosis experiences (Garety et al., 2001; Koehler, Silver, & Karon, 2013; Read et

al., 2009; Read, Perry, Moskowitz, & Connolly, 2001; Varese et al., 2012).

Therefore, psychosis may be best understood as resulting from a culmination of many different factors, rather than a reliance on one sole model of explanation.

## **Part II Recovery**

### **1.5. What is Recovery?**

Once considered an unlikely outcome, for many service-users recovery from psychosis is now an achievable aim (Kelly & Gamble, 2005).

*“Recovery is a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”* (Anthony, 1993, p. 527).

The concept of “recovery” is multifaceted, meaning different things to different people (Le Boutillier et al., 2011). The renewed focus on recovery in mental health has led to recovery being defined, measured, and enacted in a multitude of ways. An exploration of how recovery is conceptualised and understood from different perspectives will aid in understanding current thinking regarding recovery from psychosis.

In defining recovery, distinctions are sometimes drawn between *clinical recovery* and *personal recovery* (Slade et al., 2008). Clinical recovery, which operates within an illness framework, sees recovery as a dichotomous state where one is either classified as “ill” or “recovered” lending itself to clinical trials, quantitative research, and

prevalence studies. Clinical recovery may also be viewed in conjunction with some level of functional improvement such as, returning to work/education (Bellack, 2006; Slade et al., 2008). This conceptualisation of recovery is focused around the presence or absence of symptoms, periods of “remission” and “relapse”, and tends to be adopted by medical professions (Law & Morrison, 2014).

Personal recovery, described above by Anthony (1993), emerged from the survivor movement which saw the emergence of service-user’s personal accounts of illness and recovery. Personal recovery is synonymous with narratives of “living well with...” suggesting that one can live a socially, functionally and emotionally fulfilling life even in the presence of continued mental health experiences. This model of recovery is generally favoured by service-users, as research has demonstrated that few service-users view their recovery as purely symptom related, and many report being able to cope better with symptoms and reduce the impact on daily life as important, rather than complete remission (Law & Morrison, 2014). The personal model depicts recovery as a journey, and aims to encapsulate a more optimistic and less stigmatising view of mental health. It centres around utilizing personal strengths and is built on the premise that although individuals may not have full control over their mental health experiences, they can take control in other areas of their life (Bonney & Stickley, 2008; Jacob, 2015). This movement from a purely clinical to a personal conceptualisation of recovery has been fuelled by the survivor movement and qualitative research into service-user’s experiences of recovery.

### **1.5.1 The Survivor Movement**

The survivor movement, which rose out of the civil rights movement in the 1960s and 1970s saw the emergence of voices and stories from those who had long been

oppressed in society through mental or physical difficulties (Chamberlin, 1990). Service-users who had been locked away in mental health hospitals, subjected to the practices of psychiatry and labelled as ill (and often untreatable), spoke out about the harsh realities of the cruel practices of psychiatry, but from this harsh terrain stemmed stories of recovery (Pilgrim, Rogers, & Pescosolido, 2010). Voices emerged from people who were surpassing their diagnostic prognosis and living fulfilling lives, despite their experiences in psychiatric care (Kelly & Gamble, 2005). This movement pathed the way for new perspectives on mental health to develop and posed significant challenges for the dominant model of psychiatry (Frese & Davis, 1997; Menzies, LeFrançois, & Reaume, 2013). The recovery movement encapsulates a transition from people being prisoners of illness and psychiatric hospitals, at the mercy of powerful professionals, to being consumers where services are set up to meet their needs (Braslow, 2013). This new perspective of recovery allowed a more hopeful view of mental health, and thus recovery increasingly became a possible aim for both service-users and services alike.

### **1.5.2 Recovery and psychosis**

Studies exploring the subjective experience of recovery from psychosis have emphasised social support, engagement in meaningful activities, and regaining independence along with personal factors such as acceptance and developing an understanding of experiences (Connell, Schweitzer, & King, 2015; Lam et al., 2011; Windell & Norman, 2013). Research exploring recovery from psychosis describes it as a gradual and staged process. Pitt et al. (2007) described three stages of recovery which include: rebuilding the self, rebuilding life, and hope for a better future. Moving through these stages involves making meaning of experiences, building self-esteem, and creating a purpose in life, along with building relationships with friends

and family, and working collaboratively with professionals. Also highlighted in this process are the negative influences on recovery such as social exclusion, discrimination, and stigma (Pitt et al., 2007). A recent systematic review exploring service-users experiences of recovery from psychosis highlighted additional barriers to recovery such as substance use, social deprivation, and negative experiences of care (Wood & Alsawy, 2017). In contrast factors reported as helpful in this process included having hope, access to resources, receiving quality care, engagement in social relationships and religion/spirituality (Wood & Alsawy, 2017). Recovery from psychosis has been described as an idiosyncratic and non-linear process with movement in both directions between stages (Yarborough, Yarborough, Janoff, & Green, 2016).

### **1.5.3 Social recovery and psychosis**

The experience of psychosis often has a detrimental impact on social functioning, with social recovery outcomes often reported to be poor (Fowler, Hodgekins, & French, 2017; Harrison, Croudace, Mason, Glazebrook, & Medley, 1996). Social functioning refers to areas such as relationships, engagement in meaningful activities, and employment and these are often negatively impacted when people experience psychosis (Hodgekins et al., 2015). It has been suggested that achieving social recovery may be even less likely than symptomatic recovery for PWP, with males and ethnic minorities at an increased risk (Hodgekins et al., 2015). Specific interventions which target social functioning have been developed to support PWP with social recovery (Fowler et al., 2017).

#### **1.5.4 Recovery in the NHS**

The Department of health's "Implementing Recovery through Organisational Change" program was set up in 2008 to guide services in being supportive of recovery for mental health service-users (Shepherd, Boardman, Rinaldi, & Roberts, 2014a). Research stemming from this initiative led to the establishment of key recovery principals and the suggestion for organisational changes necessary to meet these aims (Boardman & Friedli, 2012; Phillips, Sandford, & Johnston, 2013; Repper et al., 2013; Shepherd, Boardman, & Burns, 2010; Shepherd et al., 2014a; Shepherd, Boardman, & Slade, 2008). The Centre for Mental Health reported "quality indicators for supporting recovery", which centred around creating a recovery orientation in services and included a specific focus on relationships between staff and service-users, along with improved working practices (Shepherd, Boardman, Rinaldi, & Roberts, 2014). These initiatives focus on enhancing hope and optimism, promoting a sense of agency and the introduction of practices such as shared decision making, person-centred care, and self-management. Additionally, this document identified approaches to support recovery that were not addressed through the recovery orientation. These included the "housing first" approach, "individual placement and support" and the introduction of "personal budgets"; which are methods of supporting those with mental health difficulties in securing finance, housing and employment (Shepherd et al., 2014). These methods offer alternatives to traditional support systems, however they have not yet been widely implemented, despite research supporting their efficacy (Alakeson & Perkins, 2012; Burns et al., 2007; Padgett, Gulcur, & Tsemberis, 2006).

Recovery orientated services largely align with a personal model of recovery and include practices such as peer support workers, the promotion of self-help, and tools

such as the Wellness Recovery Action Plan (Copeland, 2002) and the Recovery STAR (McKeith, Burns, Onyemaechi, & Okonkwo, 2010) to be used with service-users in helping to identify goals and create plans to stay well (Repper et al., 2013; Shepherd et al., 2014).

The incorporation of recovery ideology into mental health services has seen a shift away from paternal models of care to a more collaborative approach through the introduction of new forms of support such as recovery colleges (services that offer psychoeducational courses that teach self-help and coping skills designed to promote recovery), peer support workers (ex-service-users employed to promote and support recovery in others) and community treatment orders (sanctions placed on individuals to obtain compulsory treatment in the community following discharge from psychiatric inpatient care). This alteration in service delivery within the NHS, designed to support individuals towards recovery, has become increasingly contested over recent years ('RITB – 20 Key Principles', 2016).

## **1.6 Criticism of the Recovery Model**

The renewed focus on recovery in mental health has led to disagreements both in terms of how recovery approaches should be implemented and about what the term recovery means. Research has suggested that service-users and providers view recovery as having different meanings and the way that recovery is utilized both within services and by the government has been challenged (Bonney & Stickley, 2008; McWade, 2016).

### **1.6.1 Individualistic nature of the Recovery Model**

Critics of the dominant recovery model have argued against its individualistic nature, suggesting that the conceptualisation of recovery as a “deeply personal” process

places the onus of getting better on the individual (Harper & Speed, 2012). It is argued that this model suggests that people who experience mental ill health must go on a journey where they can re-establish their life goals, gain a sense of personal meaning, and generate hope for their future, with social relationships enhancing the personal journey (Price-Robertson, Obradovic, & Morgan, 2016). Price-Robertson et al. (2016) argue this view creates a fictitious boundary between what happens within the individual and the external context. They suggest that the recovery model is grounded in ideas of individualism at both a cultural and philosophical level, favouring personal traits such as self-achievement and independence, with the ideal position being to use one's own resources to overcome adversity and function independently. Cross cultural application of the recovery model has proved it as insufficient in collectivist cultures (Jacobson, Farah, & the Toronto Recovery and Cultural Diversity Community Practice, 2010). In response, Jacobson and Farah (2012) produced the "culturally responsive model of recovery" which incorporates a greater emphasis on systems of oppression and familial and social relationships.

### **1.6.2 Culturally Responsive Model of Recovery**

The culturally responsive model of recovery views systems of oppression and privilege, history, culture, and the social determinants of mental health as central to recovery (Jacobson & Farah, 2012). It suggests that mental health services can provide support to this network but are not integral to it. This model also acknowledges the fundamental role of policy, socio-political factors and the role of the family and community, explaining that these systems have an impact upon supporting recovery and enhancing resilience, or hindering it and causing vulnerability. At the individual level the model encompasses healing, empowerment,

hope and connection, but recognises that these individual factors do not occur in isolation to the wider network of systems one operates within.

### **1.6.3 Social Recovery Model**

Mezzina et al. (2006) discuss the social nature of recovery and challenge the notion that recovery is an internal process. They argue that relationships are integral to recovery rather than acting to support an internal process. They suggest five areas which are central to recovery; the personal sphere, interpersonal sphere, community arenas, material resources, and a sense of belonging. They argue that mental health services have a duty to provide support that addresses all these domains, not just the personal sphere and advocate for a movement away from “fixing” people and toward eliminating barriers, enhancing opportunities, and improving access to resources. The social underpinnings of recovery are particularly pertinent to PWP who have been hospitalised, due to the impact of psychosis on social functioning, and with hospitalisation constituting a movement away from the social network (Quirk & Lelliott, 2001; Topor, Borg, Di Girolamo, & Davidson, 2011).

### **1.6.4 The political landscape of recovery**

Under the government of Tony Blair and the Labour Party, the NHS saw a so called “modernisation” through the NHS reforms which were set out in “the NHS plan” published by the Department of Health (DoH; Department of Health, 2000). This document explained that the current NHS was failing to empower service-users, lacked incentives to improve care and was over centralised. The NHS plan aimed to increase the quality of service-user centred care and reduce waiting times (DoH, 2000). A further document, “The Journey to Recovery” was published and set out details of changes made to mental health policy (DoH, 2001). This document depicted

a bleak history of mental health services and set out a promising plan for the future, appearing to encapsulate the language of the recovery movement through use of words such as “empowering service-users” and ideas around reducing stigma and addressing difficulties to access of treatment in Black, Asian and minority ethnic groups.

### **1.6.5 Recovery as policy**

However, it is argued that these policies saw the Labour government take ownership of the ideas and insights brought about by activists involved in the recovery/survivor movement, and function to silence the challenges brought about by this movement (McWade, 2016). McWade argues that many of the changes made under the labour government were extensions of old practices, under new names, continuing to empower psychiatry rather than service-users, for example through promoting individualistic narratives and framing distress as illness. These views are echoed by proponents of *Mad Studies* who work to challenge and expose “the systemic and symbolic violence that lie at the core of the psychiatric system” and propose models of care that “are based on humanitarian, holistic perspectives where people are not reduced to symptoms but understood within the social and economic context of the society in which they live” (Menziés et al., 2013).

### **1.6.6 Recovery and neoliberalism**

It is argued that the promotion of mental health as an individual process intrinsically draws on ideas of mental ill-health as resultant from poor self-management, irresponsibility and burden, and serves neoliberalist aims through the establishment of the responsible, hardworking tax payer which can be freed from the burden of the irresponsible-ill, through the marketization of services (Gillies, 2005; Jensen & Tyler,

2015). It is suggested that individualistic approaches present ways to reduce costs by providing rationale for the cutting of welfare benefits, services, and skilled staff, therefore neatly fitting with austerity measures (Rose, 2014; Winship, 2016). After all, if recovery is a personal experience what role is there for the state?

### **1.6.7 Social and structural inequalities**

Further criticism of the recovery model argues that it fails to address the fact that marginalised individuals, through race, disability or socio-economic status, attract a larger number of diagnoses and are over represented in services (Howell & Voronka, 2012). Howell and Voronka (2012) suggest that mental health systems promoting the development of “resilience” are not only cheap, through the introduction of self-help as a treatment, but also serve to divert attention away from the real causes of distress, such as social inequality.

There is now a substantial amount of research that demonstrates how social inequalities such as homelessness, racism and poverty, serve to intensify, create, and maintain emotional distress, and how certain groups of people (e.g. Black, Asian, minority ethnic, women, sexual and gender minorities and those living in poverty) are more likely to become pathologised as a result of psychiatric practices (Baker & Bell, 1991; Caplan, 1995; Edidin, Ganim, Hunter, & Karnik, 2012; Gore & Aseltine, 2003; Hatzenbuehler, McLaughlin, & Nolen-Hoeksema, 2008; Jarvis, Toniolo, Ryder, Sessa, & Cremonese, 2011; Metzl, 2010; Ussher, 2011; van Os, Kenis, & Rutten, 2010; Weisz & Quinn, 2017). Of particular note is the well-established finding that black men are disproportionately diagnosed with schizophrenia, disproportionately admitted to hospital due to schizophrenia, disproportionately sectioned, and disproportionately under community treatment orders (House of Commons Health

Committee, 2013; Metzl, 2010; Pilgrim & Tomasini, 2012; Snowden & Cheung, 1990).

### **1.6.8 Social justice response**

Groups advocating for social change in response to the socio-political determinants of mental health, such as ‘Psychologists for Social Change’, have suggested that cuts to benefits and public services through austerity measures impact on mental health through increasing fear, instability, powerlessness, shame and isolation (McGrath, Walker, & Jones, 2016). McGrath et al. (2015) argue that while increased funding into mental health services is welcomed, policy makers must consider the wider economic and social determinants of mental health along with the psychological costs of current and future policies. They argue for the creation of social and economic equality through policy change and the creation of systems and services that work to support those in need rather than punish and humiliate (Psychologists for Social Change, 2017).

### **1.6.9 Social justice view of recovery**

In response to the issues highlighted above, and in opposition to the traditional view of recovery as adopted by services, the service-user group *Recovery in the Bin* created the social justice tool the *Unrecovery Star* (Recovery in the Bin, 2016). This tool was created in response to the more traditional tool used in recovery services *the Recovery Star* which they argue draws on neoliberalist and individualistic notions of recovery, which are seen to promote the reduction of government spending and austerity measures and favour independence and self-achievement. The *Unrecovery Star* highlights social inequalities that lead to mental distress such as poverty, racism, and

issues relating to housing and benefits, providing an alternative view of factors pertinent to recovery and distress.

#### **1.6.10 The Dimensional Model of recovery**

In response to the multitude of views held about recovery Whitley & Drake (2010) propose a dimensional model of recovery. Their model includes five dimensions of recovery: clinical, existential, functional, social, and physical. Their aim was to produce a framework which takes a more holistic approach to recovery drawing upon multiple definitions and sources of support. For example, existential recovery may include religious and spiritual factors and support may come from religious leaders, whereas functional recovery may relate to issues with housing and employment, with support coming from housing and employment specialists.

### **Part III Inpatient Setting**

#### **1.7. Inpatient setting**

The current study is centred on the experience of recovery for an inpatient population. The provision of mental health care in the UK has evolved over many years and moved through phases of mass institutionalisation to current drives to provide more “care in the community”. The history of mental health care provision is explored to aid in understanding the current climate of inpatient care in the UK.

##### **1.7.1 Institutionalisation**

Mental health care in the UK has moved through numerous paradigms which have altered the landscape for inpatient care. In the 19<sup>th</sup> century industrialised countries such as the UK saw the construction of large scale asylums designed for the care of the mentally and physically unwell through a process of institutionalisation. By the 1900s large numbers of people considered to be unable to function in the community

for physical or mental health reasons were being held and “treated” in these establishments (Fakhoury & Priebe, 2007).

### **1.7.2 Eugenics movement**

During this period the eugenics movement began to take shape, which comprised the compulsory sterilisation of individuals possessing so called “tainted genes” (Read & Masson, 2013). This movement was fuelled by the theory that mental disorders have a biological and heritable basis, and led to the sterilization of around 400,000 people, of which approximately one third were considered to have schizophrenia (Torrey & Yolken, 2009). In the late 1930s sterilization led to mass murder, and in Europe hundreds of thousands of people with mental health disorders were killed, again a large proportion of these were PWP (Read & Masson, 2013).

### **1.7.3 Deinstitutionalisation**

Following from the eugenics movement and institutionalisation, reports of overcrowding, poor levels of care and unacceptable conditions in asylums led to their closure in the 1950s (Fakhoury & Priebe, 2007). The 1960s saw continued closure of large scale hospitals making way for smaller discrete units which were established around the 70s and 80s. This reduction in beds pathed the way for an increasing focus on community treatment and people living and being treated in their own homes, and was driven by the DoH’s 1989 white paper document “Caring for People: Community care in the next decade and beyond” (DoH, 1989; Quirk & Lelliott, 2001).

### **1.7.4 Care in the community**

In the UK community service provision has increased with the addition of early intervention and assertive outreach teams, alongside a decrease in the number of

hospital beds available (Priebe et al., 2005). Research has suggested that the provision of community care has not matched the demand created by the reduction in hospital beds (Lelliott, 1996). It is suggested that a process of re-institutionalisation is beginning to take place in some countries with the number of forensic beds, involuntary admissions, and number of places in supported housing increasing (Priebe et al., 2005). It is arguable whether these changes represent a process of re-institutionalisation or the mere movement of people from one setting to another (Priebe et al., 2005).

### **1.7.5 Current inpatient climate in the NHS**

These changes have a huge impact on inpatient care. Under the current austerity measures, inpatient provision in the UK has seen a loss of over 1700 beds (Moth, Greener, & Stoll, 2015). Critics have argued that the recovery agenda of increasing resilience and personal responsibility for mental health is a response to this lack of resources and is deeply intertwined with neoliberalist aims (Howell & Voronka, 2012). Despite the reduction in the number of beds, inpatient admissions have increased (Lelliott, Audini, & Darroch, 1995; Lelliott, 1996; Quirk & Lelliott, 2001). Type of admission has also changed with those being admitted more often being sectioned (under the Mental Health Act 1983), at increasingly severe levels of distress, admitted as an emergency and in a state of acute crisis (Audini, Duffett, Lelliott, Pearce, & Ayres, 1999; Lelliott, Audini, & Darroch, 1995). These changes have led to the state of “bed crisis” that is currently in play in the NHS, where occupancy rates far exceed 100%. For service-users, this means premature leave decisions and being placed in hospitals often far away from their local area (Quirk & Lelliott, 2001). These problems are of particular significance to both London based inpatient units and acute wards. Suggestions have been made that the deficiencies in

community care lead some service-users to remain in hospital despite being deemed well enough for discharge, a process that is often referred to as “bed blocking”. Further to this, acute units have been suggested to house the most “difficult” service-users and those for whom community care is inadequate (Lelliott, 1996; Muijen, 1999). This is all coupled with increasing levels of violence and sexual harassment being reported on wards and high levels of staff turnover (d’Ettorre & Pellicani, 2017; Lelliott et al., 1995; McGeorge, Lelliott, & Stewart, 2000).

## **Part IV Literature Review**

### **1.8. Literature review**

Current systematic literature reviews exploring the subjective experience of recovery from psychosis have focused primarily on community samples (Andresen, Oades, & Caputi, 2003; Jose et al., 2015; Wood & Alsawy, 2017). Those who have experience of inpatient admission are likely to have differences in experience pertaining to quality or type of care, severity of experience, and support structures. To date there has been no systematic literature review that has focused specifically on the experience of recovery from psychosis from the viewpoint of those with experience of psychiatric hospitalisation. Exploring this topic will therefore aid in understanding the unique needs of this understudied population.

#### **1.8.1 Search strategy**

A review of the current literature exploring the experience of recovery from psychosis for individuals with a history of psychiatric hospitalisation was conducted. A systematic process was applied to the literature review which involved critically assessing the methodology of included papers and a thematic meta-synthesis was

employed to synthesise findings from the articles obtained by this search (Thomas & Harden, 2008).

A combination of search terms were entered into major electronic databases (MEDLINE, psycARTICLES, psycINFO, CINAHL complete; see Table 1 for search terms). Additional searches were completed with a mixture of the same terms entered into *Google Scholar*, which produced no additional results. Searches were completed on 27<sup>th</sup> December 2017 searching all years with no date restrictions. Two recent systematic literature reviews exploring the experience of recovery from psychosis were also read and reviewed, with additional articles handpicked from the reference lists (Jose et al., 2015; Wood & Alsawy, 2017).

Table 1:

*Electronic database search terms*

Search no.	Search Terms	No. Articles
S#1 (in abstract)	psychosis or psychoses or voice* or psychotic or schiz* or delusion* or hallucination*	395,569
S#2 (in abstract)	recover*	668,274
S#3 (all text)	hospitalis* or hospitaliz* or ward or hospital or inpatient	6,754,744
S#4	S#1 & S#2 & S#3	4,098
S#5	S#1 & S#2 & S#3 + Filter Methodology: interview, focus group, qualitative study + Limited to peer review	267

Searches were limited to peer reviewed articles to ensure methodological rigour.

Filters were applied which selected studies that used qualitative methodologies; either interviews or focus groups, to yield studies presenting service-user's subjective experience of recovery from psychosis.

The searches produced a total of 267 articles which were assessed against a set of inclusion and exclusion criteria. The 267 titles were first reviewed at title, those meeting this criterion were reviewed at abstract; and then full text. The total number of articles that satisfied the inclusion and exclusion criteria at full text was 10.

### **1.8.2 Inclusion and exclusion criteria**

The inclusion criteria were (a) studies exploring recovery from psychosis from a service-user perspective; (b) with >50% of the sample having a schizophrenia spectrum diagnosis or predominance of psychosis related symptomatology as primary concern; (c) at least one member of sample reporting a history of psychiatric inpatient admission; (d) using qualitative methods of interview or focus group; (e) with >80% of the sample being aged between 18-65. The exclusion criteria were (a) a focus on some specific aspect of the recovery process rather than exploring recovery as a whole concept; (b) focus specifically on postpartum psychosis, drug-induced psychosis or organic psychosis; (c) focus on recovery in relation to (i) another specific concept (e.g. hope, post traumatic growth) (ii) a specific symptom (see Figure 1 for flow diagram of included and excluded studies).

### **1.8.3 Rationale for criteria**

Studies utilizing an inpatient sample are scarce. As such relatively loose criteria for inpatient experience was applied. Many studies do not report participant's history of inpatient admission, therefore this criterion was set with the aim of being inclusive where many studies may be omitted due to lack of reporting. Some studies detailed inpatient status as part of the demographic information, for others inpatient status was only apparent after reviewing the full text.

The aim of this review was to gain a holistic picture of the recovery process and factors associated with it from the point of view of those who have been hospitalised for mental health. As such, studies with a specific focus on either a certain aspect of the recovery process or specific symptoms were excluded. Studies with less than 50% of the sample having a schizophrenia spectrum diagnosis were excluded/ Some studies include participants with alternative diagnoses such as bipolar, therefore 50% was set as a limit in order to remain inclusive and not limit an already modest sample of studies, whilst remaining primarily focused on the experience of PWP. Further, individuals experiencing postpartum psychosis, drug-induced or organic psychosis are likely to have differing needs and experiences, therefore studies focussing solely on these populations were excluded. Qualitative methods are best placed to provide an in-depth and person-centred view of the subjective recovery process and therefore these methodologies were deemed appropriate.

The target population for this research is an adult sample and therefore adhering to this age limit in the literature review allows a more accurate comparison between findings. However, it is noted that many studies focus on first episode psychosis (FEP) or recruit from Early Intervention Services (EIP) and as such samples may include participants younger than 18. To accommodate for this, the exclusion criteria required 80% or more of the sample to be aged between 18-65, ensuring the focus remains mainly on the adult population without restricting studies that include some younger service-users.

Figure 1. Flow diagram for inclusion and exclusion of articles in literature review.

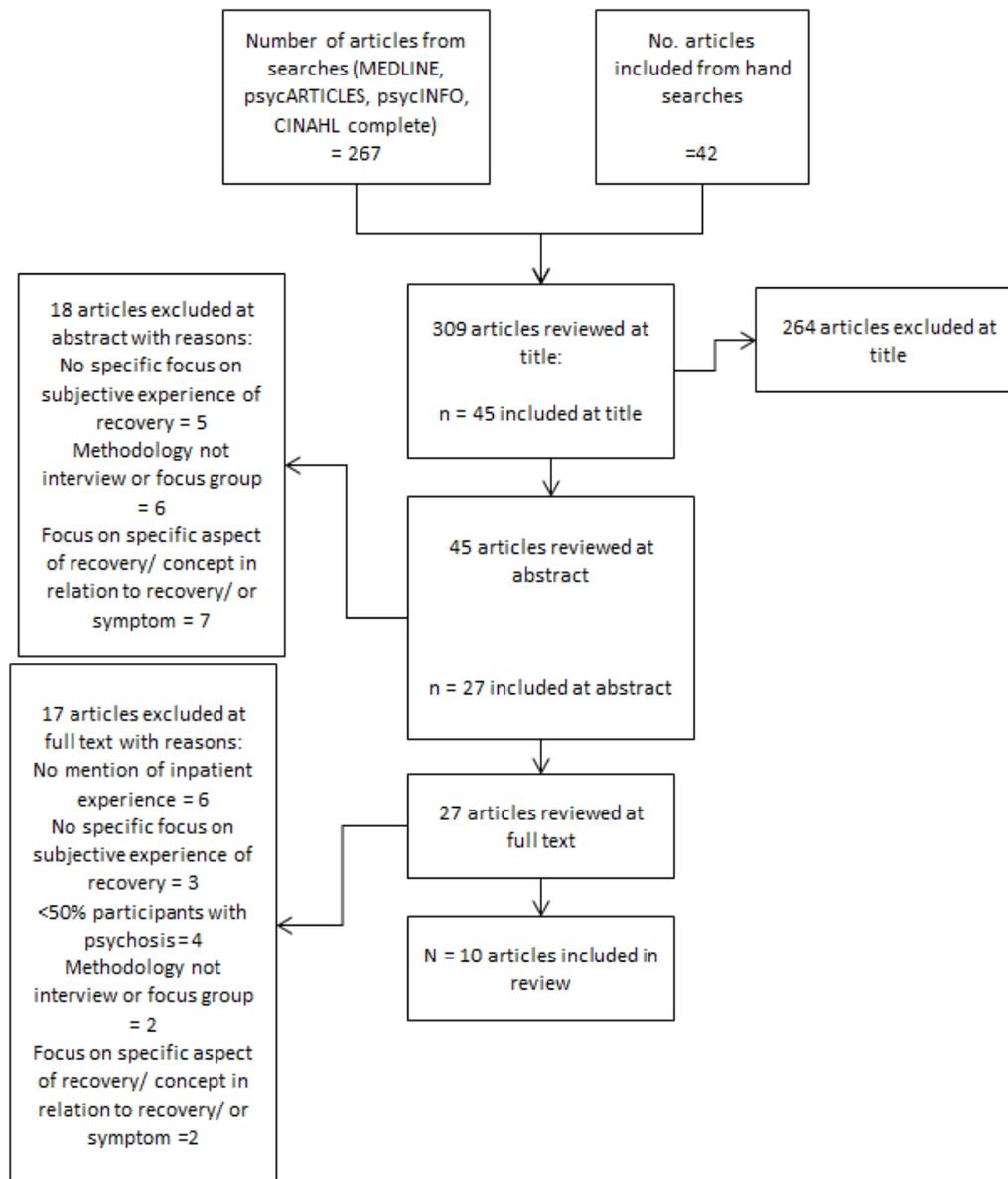


Figure 1. Flow diagram depicting the number of articles produced from literature searches included and excluded at each stage of review. Articles were reviewed at title, abstract, and full text.

#### 1.8.4 Methodological quality assessment

All articles included in the review were subject to critical appraisal of the methodology. This was done using the Critical Appraisal Skills Programme

Qualitative checklist for qualitative research (CASP, 2014). Each article was assessed against 10 criteria and awarded 2 points if the criteria were fully satisfied, 1 point if criteria were partially satisfied and 0 if criteria were not met. The highest score that can be awarded for methodological rigour is 20, indicating the study fully satisfied all criteria (see Table 2 for critical assessment of methodology scoring against CASP criteria). No articles were excluded based on methodological weakness. A critical appraisal of the methodological strengths and weaknesses of included studies is presented below.

Table 2

Quality Criteria	Connell et al. (2015)	Forchuk et al. (2003)	Laithwaite & Gumley (2007)	Lam et al. (2010)	Nixon et al. (2010b)	Noiseux & Ricard (2008)	Spaniol et al. (2002)	Tan et al. (2014)	Thornhill et al. (2004)	Tooth et al. (2003)
Clear statement of aims	2	2	2	2	2	2	2	2	2	2
Appropriate qualitative methodology	2	2	2	2	2	2	2	2	2	2
Appropriate research design	2	2	2	1	2	2	2	1	1	2
Appropriate recruitment strategy	2	2	2	1	2	2	2	1	1	1
Appropriate description of data collection	2	1	2	2	1	2	2	2	2	2
Consideration of relationship between researcher and participants	1	0	2	0	1	2	1	2	2	1
Consideration of ethical issues	2	0	2	1	2	2	1	2	1	1
Sufficiently rigorous data analysis	2	1	2	1	2	2	2	2	2	1
Clear statement of findings	2	2	2	2	2	2	2	2	2	2
Consideration of value of research	2	1	2	2	2	2	2	2	2	1
<b>Total score</b>	<b>19</b>	<b>13</b>	<b>20</b>	<b>14</b>	<b>18</b>	<b>20</b>	<b>18</b>	<b>18</b>	<b>17</b>	<b>15</b>

*Critical assessment of methodology against CASP criteria.*

### 1.8.5 Critical appraisal of methodology

The following 10 studies were included in the review: Connell et al. (2015); Forchuk, Jewell, Tweedell, and Steinnagel (2003); Laithwaite and Gumley (2007); Lam et al. (2011); Nixon, Hagen, and Peters (2010b); Noiseux and Ricard (2008); Spaniol, Wewiorski, Gagne, and Anthony (2002); Tan, Gould, Combes, and Lehmann (2014); Thornhill, Clare, and May (2004); Tooth, Kalyanasundaram, Glover, and Momenzadah (2003) (see Table 3 for summary of study information).

Two studies fully satisfied all criteria from the quality assessment (Laithwaite & Gumley, 2007; Noiseux & Ricard, 2008). All studies fully satisfied the first two criteria which were related to having a clear statement of aims and appropriate use of qualitative methodology. Two studies failed to fully justify their research design (Lam et al., 2011; Tan et al., 2014). For example, Lam et al. (2010) provide little justification or explanation for their methods.

Four studies failed to fully explain the recruitment process or provided little discussion around reasons for refusal to participate (Lam et al., 2011; Tan et al., 2014; Thornhill et al., 2004; Tooth et al., 2003). Appropriate description of the process of data collection is important for readers to understand how the data were collected and for the study to be auditable. Two studies failed to fully satisfy this criterion (Forchuk et al., 2003; Nixon et al., 2010b).

In qualitative research, examining the influence of the researcher on both the participants and the research process is necessary to avoid potential bias. Three studies made no attempt to examine the relationship between the participants and researcher and how this may impact results (Forchuk et al., 2003; Lam et al., 2011; Nixon et al., 2010b). Three studies only partially satisfied this criterion (Connell et al., 2015; Spaniol et al., 2002; Tooth et al., 2003). Four studies made little mention of issues relating to ethics such as gaining informed consent or ethical approval (Lam et al., 2011; Spaniol et al., 2002; Thornhill et al., 2004; Tooth et al., 2003) and one study made no mention of ethical issues at all (Forchuk et al., 2003).

Three studies only partially satisfied the criteria relating to applying sufficient rigour to the process of data analysis (Forchuk et al., 2003; Lam et al., 2011; Tooth et al., 2003). For example, Lam et al. (2010) only provided a brief description of the

analysis process, with little detail of decision making processes or potential for bias in the generation of themes. Similarly, both Forchuk et al. (2003) and Tooth et al. (2003) failed to be transparent about their decision-making processes. Criterion nine was fully met, as all studies clearly stated their findings. However, two studies made poor attempts at suggesting clinical implications, or areas for future research, which impacts upon the usefulness of these findings to the wider context (Forchuk et al., 2003; Tooth et al., 2003).

Additional methods to enhance methodological rigor were employed by nine of the 10 studies. Five studies employed a process of multiple coding or independent review (Connell et al., 2015; Lam et al., 2011; Nixon et al., 2010b; Tan et al., 2014; Tooth et al., 2003) which enhances the credibility and robustness of the data (Johnson & Waterfield, 2004). Five studies used respondent validation enhancing the dependability and credibility of the data (Laithwaite & Gumley, 2007; Noiseux & Ricard, 2008; Tan et al., 2014; Thornhill et al., 2004; Tooth et al., 2003).

Additionally, two studies (Noiseux & Ricard, 2008; Spaniol et al., 2002) employed a process of triangulation, which enhances validity and adds to the robustness of the data (Johnson & Waterfield, 2004).

Table 3:

*Summary of study characteristics for articles included in the review*

Authors	No. Participants	Demographics (M/F, age range)	Diagnosis	No. inpatient	Service Context/ Recruitment	Methods and analysis	Aim
Connell et al. (2015)	20	14M/6F, 18-25, all FEP	psychotic disorder	N/K	Early psychosis services, Brisbane AUS	1 semi-structured interview, IPA	To explore subjective factors associated with FEP
Forchuk et al. (2003)	10	7M/3F, 26-51	on going problems related to psychosis'	9	non-probability purposive sampling, recruited from tertiary care psychiatric hospital and general hospital, Canada.	Interviews, monthly for 6 month and then at 9 and 12 months (9 per participant) before and during medical treatment. Ethnographic analysis.	To understand experience of recovery from psychosis
Lathwaite & Gurnley (2007)	13	13M, 22-60	11 schizophrenia, 2 bipolar	13	High secure mental health hospital, UK	1 in-depth unstructured, openended interview, social constructionist grounded theory	To understand experience of recovery in high secure setting
Lam et al. (2010)	6	3M/3F, 23-29, all FEP	4 paranoid Schizophrenia, 1 acute transient psychotic disorder, 1 unspecified psychosis	N/K	EIP service, China	Focus group, content analysis	To explore the meanings of illness and recovery in FEP
Nixon et al. (2010b)	17	2M/15F, 25-64	psychosis	N/K	recruited through advertisement, word of mouth, Western Canada	Narrative interview, thematic analysis	To explore lived experience of recovery from psychosis
Noisoux & Ricard (2008)	16	8M/8F av. age 35	16 schizophrenia	N/K	Recruited from psychiatry centre, self-help group, community setting, Canada.	semi-structured interview, Grounded Theory	To propose a theoretical explanation of recovery
Spaniol et al. (2002)	12	6M/6F, 30-53	schizophrenia or schizoaffective disorder	N/K	randomly selected from a larger study of 135 participants, USA	interviews every 4-8 months for 4 years, thematic analysis	To describe the recovery process from psychosis
Tan et al. 2014	8	6M/2F, 22-26	8 FEP	8	EIP service, UK	semi-structured interview, Grounded Theory	To understand experience of FEP and recovery
Thornhill et al. 2004	15	6M/9F, 30-70	7 schizophrenia, 2 schizoaffective disorder, 4 bipolar/mania, 2 psychotic episode, 2 depressive	14	Purposive sampling through advertisement.	Interview, narrative analysis	To explore narrative accounts of recovery from psychosis
Tooth et al. (2003)	57	43M/14F	Schizophrenia	mean 6 admissions, range 0-30 admissions	Recruited from advertisement and government and non-government mental health organisations, Queensland, AUS.	Interview (4 part), thematic analysis	To provide consumer perspectives on recovery from schizophrenia

*Note.* FEP = first episode psychosis; N/K = not known. Where data is missing it was not provided in the article e.g. Tooth et al. (2003) did not provide age of sample.

### **1.8.6 Thematic synthesis**

A thematic synthesis was employed to draw together and describe the findings of the papers included in this review (Thomas & Harden, 2008). The aim was to provide a rich description of the data, rather than of a particular aspect of the data, therefore all data within the results section of articles was included in the analysis, including direct quotes from participants and the author's interpretations of the data. An inductive approach was employed, where analysis stayed close to the data itself with no *a priori* framework imposed. This was done to capture a broad and holistic picture of what is currently understood about the subjective experience of recovery from psychosis for those who have experience of psychiatric hospitalisation. The text was analysed at a semantic level so that the codes and themes generated stayed close to the data itself without attempting to infer meaning that goes beyond surface level interpretations of the text (Braun & Clarke, 2006). As such this review aligns with an essentialist epistemological positioning and aims to describe the subjective reported experience, and meanings as understood by the participants, and subsequently researchers involved in the primary analysis of the data.

Thomas and Harden (2008) suggest a method for the qualitative thematic synthesis of research results. They advise a three-stage approach which involves: (1) the line by line coding of results sections; (2) production of descriptive themes; (3) production of analytical themes. This three-stage process involves applying codes to each line of text and then developing descriptive themes that describe these codes. The final stage involves going beyond description to produce analytical themes that capture important concepts described in the data, relevant to the review aim.

The results sections of all articles were read and re-read to gain familiarity with the findings. A process of by-hand line-by-line coding was employed where each line of text had a corresponding code applied. Initial codes comprised brief descriptors capturing the essence of the text. Some lines comprised more than one code and some codes corresponded to several lines of text. An example of a code applied would be “psychosis as a positive experience” applied to the text “participants experienced an intense and pleasurable feeling of connectedness with the universe during their psychoses”. As coding progressed, existing codes were translated across texts and new codes were developed where existing codes were insufficient to capture the essence of the data.

Once all text was coded, codes were read and re-read to gain a holistic picture of the data captured in these articles. Codes were then extracted and arranged into descriptive themes using a tree diagram. Codes that shared similarities in meaning or to the concepts which they related, were grouped together. For example, the codes “hospital as unsafe” and “the trauma of hospitalisation” were grouped together as both corresponded to participants’ negative experience of being an inpatient in hospital. Themes were combined where multiple themes seemed to share some underlying similarity, and broader overarching descriptive themes were developed. Higher-order analytical themes were then created by grouping descriptive themes together and extracting the meaning or essence captured within those themes. This process led to the development of superordinate and subordinate themes that sufficiently captured all the descriptive themes and were relevant to the review aim.

### **1.8.7 Literature review results**

The thematic synthesis led to the following superordinate and subordinate themes:

*The Journey of psychosis* which consisted: *pre-psychosis, experience of psychosis,*

and recovery; *Factors influencing recovery*, which consisted: *barriers* and *facilitators*; *The experience of mental health services*, which consisted: *supportive relationships*; *invalidation, inconsistency, and imbalance*; and *the trauma of hospitalisation* (see Table 4 for list of themes with corresponding number of contributing articles). The themes and subthemes are described below.

Table 4:

*Themes from thematic analysis of literature*

<b>Journey to recovery</b>	<b>No. articles</b>	<b>Factors influencing Recovery</b>	<b>No. articles</b>	<b>Experience of mental health services</b>	<b>No. articles</b>
<b>Pre-psychosis</b>	<b>5</b>	<b>Facilitators</b>	<b>10</b>	Supportive relationships	5
Trauma & Adversity	5	Engagement in a treatment	7	Invalidation, inconsistency, and imbalance	8
<b>Experience of Psychosis</b>	<b>10</b>	Returning to roles and activities	5	The trauma of hospitalisation	9
Psychosis as enhancing spirituality and connection	4	Religion & spirituality	5		
The torment of psychosis	10	Relationships	8		
<b>Recovery &amp; the future</b>	<b>10</b>	Self-management	8		
Process/meaning of recovery	10	Psychological factors	8		
The continued struggle	7	<b>Barriers</b>	<b>10</b>		
		Medication & illness	8		
		Stigma/discrimination	8		
		Substance use	4		
		Social disadvantage	4		
		Relationships	4		
		Religion/spirituality	2		

### 1.8.7.1 Journey to recovery

The journey to recovery was understood as consisting of three stages: the experience prior to becoming unwell, the experience of psychosis itself, and the movement towards getting better and into an experience of recovery.

### ***Pre-psychosis:***

The pre-psychosis stage encompassed a recognition of factors pertinent to the development of psychosis. Five of the 10 papers reported experiences participants had prior to the onset of their psychosis experiences.

### ***Trauma & Adversity***

The analysis revealed that many participants had experiences of childhood trauma or early adversity and these were understood as key contributors to the development of psychosis. Experiences such as childhood abuse, death of loved ones, bullying and interpersonal adversity were commonly reported.

*“Most of our participants had unfortunately experienced intense trauma in childhood. Angela, Pam, Bonnie and Holly suffered sexual abuse as children. In her teen years Angela was also raped while Pam related an incestuous relationship with her brother”* (Nixon et al., 2010b, p. 624).

### ***Experience of psychosis***

All articles described participants lived experience of psychosis. The experience of psychosis was an idiosyncratic one with participants offering unique and varying descriptions. Participants in all studies described psychosis as a negative experience, however, four studies also included participants who viewed their experience of psychosis as positive.

### ***The torment of psychosis experiences***

The negative experience of psychosis was generally reported as a loss of the self and a descent into a scary and frightening mental experience resulting in a loss of touch with the outside world and intense feelings of fear. Psychosis was felt to be a chaotic

and confusing experience where individuals were tormented by experiences of hallucinations and voices and lacked understanding of what was happening to them.

*“Almost all the participants began by describing how schizophrenia symptoms could produce terrifying, even unbearable moments for themselves and those around them. They described specific persistent symptoms such as negative or disruptive mental aberrations, delusional thoughts, and auditory or visual hallucinations. They reported a sense of having their souls invaded and of being trapped in an extended ‘descent into hell’.”* (Noiseux & Ricard, 2008, p. 1153).

#### *Psychosis as enhancing spirituality and connection*

Reports of positive experiences generally focused on a spiritual sense of becoming more connected to others or a higher power, often comprising religious undertones. For others, psychosis provided a sense of being special. In addition, some participants felt that the experience of psychosis had enabled them to become stronger or better versions of themselves.

*“Many participants experienced an intense and pleasurable experience of connectedness with the universe during their psychosis”* (Nixon et al., 2010b, p. 626).

*“Participants spoke of the illness as life enhancing. Three participants (two tertiary level students and one university graduate) actually said that their illness experience had improved them: more clear thinking (P6); more mature (P1); more considerate (P3).”* (Lam et al. 2010, p. 584).

**Recovery:**

All articles commented on either the process, or the meaning of recovery. Recovery was described as a staged process and the meaning of recovery was viewed differently among participants. Seven studies described participant's views about their future in relation to the continued journey of recovery and illness.

*Process/meaning of recovery*

The process of recovery involves a journey through stages which may be initiated by a sense of hope or a strength to fight back, and along which individuals utilise varying internal and external resources to facilitate them in moving forward. During this process a gradual decrease in symptoms and increase in engagement in previously held roles, relationships and activities occurs. This process is often experienced as a regaining of the self or a return to what is seen as normal, and through which one is gradually able to regain control and make sense of their experiences.

*“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. The conflict can only be resolved by making a choice between living differently or letting themselves decline— in essence, struggling to live or dying in anguish. The majority of the participants associated this sudden seizing on the desire to live and rejection of the status quo with a subsequent reduction in their symptoms, an abatement of their suffering, and a return to ‘a more normal life’ and a functional role in society.”* (Noiseux & Ricard, 2008, p. 1154).

The meaning of recovery is highly personal and descriptions vary between individuals. For some the presence of medication was a sign that one was not recovered, for others recovery meant moving from “struggling with” to “living with” illness, and to others as a regaining of previous functions, reduction in symptoms or getting back to what was considered “normal”.

*“[Recovery means] one could think like others [in the] mainstream, have normal routines in life like others, have normal social relationships as opposed to self-imposed isolation from others.”* (Lam et al. 2010, p. 583).

#### *The continued struggle*

Thoughts relating to the future for individuals who have experienced psychosis consisted of many hopes and fears. For those who were recovering, the traumatic experience of psychosis left many with fears of relapse. For those who did not consider themselves to be in recovery feelings of hopelessness and concerns of isolation emerged. Many studies reported narratives around endurance, on-going management and continued struggle which was sometimes compared to living with a long term physical health condition.

*“A key theme in endurance narratives is an acceptance of life as a struggle, and although some aspects may be positive, an acknowledgement of the need to contend with ongoing difficulties”* (Thornhill et al. 2004, p. 190).

#### **1.8.7.2 Factors influencing recovery**

All articles reported factors that helped and hindered recovery. Helpful and unhelpful factors vary among individuals however some factors were more consistently reported as either helpful or unhelpful.

## *Facilitators*

### *Engagement in a treatment*

Engagement in a form of treatment was often reported as helpful to recovery.

Treatment involved psychological therapy, support groups, medication and non-traditional therapies such as reiki or meditation. Having choice in which treatment one engages in, and being able to challenge or reject traditional treatment models (e.g. medicalised views of psychosis, medication, diagnosis) was also seen as important.

*“Ms. P. used psychotropic medication and worked with a therapist and community treatment team that she says ‘really care for me’. She credits her therapist for her emotional growth and improvement.”* (Spaniol et al. 2002, p. 331).

### *Returning to roles and activities*

Returning to previously held roles and activities helped by providing a sense of normality, a strengthening of relationships, and acting as a distraction. Engagement in hobbies, creativity and attending skills courses also helped by facilitating a sense of achievement and bolstering confidence. Many studies also reported that becoming involved in volunteer work or activities where one was giving back to the community was important to recovery.

*“Regardless of their particular form of volunteer work, all of these participants stressed the importance of ‘giving back’ as an essential aspect of their ongoing recovery process” (Nixon et al., 2010b, p. 629).*

### *Religion and Spirituality*

Religion and spirituality allowed people to feel more connected with others and provided individuals with a valued role within the community. God was often cited as a source of both strength and support. Spirituality was expressed and experienced through different avenues with which individuals reported a greater sense of awareness.

*“If I’m feeling a bit poorly, I know that just going to the church is going to make me feel better” (Spaniol et al., 2002, p. 333).*

### *Relationships*

The creation of trusting and supportive relationships with individuals who were seen to care was an important factor in recovery. Relationships that facilitated recovery were with family, friends, professionals, other service-users and members of the community. Relationships were seen to provide important sources of support and helped individuals learn about themselves which facilitated the recovery process. Improved relationships were often linked to improvements in mental health.

*“Participants also spoke about how they had changed over the years; how this change had been facilitated by their relationships with staff or family and how those relationships had also changed during their hospital admission”.*

(Laithwaite & Gumley, 2007, p. 310).

### *Self-management*

Being able to cope by oneself and using one’s own resources was cited as an important factor in the majority of studies. For the most part, the emphasis was on individuals both discovering and employing what helped by themselves. The process of finding helpful strategies often took a great deal of determination and perseverance. Occasionally others, such as fellow service-users or staff, were cited as being involved in suggesting helpful strategies that individuals could use by themselves to cope.

*“The keys to well-being are simply strategies or ways of doing things that make individuals feel good about themselves and give them a sense of direction, but the keys are individual and personal, and each person must find them for himself.”* (Noiseux & Ricard, 2008, p. 1155).

### *Psychological factors*

The majority of studies commented on the helpfulness of psychological factors in the recovery process. A process of being able to make sense or ascribe meaning to experiences was an important step in facilitating the early stages of recovery. Having

hope and optimism along with regaining a sense of control and finding purpose in life, were also factors individuals reported as helping them to move forward. Alongside this process, individuals learnt to accept their experiences and gained confidence, which helped motivate them to continue fighting on.

*“Donald describes a crucial step on his journey of recovery was realizing that his voices were meaningful within his life experience, for example, that he heard the voice of the catholic priest who sexually abused him as a boy, of his dead father, and of his girlfriend who committed suicide. He was then able to grapple with the issues they raised (such as comments about how he was guilty or to blame for the abuse) and thus demystify and disempower the voices.”* (Thornhill et al. 2004, p. 190).

## **Barriers**

### *Medication and illness*

Whilst medication was reported as a facilitator for some, more often medication was spoken about as a barrier to recovery. Medication was seen to represent a medicalised view of mental health as an illness, and individuals spoke of the negative side effects they endured as a result. For some, medication was seen as a method of coercion and control and individuals reported feeling a lack of choice. Experience of physical illness also made recovery more difficult.

*“All were prescribed atypical antipsychotic medication but nevertheless their view was unanimously negative. Concerns about perceived side effects of*

*medication were significant and recurrent. These included impaired concentration (P1, 3, 4, 5, 6), dizziness (P2, 3), mental dullness (P2, 4, 6), slow responses (P2, 4) and weight gain (P2, 3, 5).” (Lam et al., 2010, p. 583).*

### *Stigma and discrimination*

Individuals spoke of experiencing discrimination and stigma from an array of sources including staff, the public and the wider socio-political system. Stigma was often associated with being labelled a “psychotic patient” and some felt actively rejecting labels was paramount to recovery. Stigma was seen to pose a challenge to both social and self-acceptance.

*“I received quite a bit of mocking I remember when I was being taken into hospital and that really . . . by the bloody ambulance people coming in and I really, thinking back did not need that at the time’ [P2].” (Tan et al., 2014, p. 90).*

*“All but two of our participants felt it was important to reject any diagnosis or label given to them by mental health professionals, as they felt the stigma associated with such labels was detrimental to their ongoing recovery process.” (Nixon et al., 2010b, p.630).*

### *Substance use*

Substance use was reported as a common struggle for individuals and presented a major barrier to recovery. The need to address substance use was an essential step in the recovery process. Drugs were used by some to cope, but carried additional social implications (e.g. engagement in dangerous social environments). For others, drugs were cited as a trigger to their psychotic experiences.

*“I think it’s like you’re building up to this sort of threshold and it could have been at any time. But just having the drugs I think that just tipped me over really”.* (Tan et al. 2014, p. 87).

### *Social disadvantage*

Social disadvantage included experiences of poverty, racism, homelessness and difficulties with social integration. These experiences were reported as a barrier to recovery and many reported resultant struggles with finances and employment.

*“A 42-year-old African-American man put it this way ‘You just resign yourself to the fact that there’s never enough money’. Participants quality of life was almost entirely dependent on the meagre resources available through entitlement and benefit programs.”* (Spaniol et al., 2002, p. 332).

### *Relationships*

Although mainly cited as a facilitator, for some relationships presented a barrier to recovery. Here individuals spoke of a lack of understanding from others which often led to further loneliness and isolation, making recovery more of a challenge.

*“ . . . they thought I was like going through a . . . like a . . . me own thing or whatever. They just thought I was going through something, so they just thought leave him to it, he’ll be all right in a couple of years or whatever.”*

(Tan et al., 2014 p. 90).

### *Religion/Spirituality*

Two studies reported religion/spirituality as a barrier to recovery either through enhancing a divine sense of “specialness” that prevented integration with others or by exacerbating symptoms of psychosis.

*“Pam explained, ‘I just absolutely felt that God had planted me in this experience for some higher purpose in my life’. Similarly, Arthur stated that, ‘Sometimes I feel I am on a mission from God, ’”.* (Nixon et al., 2010b, p. 630).

#### **1.8.7.3 Experience of mental health services**

Many participants spoke of their experience of mental health services. Some reported both positive and negative experiences however more often mental health services were viewed in a negative light, particularly the experience of hospitalisation.

### *Supportive relationships*

Five of the 10 studies reported positive experiences of mental health services.

Positive accounts mainly pertained to supportive relationships with helpful staff who were seen to be caring and instrumental in the recovery process.

*“[Its a] good relationship. I talk to them, they talk to me. I try not to get in trouble. I don’t think that it is terrible in here and staff is great, they are great to me.”* (Forchuk et al., 2003, p. 148).

### *Invalidation, inconsistency and imbalance*

Negative accounts of mental health services pertained to experiencing stigma and lack of understanding from staff, along with reports of damaging power imbalances in relationships between staff and service-users. Individuals also spoke of inconsistencies in support and service provision, worries about getting into trouble, and fears around the loss of support following improvements in mental health.

*“Many felt invalidated, not listened to and reported having the impression that the only thing that mattered was the professional’s expertise and knowledge and not their experience of the disorder. They also reported a lack of attention to individual problems, a focus on symptoms and medication to the exclusion of everything else and stigmatising practices.”* (Tooth et al., 2003, p. 73).

### *The trauma of hospitalisation*

Being an inpatient in hospital was reported in an overwhelmingly negative light.

Although one study reported hospital as a positive safe space, the majority of reports centred around feelings of imprisonment, fears around violence and safety, and a sense that hospitalisation was not helpful. Hospitalisation was described as traumatic and participants spoke of fears of rehospitalisation, an exacerbated sense of being in the “sick role” and being subject to what were experienced as damaging medical practices.

*“Mary talked about ‘being convicted of’ five psychotic episodes. She experienced hospital as ‘a prison’ in which there was a continual danger of attack. As a voluntary patient, Mary wished to exercise her right to leave, but was threatened with compulsory medication.”* (Thornhill et al. 2004, p. 188).

### **1.8.8 Summary of literature review**

The review of current literature suggests that psychosis is often viewed as a scary and traumatising experience, where many factors such as stigma and social disadvantage can hinder the process of getting better. This review revealed that individuals saw recovery as a journey, but one that was often linked with narratives around continued struggle and self-management. Through the process of recovery, a range of different factors such as positive relationships and gaining a sense of hope and meaning were seen to facilitate this process. The experience of psychiatric hospitalisation was often a negative experience, providing additional barriers around fears for safety and lack of freedom, and many spoke of the “trauma of hospitalisation”.

### **1.8.9 Strengths and limitations**

This is the first review to explore service-user views of recovery from psychosis specifically in relation to those who have experience of being an inpatient in psychiatric care. Research considering service-user views in inpatient settings is scarce, and therefore this section of service-users often do not have their voices heard.

This review allows an exploration of the experiences, views and unique needs of this under-represented group. This is especially useful as these individuals arguably represent a group in society who are most in need of quality care and support from services; it is therefore important that their views and opinions are heard. As such, further research into the needs and experience of those in inpatient care is needed.

The number of studies exploring inpatients experience of recovery from psychosis is limited. An inclusion criterion for this review was such that only one participant in a study sample needed to have had experience of being an inpatient. This criterion was set in direct response to the lack of research in this area and to remain inclusive and not diminish an already limited sample of studies. As such, some included studies had relatively few participants with inpatient experience, and therefore the findings from this review are not solely confined to this specific groups experience. To obtain a more refined view of the unique experiences of recovery for inpatients, subsequent reviews should take a more exclusive focus in relation to this criterion. As research in this area expands, obtaining a more distilled view of the experiences that inpatients face may be possible. The current study therefore aims to add to this area of limited research by exploring recovery from the perspective of those who are currently inpatients in hospital.

## **1.9 Rationale for current study**

Much of the work on recovery has come from individuals deemed to be in recovery and so there is a lack of research into what recovery means to those who continue to face adversity and distress (Rose, 2014). Further to this, very little research exists on the specific experience of recovery for people in inpatient units. Current research exploring the experience of recovery from psychosis has tended to include both community and inpatient samples and little research focuses solely on the experience of those who are currently in inpatient care. These individuals have often faced increasing levels of adversity and periods of chronic and severe distress in comparison to those who have no experience of hospitalisation (Herman, 2015; Read, 1998; Sansonnet-hayden, Haley, Marriage, & Fine, 1987).

In addition, psychosis as a diagnosis is often viewed in a more medicalised way than other diagnoses, therefore gaining an understanding of factors that are important for recovery, beyond pharmacology, is especially important for this group. Further, many service-users are repeatedly admitted to hospital, which suggests that their recovery needs are not being met (Geddes et al., 1994; Gitlin et al., 2001; Robinson et al., 1999; Wiersma et al., 1998). Repeated admissions are not only distressing to service-users but also put strain on the NHS which is currently oversubscribed and experiencing “bed crisis” (Samele & Urguia, 2015). As such understanding more about the experience of these individuals will aid in improving the support provided to some of the most vulnerable and disadvantaged in society.

### **1.9.1 Aims**

The aim of the current study is to understand the factors which service-users who experience psychosis and are currently inpatients in a psychiatric hospital, feel are important to their recovery, using Q-methodology. This study aims to explore the

distinct viewpoints that are held among this group of service-users in order to further understanding and contribute to service development. This is an exploratory study therefore there are no specific hypotheses to be tested. Instead, it is hoped that this study will uncover the viewpoints and opinions currently held by this population in relation to recovery from psychosis.

### **1.9.2 Rationale for Q-methodology**

Q-methodology is concerned with the study of subjectivity and aims to uncover the first-person viewpoints that are present among a group of people on a given topic (Watts & Stenner, 2012). The literature review indicates that PWP hold different views about what is important to their recovery. The product of Q-methodology is the main distinct viewpoints that are present among a group of people. A strength of Q-method is its dual focus on revealing similarities between participant's views, whilst allowing the exploration of differences between opinions. Recovery is a multifaceted concept, therefore Q-method's ability to discern differences between groups lends itself toward this study's aims. The current literature exploring the experience of recovery from psychosis in an inpatient population is scarce, with the majority of studies employing an interview design. Q-method differs from other methodologies in that it takes a holistic approach to data analysis. In comparison with a number of qualitative techniques, which often utilise some form of analysis involving the amalgamation of themes across the subjective viewpoints of participants, Q-method extracts whole viewpoints and explores how themes emerge within the viewpoint with which they are expressed (Watts & Stenner, 2012). As such Q-method provides a useful and novel approach to exploring this study's aims of understanding inpatient's views on factors that promote recovery from psychosis (please see methods chapter for detailed discussion of Q-methodology).

## **Chapter 2 Method**

### **Chapter outline**

This chapter begins with an exploration of the epistemological positioning of Q-method and the current study. The Q-methodology design, its development, along with the aims and criticisms of the methodology are explored. The chapter proceeds in describing the process of developing the Q-set and goes on to report the materials and participants involved in the study. The procedure of completing the Q-sort task with participants is outlined along with details relating to the recruitment process. The chapter concludes with a consideration of issues relating to ethics and a description of the data analysis process.

### **Part I Epistemology**

#### **2.1 Constructivism vs Social Constructionism**

Q-methodological studies generally uphold one of two epistemological positions, that of constructivism or that of social constructionism (Watts & Stenner, 2012).

Constructivist paradigms suggests that factors inherent to the individual such as one's internal thoughts and feelings shape the way individuals view and make sense of the world around them (Blaikie, 2007). Constructivism suggests that the world is not viewed as an objective reality that each of us sees in an identical fashion, but that we are all subject to affective and cognitive processes which influence the way we perceive the world around us. What is important to one may not be to another, and varying levels of attention may be paid to varying objects by different individuals, influencing and altering the internal process of meaning making. Stephenson described Q-method as the objective measure of subjectivity and coined the term "operant subjectivity", which is the name of the main Q-methodology journal

(Stephenson, 1953). Through the sorting process, individuals construct an objective representation of their subjective viewpoint (Ramlo & Newman, 2011).

Social constructionism differs from constructivism in that the area of focus is the shared social process of meaning making, with less thought being given to personal or internal facets of this process. Social constructionists argue that meaning making happens between rather than within individuals, and is concerned with both dominant and marginalised discourses and understanding how and why groups of people make sense of the world (Blaikie, 2007).

Compared with the constructivist's Q-method with a self-referential focus, social constructionism favours object-reference, multiple participant designs and the aim of uncovering the dominant discourses present in relation to a given topic (Watts & Stenner, 2012). In this light, Q-methodology may comprise a measure of the social constructions of a given subject matter. Edley (2001) argues that the incorporation of para-sort information in Q-method, adds to the sophistication of this methodology, allowing it to go beyond discovering the viewpoints present, and toward understanding how and why those views came to be held. The para-sort information refers to the additional information that is collected outside of the Q-sort task, for example participant feedback or comments, demographic information, and observations of how participants engage with the task.

Both constructivism and social constructionism therefore have a place within Q-methodology. The current study employs a multiple participant design and aims to understand the main viewpoints that are present among a group of service-users about recovery. Social constructionism therefore provides a useful framework to understand

and make sense of the emergence of these points of view and lends itself to exploring why and how different groups of service-users hold different views about recovery.

## **Part II Design**

### **2.2 Q-Methodology**

Q-methodology, which was developed by Stephenson (1935) is concerned with the study of subjectivity through card sort based decision making exercises (Brown, 1993). Studies utilising Q-methodology aim to understand what people think or feel about a given topic and are designed to capture the first person viewpoints of a group of people (Watts & Stenner, 2012). This is done using a card sorting task where participants, who are known as the P-set, are given a set of statements (the Q-set) which they must sort in a particular order based on their opinion in response to a subject matter. The ordered set of statements is called a Q-sort. Stephenson explained that an individual renders a formally heterogeneous set of statements homogenous on the basis of projection of feeling and self-reference (Stephenson, 1982). The analysis in Q-method involves a by-person factor analysis which groups together people who share similar viewpoints. Factors are produced which explain the most amount of variance within the data and therefore represent the most salient and distinct viewpoints that are present among the group. The supplementation of para-sort information enriches the process of factor interpretation, and using a social constructionist framework, allows the exploration of who thinks what about recovery and why.

#### **2.2.1 Criticisms of Q-methodology**

Q-methodology has been criticised in relation to issues of reliability (Thomas & Baas, 1992). However, it is neither a requirement or an assumption that the viewpoints

produced in Q are fixed. In fact, it is acknowledged that these viewpoints are subject to change (Watts & Stenner, 2012). And thus, no assumptions are made that re-testing the P-set at another time point yield similar results (Van Exel & De Graaf, 2005). Considering Q-method's positioning as outside the traditional qualitative-quantitative continuum, criticisms of Q-method often arise from those approaching the methodology from a purely quantitative or qualitative stance. An understanding of the unique hybridisation of these two standpoints in Q-method is therefore important.

### **2.2.2 Development of the Q-Set**

The process of developing the Q-set consists of many stages and must be adapted to fit the requirements of the study (see Figure 2 for stages of Q-set development). As stated by Watts and Stenner (2012) "There is no single or correct way to generate a Q-set", however there are steps that can be useful to follow. The aim in Q-set development is to create a set of items that cover the topic domain in as broad a fashion as possible without overlap or omissions (Watts & Stenner, 2012).

Figure 2. Stages of Q-set development

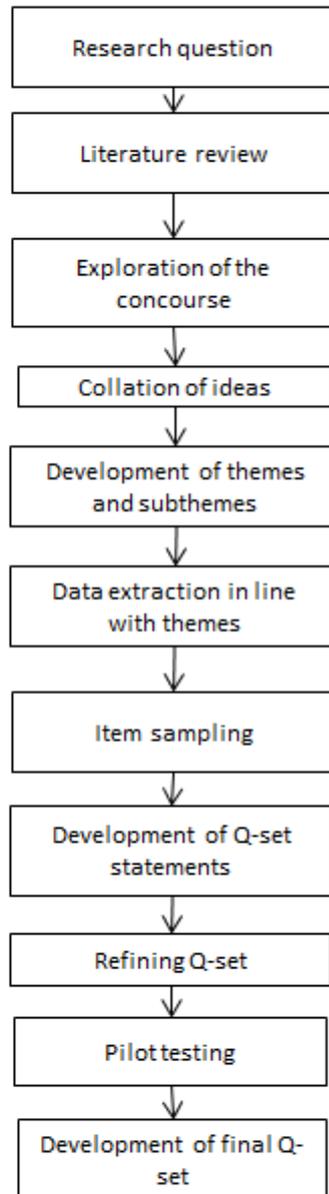


Figure 2. Flow diagram showing each stage of Q-set development

### **2.2.2.1 Structured and unstructured approach to Q-set development**

There are two main methods of Q-set development: the structured or unstructured approach. The structured approach to Q-set development involves a systematic and rigid method which is comparable to the process of scale development (Watts & Stenner, 2012). First the discourse is explored. In Q-methodology, the discourse refers to the flow of communicability about a certain topic and comprises ideas, thoughts, opinions, views, and discourses around a given topic or phenomenon (Brown, 1993). An exploration of the discourse may include reviewing the literature, media sources, interviews, books, official legislation, white paper documents etc. to gain an in-depth understanding of the topic. Following exploration of the discourse, themes are identified and extracted until saturation occurs. Themes represent aspects of the subject matter and the aim is to extract themes that suitably cover the range of opinions and discourses present. Once a representative set of themes has been obtained, the next step is to extract data in relation to these themes. Data items are extracted in the form of quotes, statements or questionnaire items, ensuring equal and complete coverage across all themes. Item sampling involves extracting an equal number of statements from each theme which are used to form the Q-set. A process of quota sampling is sometimes employed whereby a set number of items are extracted from each theme (Watts & Stenner, 2012). The Q-set statements are created through a process of rewording and refining the sampled statements. The resultant Q-set therefore represents items which cover all the themes and sub-themes. The most formal demonstration of this approach is the balanced-block approach developed by Fisher (1960).

The unstructured approach to Q-set development involves a similar process, but with less structure and more fluidity (Watts & Stenner, 2012). The process here involves

understanding the subject matter, exploring the concourse and sampling items but without the systematic and representative nature of the structured approach. As such the unstructured approach is driven more by the researchers own knowledge on the subject matter and without the use of set quotas for each theme.

#### **2.2.2.2 Structured vs unstructured**

Each approach has its advantages and drawbacks. The lack of a systematic approach in the unstructured version lends itself to difficulties in relation to under or over representation of specific areas of the subject matter, due to overlap or omission. The result therefore is an unbalance Q-set, not representative of the topic domain (Watts & Stenner, 2012). However, this process allows more creativity and affords the researcher more freedom in utilizing their own expertise on the subject matter. Again, this has its drawbacks in the potential for the researchers own interest and knowledge to bias the process.

With the structured approach, assuming adequate exploration of the subject matter *a priori*, these errors may be avoided. However, the equal significance awarded to each theme in this process may lead to areas of little importance being overvalued.

Considering these points, and in order to maintain methodological rigour and avoid the potential for imposing researcher bias, this study utilized a structured approach to Q-set development.

#### **2.2.2.3 Exploring the concourse**

The first step in developing the Q-set was to explore the concourse (Watts & Stenner, 2012). The aim of this process was to obtain a broad and inclusive picture of what is thought and understood about recovery from psychosis. It is advised to start with an academic literature search, and following which additional sources such as

questionnaires, television programs, interviews, popular texts etc. can be consulted to provide a balanced and representative coverage of the topic domain (Watts & Stenner, 2012). The following sources were consulted for exploration: academic literature, recovery outcome measures, mental health websites, personal accounts of recovery, service user films, NHS websites, NICE guidelines, policy and white paper documents. These sources were considered to provide a broad perspective of how recovery is thought about in different arenas by varying populations and stakeholders. Recent literature reviews exploring recovery from psychosis were included to provide an initial framework of themes. These studies have reviewed a vast array of the psychosis recovery literature and have synthesized the findings to produce accounts of what people who experience psychosis feel is important to their recovery, therefore providing detailed and relevant information to inform the content of the Q-set (Law & Morrison, 2014; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Soundy et al., 2015; Wood & Alsawy, 2017; Wood, Price, Morrison, & Haddock, 2013). In addition, the literature review conducted as part of this thesis provided specific detail regarding recovery from psychosis in an inpatient population. These sources of information were read and re-read to generate a detailed understanding of recovery from psychosis.

#### **2.2.2.4 Identification of themes**

Themes were identified through a process of exploration and review of the discourse, sampled from the sources listed above. During this process, ideas and opinions in relation to recovery were collected in the form of statements. Themes and subthemes were developed alongside this process by grouping together data which shared some similarity or corresponded to a particular aspect of recovery. This process of

exploration and identification continued until saturation occurred and no new themes emerged.

Exploring the concourse resulted in the identification of 29 themes relevant to recovery from psychosis in an inpatient population. These themes were reviewed and scrutinised and multiple themes which shared some commonality were combined to produce over-arching themes with related subthemes. Subthemes captured some distinct aspect of the over-arching themes. This process produced 11 themes with related sub-themes (see Table 5 for themes and subthemes).

#### **2.2.2.5 Data extraction**

Once the themes were developed a process of data extraction took place to generate statements for the Q-set. This process involved the continued sampling of data items in line with the identified themes. For this study, data was obtained from readymade Q-samples and quasi-naturalistic Q-samples. Readymade Q-samples involve extraction of data from sources other than the participants themselves, for example from policies and guidelines or outcome measures. Quasi-naturalistic Q-samples involves obtaining data from participants through secondary sources e.g. academic literature involving interviews with participants (McKeown & Thomas, 2013).

Obtaining data from both these sources allowed a broad and representative view of recovery. During this process material such as direct quotes, ideas, research findings and items from outcome measures were collected which totalled approximately 350 data items. These were then grouped together in relation to the themes and sub-themes identified. Duplicates and statements expressing similar ideas were removed leaving 272 statements under the 11 themes and subthemes.

### 2.2.2.6 Q-Sampling

The next step involved generating a list of statements to form the Q-set. The aim was to create a miniature version of the concourse and involved reducing the number of statements to between 40-80 which is suggested as a suitable size for a Q-set, whilst maintaining a representative coverage of the topic (Curt, 1994; Stainton Rogers, 1995; Watts & Stenner, 2012). As stated by Watts and Stenner (2012) “concourse is to Q-set what population is to person sample”. The 272 statements were printed and laid out under the 11 themes and subthemes. Data items and themes were read and reviewed. In line with the structured approach to Q-set development, a process of quota sampling was employed whereby, two items were sampled from each subtheme. This process involved refining and reducing the items in each subtheme to fully capture the views, and opinions expressed. Where items shared some similarity, they were combined. For example, under the “Relationships – Professionals” subtheme were the following statements: “How understood I feel by staff”; “Feeling accepted by staff”; “Staff that are empathic towards me”. These statements appeared to capture opinions about how service-users experienced staff. These items were combined to form the statement “How understanding staff are towards me”. Part of this process involved selecting statements which were the most representative of the subtheme, to condense the number of items whilst maintaining a representative picture of the concourse. This process resulted in 56 items considered to capture the essence of the data in each subtheme. Each subtheme comprised two items, however two subthemes (“Relationships – General” and “Functional – Activities”) had three items each as these additional items captured something distinct in the data that was not present elsewhere.

Table 5:

*Themes and subthemes for Q-set development*

<b>Relationships</b>	<b>Societal</b>	<b>Basic needs</b>	<b>Psychological</b>	<b>Spirituality</b>	<b>Functional</b>
Professional	Community	Financial	Identity	Religion	Activities
Family	Stigma	Accommodation	Hope and optimism		Employment/Skills
General	Political	Physical health	Understanding Strengths and goals		
<b>Treatment</b>	<b>Symptoms</b>	<b>Autonomy</b>	<b>Empowerment</b>	<b>Substance use</b>	
Support	Psychosis symptoms	Self-reliance/management	Control	Drugs/alcohol	
Hospital setting	General mental health	Time alone	Choice		
Life as an inpatient					
Medication					

**2.2.2.7 Creating the Q-Set**

The next step was to transform these statements into a usable Q-set, by a process of refining and rewording. Consideration of wording was important for the current study as difficulties with concentration or confusing thought processes are commonly reported among PWP (Cella, Reeder, & Wykes, 2015). Close attention was paid to word statements in a clear and concise fashion to minimise misunderstanding or confusion. This is an important consideration as badly worded items can result in incorrect placement of items or items being treated in the same way, for example, by sorting those that are difficult to understand as “unimportant”. These errors intrinsically impact upon the validity of the Q-sort and therefore impact the results of the study (Watts & Stenner, 2012). The wording of items was carefully thought about and care was taken to make statements as simplistic and easy to understand as possible. To maintain some continuity in presentation of items, a similar prefix was selected for all statements, with all statements beginning with ‘How...’. Additionally all items were kept to a similar length (Watts & Stenner, 2012). For example, the statement “Staff treating me with dignity and respect” was reworded to “How much staff treat me with dignity and respect”. This was done to assist with ease of

understanding and to maintain some standardisation. A similar technique for standardisation of wording has been used in a previous Q-method study, which was found to be acceptable by participants (Wood et al., 2013).

Some statements were negatively worded, for example “How worthless I feel” and “How lonely and isolated I feel”. To avoid the possibility that all negatively worded statements are ranked at “most unimportant” it was decided to transform these into positive wording for example “How much self-worth I feel” and “How able/supported I am to manage feelings of loneliness and isolation”. In transforming these items into positive wording two of the statements were removed as once transformed they were felt to replicate items already in the Q-set, these were “How powerless I feel over my treatment/care” and “How much alcohol and drugs affect my mental health”. As such the resultant Q-set contained 54 items (see Appendix A). The statements were reviewed by experts in the field consisting of two clinical psychologists, and a trainee clinical psychologist, with expertise and experience in working with PWP. Alterations to wording were made and the final 54 statements were considered to sufficiently cover the subject matter with no obvious omissions.

The condition of instruction refers to the question that participants answer with their Q-sort. For this study the condition of instruction was “Which factors are most important to your recovery?”. Q-set items are then sorted from most important to most unimportant in response to this question. The dimension refers to the polarised scale that participants order their Q-set in relation to. The dimension for this study was *most important to most unimportant*. To ensure that items eliciting the strongest response were sorted at either pole, *most to most* was favoured as it was considered that sorting from *most to least* could result in the items eliciting a weak or neutral

response being sorted at the *least* pole, rather than in the middle, as is the aim in Q-methodology (Watts & Stenner, 2012).

### 2.2.2.8 The distribution

The next step involved creation of the distribution grid. A normal distribution grid is used to guide participant's placement of Q-set statements during the task (for distribution grid see Figure 2.1). As stated by Brown (1980) following his comparisons of varying arrays, "distribution effects are virtually always nil" and so the exact shape or size of the distribution was not of paramount importance, rather that it had the appropriate number of spaces and was vaguely symmetrical. In Q-method it is the arrangement of items within the distribution that is important. Using a forced normal distribution grid however may be experienced by some as restrictive. Research both supports and rejects the use of free-distributions (Block, 2008; Bollard, 1985; Brown, 1971, 1980). However, using a free distribution creates added pressure on the participants by increasing the amount of decisions required. Further to this, using a forced distribution that is fixed for each participant lends itself to a far simpler data analysis process. For the current study, minimising the amount of decisions needed was considered important in regard to the client group, therefore a fixed distribution was selected to reduce the burden on participants.

When designing the shape of the distribution grid there were two things to consider. The first was the range (e.g. +5 to -5 or +4 to -4), which dictates the number of decisions participants need to make. As a guide, Brown (1980) suggests for Q-sets of 40-60 an 11-point distribution should be used. The second thing to consider, was the depth, which pertains to the spread of items around the 0 point. Steep slopes allow participants to place more items around the 0 point and so this may be used when participants are expected to be unsure about a topic or have less knowledge on a topic



The relativity of the sorting procedure was explained to participants prior to completing the task.

#### **2.2.2.9 Piloting**

The test materials were piloted on four lay persons to get feedback about the acceptability of items and processes involved, and to ensure that the instructions and task materials were presented in a way that was easy to understand. After piloting two statements were re-worded as they were considered unclear. Piloting revealed the task to be easily completed with little additional prompts required. Participants in the pilot commented that more statements were sorted as important to recovery than unimportant, and as such all 4 participants had a larger *important* pile of Q-set cards compared with the *neutral* and *unimportant* piles. This resulted in a greater number of cards to consider in the sorting process for those initially categorised as important. This also meant that items that were deemed to be important were sometimes rated in negative positions.

This discovery was not felt to be a fault of the task, as described above the Q-sort is judged in terms of relativity rather than absolute positioning. It was also felt that having more items deemed as important was a useful occurrence as finding out what is more important to participants in recovery may provide more useful data than the discovery of those that are not important. After the alterations were made from the pilot the final Q-set was developed and can be seen in Table 6.

Table 6: *Q-set statements with corresponding number for each statement*

<b>Q-set no.</b>	<b>Q-set statements</b>
1	How much the government supports people with my difficulties
2	How often my mental health experiences happen
3	How much my medication helps me
4	How much I feel my life has purpose
5	How much I feel part of a community/society
6	How involved my family/loved ones are in my treatment/care
7	How much my mental health experiences affect my memory & concentration
8	How able/supported I am to manage feelings of loneliness and isolation
9	How much control I have over my circumstances (money, living, employment etc.)
10	How many activities there are for me to do in hospital
11	How supported/able I am to socialise with others
12	How suitable my housing is (outside of hospital)
13	How much my mental health experiences affect my mood/emotions
14	How confident I am in my skills and abilities
15	How much I believe I am more than my diagnosis/illness
16	How much therapy helps me
17	How much I enjoy my activities/hobbies in the community
18	How much the impact of my physical health issues can be reduced
19	How able I am to support myself and/or my family financially
20	How positively others view me
21	How safe I feel in hospital
22	How easily I can access meaningful activities in the community
23	How much the side effects of medication can be reduced
24	How comfortable the hospital ward/environment is
25	How often I exercise and eat well
26	How positive I view my relationships to be
27	How much my mental health affects my personal freedoms and rights
28	How able I am to cope with my mental health experiences myself
29	How much support I get with financial problems
30	How well society understands my mental health difficulties
31	How much support I get from family/loved ones
32	How much staff treat me with dignity and respect
33	How understanding staff are towards me
34	How much my religion/spirituality helps me to cope
35	How able I am to manage feelings of boredom
36	How supported I feel by mental health services
37	How much my mental health affects my ability to work
38	How much my religious/spiritual beliefs are respected by others
39	How easily I can access employment/education/skills courses
40	How much others respect my right to be alone
41	How much distress my mental health symptoms/voices cause me
42	How stable my living arrangements are
43	How much I feel I have equal opportunities compared to others
44	How able I am to look after myself (e.g. daily tasks)
45	How much I'm able to reduce feeling a burden to others
46	How much private time I have to myself
47	How available hospital/ward staff are to support me
48	How involved I am in my treatment and care
49	How able/supported I am to reduce my drug/alcohol intake
50	How supported I am to set goals for myself
51	How much I understand why this is happening to me
52	How much my diagnosis is explained to me
53	How much I believe things can get better
54	How much self-worth I feel

## **Part III Materials**

### **2.3 Materials**

The following section outlines the materials used during the study.

#### **2.3.1 Distribution grid & condition of instruction**

The Q-sort distribution grid was printed across six A4 sheets of paper and laminated for ease of use. A card indicating “most important” was set to the right and one with “most unimportant” to the left, in order to make the sorting direction as clear as possible. The condition of instruction “Which factors are most important to your recovery?” was printed and laid out above the distribution table to allow a visual prompt.

#### **2.3.2 The Q-set**

The Q-set statements were printed onto identically sized laminated cards, each with a randomly allocated number printed on the reverse to aid in data recording and input processes.

#### **2.3.3 Pre-sort category cards**

Three cards indicating the categories for the pre-sort task (*important* to recovery, *unimportant* to recovery, and *neutral*) were printed and laminated to aid as visual prompts and to minimise confusion and cognitive burden.

#### **2.3.4 Participant information sheet (PIS)**

The PIS explained all details relating to the study, such as the study aims, an explanation of the Q-sort task, detail around the benefits and costs of taking part, and instructions around complaint procedures. The PIS outlined the right to withdraw and processes related to confidentiality, anonymity and data handling. The names and

contact details of the research team were included on the PIS so participants could get in contact if they had any questions or queries. The contact details for the patient liaison service and the study sponsor were also included to ensure that participants could get in contact with someone if they wished to make a complaint (See Appendix B for participant information sheet).

### **2.3.5 The consent form**

The consent form consisted of a set of statements with tick boxes to indicate that participants had read, understood and agreed to the information set out in the PIS (see Appendix C for consent form).

### **2.3.6 Contact details sheet**

Participants were given a contact details sheet to provide an address or email address if they wished to be contacted with a summary of the study findings after completion (See Appendix D for contact details sheet).

### **2.3.7 Demographic information form**

The following demographic information was collected from participants on a self-report basis; age, gender, diagnosis, religion, ethnicity, education history, marital status, number of years contact with NHS for mental health, number of years duration of psychosis experiences, number of hospital admissions, and current symptoms. This information was gathered to add to the richness of the data from the Q-sort task and was used to aid the interpretation process (See Appendix E for demographic information sheet).

### **2.3.8 Blank distribution grid**

A printed blank distribution grid was used to record the number of each statement in the participants completed Q-sorts. (See Appendix F for blank distribution grid).

### **2.3.9 Participant feedback sheet**

The participant feedback sheet consisted of four questions relating to the Q-sort task. The first two questions asked participants to provide reasons for the positioning of the three most important and most unimportant items. The next question asked participants whether they considered there to be any factors relating to recovery that were not included in the Q-set. The final question asked for general feedback on the task (see Appendix G for participant feedback sheet).

## **Part IV Participants**

### **2.4 Participants**

The current study was interested in capturing the viewpoints of PWP who are currently inpatients in a mental health hospital. Participants were recruited from four acute wards at a London based psychiatric hospital. Opportunity sampling techniques were used, whereby all those who met the inclusion and exclusion criteria were invited to take part in the study until the desired number of participants was achieved.

The number of participants required for Q-method is comparably fewer than in quantitative techniques. In regard to sample size, the aim in Q-method is to have a large enough sample such that viewpoints that exist among the population being sampled, are revealed in the data (Watts & Stenner, 2012). As stated by Brown (1980) the number of people who hold each view point is a different question completely, and one that Q-methodology does not concern itself with. In Q-method, a greater number of participants is not necessarily superior, and could in fact be problematic, in that large P-sets may lead to the subtleties in the data being lost and therefore negates the qualitative nature of Q-method (Watts & Stenner, 2012). In contrast to other methodologies, in Q-method the participants are the variables, as

such Kline (1994) suggests having twice as many Q-set items as participants.

Alternative guidelines advise having less participants than Q-set items with the rule of thumb being between 40-60 (Stainton Rogers, 1995; Watts & Stenner, 2012). In light of these suggestions, this study aimed to recruit 40 participants from four acute inpatient wards at a London based hospital. It was considered that number of participants would be an appropriate size to provide a representative sample and enough to capture the prevailing viewpoints.

#### **2.4.1 Inclusion & exclusion criteria**

The inclusion criteria were: participants with a schizophrenia-spectrum diagnosis or those who met entry criteria for an Early Intervention for Psychosis service to allow for diagnostic uncertainty in early phases of psychosis, aged between 18-65, who are deemed by the psychology team as appropriate to participate in the task (in relation to severity of illness and capacity to consent). The exclusion criteria were non-English speakers (due to translation costs), those deemed too unwell to participate (by the psychology team), anyone lacking capacity to consent, and anyone already taking part in a research study relating to recovery (as it was considered that this may influence their responses in the current study). The inclusion and exclusion criteria were screened by the psychology team with reference to clinical notes.

### **Part V Procedure**

#### **2.5 Recruitment**

Assistant psychologists (APs) working across four wards in the recruiting hospital were contacted with details of the study, and assisted the researcher in the recruitment process. APs were provided with study protocol and the inclusion and exclusion criteria, which were discussed with the researcher. APs screened service-users against

eligibility criteria, suitable participants were approached to briefly discuss the study and were provided with a PIS. Those who were interested in taking part in the study were asked to fill out a tear off slip from the PIS indicating their consent to being contacted by the researcher.

### **2.5.1 Informed consent**

The researcher was introduced to potential participants by the APs to discuss details of the study and gain written consent. The researcher met with the participants in a private room and explained the aims of the study and described what the task would involve. The information on the PIS was discussed, and participants were encouraged to ask questions. A written consent form was presented and details relating to confidentiality, anonymity and the right to withdraw were explained. Participants indicated their agreement with each statement in the consent form by ticking the relevant box and providing a name, date and signature on the form. Once consent was obtained a date or time to complete the study was arranged.

Participants met with the researcher individually in a separate room on the ward to complete the study. After obtaining informed consent, participants were provided with the contact details form and demographic information was obtained on a self-report basis.

### **2.5.2 The Pre-sort**

Participants were given a full description of all parts of the task at the outset.

Participants were presented with the pre-sort category cards which were laid out in front of them along with the condition of instruction. They were then handed the Q-set and asked to sort the Q-set cards into three piles important; unimportant; or neutral, in response to the condition of instruction ('Which factors are most important

to your recovery?’). The *important* pile was placed to the right, *unimportant* to the left and *neutral* to the middle corresponding with the order of sorting on the distribution grid. Participants were informed that the neutral pile should contain items that they were indifferent about, those that triggered mixed feelings in relation to their importance, or those that they were undecided about.

### **2.5.3 The Q-sort**

Once participants had sorted the Q-set into three piles they were presented with the distribution grid. Participants were instructed to begin with the important pile and place the other two piles to the side. Participants were informed that this pile would now be arranged in order of most to least importance. Participants were instructed to lay out the cards in the important pile in front of them so that they were all visible. They were instructed to consider all cards on the table and to select the three most important to them and place them in the +5 column. They were then asked to select the four next most important cards and place them in the +4. Participants were informed that they could make changes to the positioning of items at any point. This process was repeated until all the cards in the important pile had been sorted onto the grid. The same process was then completed for the unimportant pile, this time selecting the three most unimportant to begin with, and then for the neutral pile. Once all cards were sorted participants were instructed to examine their Q-sort and were given opportunities to make changes.

### **2.5.4 Post task feedback**

Following the Q-sort task, participants were provided with the (optional) feedback form, and asked to fill in details relating to the four questions about the task. Once this was complete participants were thanked for their involvement and presented with

a £10 voucher as compensation for their time and participation in the study.

Following completion, the Q-sort was recorded by the researcher on the printed distribution grid.

### **2.5.5 Para-sort information**

Throughout the Q-sort task the researcher recorded notes on information outside of the sort for example, how the participants engaged with the task, comments that were made, explanations given in relation to specific Q-set items etc. This information was used to aid the interpretation of results.

## **Part VI Ethics**

### **2.6 Ethical considerations**

Conducting research in inpatient settings presents several ethical considerations. The British Psychological Society (BPS, 2014) has set out guidelines and standards that should be appropriately followed in human research. These guidelines along with additional ethical considerations are discussed below in relation to the current study.

#### **Valid and informed consent**

The participants involved in this study are PWP who are currently inpatients in a psychiatric hospital. Service-users who are hospitalised are often acutely unwell or in crisis, and as such may not possess the capacity to make an informed and valid decisions to consent to taking part in the study, under the Mental Capacity Act (2005). The researcher met with a member of the psychology team at the start of each recruitment session to discuss these issues along with the inclusion and exclusion criteria. Participants deemed by the psychology team to lack the capacity to consent or who were considered too unwell, were not approached to take part in the study.

### **Informing participants**

In order to gain informed consent participants must first be in possession of the full details of the study. Providing full details of the study is important so that participants are fully aware of what they are consenting to. For those participants deemed eligible, a set protocol of obtaining informed consent was followed. Full details such as, time, requirements from the participants, potential risks, benefits, contact details for research team, complaints procedures etc. were written in the PIS, which was provided to participants and discussed with the researcher prior to commencement of the study. Participants were encouraged to ask questions and given as much time as needed (up until the end of the recruitment period) to consider the information prior to making a decision to take part. During this phase the researcher used her clinical skills to assess capacity, through ensuring participants were able to weigh up and consider the pros and cons of the information and were able to retain the information provided. This process of informally assessing capacity was continued throughout the task. A consent form outlining the details of the study, anonymity, confidentiality, data storage, requirements from the participant and details of how data will be reported was presented to each participant by the researcher and opportunities to ask any questions or discuss concerns were provided. Those who agreed to take part and were deemed to have the capacity to make an informed choice, were then asked to indicate their agreement by providing written consent.

### **Assessment of risk**

Assessment and communication of potential risks to participants was considered. The current study was deemed to pose very little risk to participants. It was considered that engaging in a task where participants are asked to think about their experiences

could cause some participants to become upset. As such this potential risk was set out in the PIS and discussed with participants.

### **Confidentiality**

Subject to the Data Protection Act (1998) the confidentiality of participant's data is a requirement in research, unless otherwise agreed prior to participation. To insure confidentiality participants completed the Q-sort task individually in a separate room and participant responses were not discussed with anyone not directly involved in the research. Participants were informed, prior to obtaining informed consent, that confidentiality agreements would only be broken if it was deemed there was a significant risk posed either to themselves or someone else. Participants were informed that this would result in a Clinical Psychologist at the hospital being informed of the potential risk, all other information not relevant to the risk would remain confidential.

### **Anonymity**

Participant's anonymity was assured by assigning participants with a number so that no identifiable information was stored with the study data. Participants were informed that identifiable information would not be printed in the write up, but their views and opinions may be. Participants were informed, during the informed consent process, that there may be small chance that they could be identified based on what they say, however this was considered unlikely.

### **Data storage**

The procedures involved in the storing, handling and destruction of data involved in this study were in compliance with the Data Protection Act (1998). A record of the name-number allocation and other personal information was stored securely in a

locked cabinet at the University of Essex or the hospital. Electronic data items containing personal information were stored in an encrypted file and saved on the University of Essex secure drive.

### **2.6.1 Ethical approval**

This study was reviewed and gained ethical approval from the National Research Ethics Committee (see Appendix H) and the local NHS trust research and development department (see Appendix I).

## **Part VII Reflexivity**

### **2.7 Reflexivity**

Reflexivity is concerned with an ability to understand the influence and impact that one's thoughts, beliefs, and actions have in the research process. It is concerned with how one relates to the subjects and the subject matter, and how this shapes interactions and the creation of knowledge and meaning throughout the process (Bolton, 2010). Researcher reflexivity refers to the ways in which the researcher shares their reflections on the research process and makes explicit details relating to how the results were obtained (Henwood, 2008). Aspects of the researchers own background along with the beliefs that are held therefore influence the way the researcher engages, and have the potential to impact upon this process. For this reason, it is important for researchers to make explicit details relating to their personal stance and background. The researcher is a white female aged between 25-35, with 7 years' experience of working in mental health services and is currently working as a trainee clinical psychologist in the NHS. The researcher has no personal experience of psychosis and acknowledges the likely differences in background and life experience compared with the participants in this study (Burnham, 2013). The

inherent power imbalance between researcher and participants was considered as this may influence the way the researcher is experienced by participants. As such the researcher takes a curious and open stance to understanding the experience of participants rather than a detached position of observation and recording of data (Bolton, 2010). This is an important consideration when research is focused on the experience of marginalised groups where one must be aware of not imposing a view of people as occupying fixed positions of marginality, but of viewing people as multiply positioned and remaining curious to their experience (Phoenix, 1998). The researcher also acknowledges an interest in the social and political determinants of mental health and is alert to the possibility that these interests may influence the researchers own meaning making process. Hughes (2006) speaks of how the researcher's own experiences and identity are implicit in the knowledge and understanding produced during research. As such an awareness throughout of how the researcher's own social reality and identity play an integral role in this process will be considered.

## **Part VIII Analysis**

### **2.8 Statistical analysis**

A Q-method software package (PQ-method version 2.11, Schmolck, 2002) was used to analyse the data to produce factors which explain the maximum amount of variance. Factors produced were based on groups of participants who shared similar viewpoints about what was important to them in their recovery.

The Q-sorts of participants were inter-correlated and subject to a by-person component analysis using the dedicated computer software PQ-method (Schmolck, 2002). A principal component analysis (PCA) was employed which uses techniques

comparable to a by-person factor analysis, whereby Q-sorts that share similarity are grouped together to form factors. The data was then subject to orthogonal rotation to maximise the amount of variance explained whilst ensuring factors did not inter-correlate. A varimax rotation was selected as both varimax and PCA are suggested to be the statistically superior methods of extraction and rotation, explaining the maximum amount of study variance (Watts & Stenner, 2012).

### **2.8.1 Factor extraction**

The factor extraction process drew upon both statistical and theoretical considerations (Brown, 1980; McKeown & Thomas, 2013). As Q-method is a mixed method of analysis implementing both was important for the final solution to be meaningful. Factors with large numbers of Q-sorts loading on them, increases the stability of the factor as the factor arrays are created by weighted averages (Watts & Stenner, 2012). Several criteria are suggested for consideration in relation to decisions pertaining to the number of factors to extract, and aid in assessing the strength of the factor solutions. These are: the Kaiser-Guttman criteria (Guttman, 1954; Kaiser, 1960, 1970); Humphrey's rule (Brown, 1980); and the significance level of factor loadings (Watts & Stenner, 2012), which are explained further below. All these criteria were considered when determining the final factor solution. It is considered that the best solution mathematically is not necessarily the best solution, as such statistically "weaker" solutions may be favoured on the grounds of theoretical significance (Brown, 1978; Ramlo, 2016). Therefore, relevant theory was held in mind when interpreting the final factor structure. Most pertinent was that the final factor structure met the aims of the research, made good sense of the data, was theoretically and statistically acceptable, and was sensitive to the viewpoints and the data (Watts & Stenner, 2012).

### 2.8.2 From Q-sorts to factors

Kaiser-Guttman criteria:

When selecting how many factors to extract certain criteria can be employed to ensure the statistical strength of the solution. The Kaiser-Guttman criteria suggests that factors should all have an Eigenvalue of 1.0 or more (Guttman, 1954; Kaiser, 1960, 1970). An Eigenvalue is representative of a factor's statistical strength and explanatory power. A factor with an Eigenvalue of 1 has the explanatory power of one study Q-sort, therefore factors with Eigenvalues of less than 1 are understood to possess weak explanatory power, and statistically their inclusion should be questioned (Watts & Stenner, 2012). Therefore, only factors with an Eigenvalue above 1 were considered for inclusion in the analysis.

Humphrey's rule:

A further criteria considered was Humphreys rule, which suggests that the cross product of a factor's two highest loading should be greater than twice the standard error (Brown, 1980). The standard error is calculated in reference to the number of items in the Q-set.

Factor loadings:

A third consideration was the significance level of factor loadings. PQ-method (Schmolck, 2002) provides factor matrix depicting factor loadings for each Q-sort on each factor. Factor loadings explain how strongly a given Q-sort is correlated with a factor. For example, a factor loading of 0.86 on factor 1 indicates that the viewpoint expressed by this Q-sort shares a strong association with that expressed by factor 1. A Q-sort with a loading of 0.12 suggests there is little commonality between what is expressed in the Q-sort and factor 1. In order to be interpretable, factors should have

at least 2 Q-sorts loading significantly on them (Watts & Stenner, 2012). The following equation was used to calculate a statistically significant factor loading for this study (Watts & Stenner, 2012):

- $2.58 \times (1 \div \sqrt{\text{No. of items in Q-set}})$

Q-sorts with statistically significant loadings were flagged, indicating their inclusion in the process of creating factor arrays. These Q-sorts represent viewpoints that exemplify those expressed by a given factor and are sometimes referred to as defining Q-sorts.

Q-sorts that load on two or more factors suggest the view expressed by this Q-sort shares something in common with multiple factors. As such, the view expressed by a multiple loading Q-sort will be somewhere in between the two distinct views expressed by each factor it loads on. Q-sorts that do not load significantly on any factor suggest the view expressed by the Q-sort shares little in common with any of the views expressed by the factors. In order to maintain the distinctness of views expressed by factors, multiple loading and non-loading Q-sorts were not included in the process of creating factor arrays.

### **2.8.3 Factors to factor arrays**

The creation of factor arrays consists of the weighted amalgamation of defining Q-sorts. The viewpoints of the Q-sorts that each loaded significantly on one factor were combined with those in the same factor to produce a shared viewpoint, amounting to a process of creating a mean average viewpoint. Q-sorts with higher loadings contribute more than those with lower loadings, as such factor arrays constitute weighted averages of the viewpoints held among the group (Stenner, Cooper, & Skevington, 2003). The end result is a single Q-sort for each factor that represents the

shared viewpoint expressed by the participants that loaded significantly on that factor, known as the factor array. Each factor array consists of each item of the Q-set with a corresponding ranking (-5 to +5) signifying its positioning on the Q-sort distribution grid.

#### **2.8.4 Factor arrays to interpretation of viewpoints**

Once the factor arrays were created the next step was to interpret their meaning.

Interpretation comprises “a careful and holistic inspection of the patterning of items in the factor array” (Stenner et al., 2003). The aim of this process was to uncover the viewpoints that exist among the data. To aid this process the factor arrays were each written out onto Q-sort distribution grids to allow for visual inspection of item positioning. The “crib sheet method of interpretation” was employed in order to allow for cross factor comparison (Watts & Stenner, 2012). This method involves considering the positioning of each item of the Q-set within a factor in relation to the other three factors. This method allows exploration of similarity and differences between the factors, and ensures that items of potential significance that are sorted towards the middle of the distribution (-1, 0 +1), are not ignored.

To embellish this process and provide an in-depth and valid interpretation, the qualitative data from participant’s feedback forms and notes made during the session were used to supplement this process. The addition of this information allowed a more detailed account of participant’s views to be uncovered and expressed. The demographic information collected from participants during the study was also incorporated in the interpretation process. This allowed a deeper understanding of the characteristics of the participants who were expressing these views. The addition of this qualitative data facilitated the interpretative process in moving from simply

descriptive, to developing a more theoretical understanding of what participants really felt and thought about recovery from psychosis.

The interpretation process in Q-methodology involves the use of abduction theory. Abduction theory involves devising a theory to explain what is observed, the aim of which is to provide explanation and generate new understanding (Peirce, 1931). The use of abduction theory posits that interpretations go beyond description, and instead one attempts to make meaning of the observations, where what is seen in the data is used as sign or clue for potential meaning or explanation (Shank, 1998; Watts & Stenner, 2012). Abduction theory was employed throughout both the analysis and interpretation process. Both the qualitative data and factor arrays were inspected and the use of abduction theory allowed the generation of hypotheses in order to understand and provide new insights in relation to the viewpoints being expressed.

### **2.8.5 Analysis of consensus statements**

The output from PQ-method (Schmolck, 2002) includes data on distinguishing and consensus statements for each factor. Distinguishing statements are those ranked significantly differently in one factor when compared with the other three factors. Distinguishing statements were used to inform the interpretation process to help establish the uniqueness of the viewpoint being expressed by each factor.

Consensus statements are those ranked similarly by participants across multiple factors. Consensus statements may still be used in the interpretation process to inform an understanding of the viewpoint being expressed, but add little to the process of differentiation between factors. The table of consensus statements was inspected to establish which statements participants held similar viewpoints about and help to illuminate areas of agreement across factors.

During the analysis process consensus statements were separated into those which participant's consensus was positive, indicating participants were in agreement that the item was helpful to recovery, and those where the consensus was negative, indicating participants were in agreement that the item was not helpful to recovery. The analysis of consensus statements was supplemented by the qualitative feedback and provided an understanding of participants' shared opinions across factors, adding to the richness of the overall data analysis.

### **2.8.6 Analysis of qualitative feedback**

Participants were asked to fill in an optional feedback form at the end of the Q-sort task (see Appendix G). The qualitative data from the feedback forms along with notes made by the researcher during the task, were used to supplement the interpretation of factors and the analysis of consensus statements. This data added to the richness of interpretations, and allowed the generation of meaningful hypotheses in relation to understanding participant's views about recovery (Watts & Stenner, 2012).

Participants also provided feedback relating to their experience of completing the task and were asked to indicate items they felt were missing from the Q-set. This feedback was collected and is presented in results in the chapter.

## **2.9 Dissemination**

The results of the research will be shared with the staff teams from the recruiting hospital, along with other acute inpatient units throughout Essex. Relevant journals that may be interested in this area of work such as the *International Journal of Social Psychiatry*, *Psychology & Psychotherapy: Theory, research and practice*, the *British Journal of Clinical Psychology*, *Operant Subjectivity*, and the *Journal of Mental Health* will be contacted. Participants who provide consent to being contacted

following completion of the study will be provided with a written summary of the project and findings.

## Chapter 3 Results

### Chapter outline:

This chapter begins by describing the demographic information for participants included in the data analysis and a rationale for excluded data is given. The process of statistical analysis is presented along with an examination of the assumptions required for Q methodology analysis. The factor solution resulting from the data analysis is presented along with narrative interpretations of the viewpoints expressed by each factor. Information relating to distinguishing and consensus statements is then provided along with an evaluation of the qualitative feedback from participants.

### 3.1 Participant information

A total of 38 participants were recruited across four acute wards in a psychiatric hospital. The data of 36 participants who completed the study were included in the analysis. Participant's data is self-report, 32 (89%) were male and 4 (11%) were female. Their ages ranged from 23-65 with a mean sample age of 40 years (SD 13.08). When asked their diagnoses, 15 (42%) reported a diagnosis of schizophrenia, 6 (17%) reported multiple diagnoses, 5 (14%) reported no diagnosis, and 4 (11%) were unsure of their diagnosis. Schizoaffective disorder, psychosis, schizotypal personality disorder, bipolar, anxiety, and drug induced psychosis were each reported as the primary diagnosis by 1 (2.8%) participant. When asked to describe their ethnic background, 16 (44%) described themselves as White, 13 (36.1%) described themselves as Black, 3 (8.3%) as Mixed, 3 (8.3%) as Asian and 1 (2.8%) participant described themselves as Other. Participants were asked to report their psychosis experiences, 18 (50%) described experiencing paranoia or unusual beliefs, 14 (39%) reported hearing voices, 13 (33%) described seeing things that were not there, 19

(53%) reported experiencing disorganised thoughts, and 24 (67%) reported experiencing negative symptoms such as low mood or difficulties with motivation. Of the entire sample, 28 (78%) reported current experience of psychosis symptoms (see Table 7 for demographic information of study participants).

### **3.1.1 Excluded participants**

Two participants were excluded from the analysis as it was concluded that their data were invalid due to their lack of engagement with the task (Krueger, Donner, Kirsch, Maack, & Krueger, 2001). Q-sorts represent participants subjective viewpoint in relation to a subject matter, through a process of meaningfully sorting items with a self-referential focus (Watts & Stenner, 2012). Where this process has not been completed meaningfully, the end result is a Q-sort that is not a valid representation of the subjective viewpoint of that participant. Including Q-sorts that are not meaningfully sorted in the analysis impacts upon the factor solution as all Q-sorts are intercorrelated and contribute to the creation of factors.

Mental capacity was assessed during the process of gaining informed consent and continually during the task, as per the inclusion and exclusion criteria for participation (Mental Capacity Act, 2005). It has been suggested that Q-sorting requires a high level of cognitive processing and although these participants were deemed to possess the mental capacity to participate, their engagement in the task provided sufficient evidence that the cognitive requirements of the task were too high (Tubergen & Olins, 1978). One participant completed half of the task meaningfully, by reading through the statements and considering how important they were. However, during the second half of the task the participant appeared to become disengaged and placed the Q-set items onto the distribution grid without reading them, and in the order they were already in on the table. Similarly, the second

participant struggled with understanding the task instructions and became confused with which items were important and which were unimportant. This participant also appeared to tire during the session and became disengaged with the task. Both participants struggled to respond to prompts and as such it was concluded that the final Q-sorts were not representative of these participants viewpoints and so their data was excluded (Cramm, Finkenflügel, Kuijsten, & Exel, 2009).

Table 7:  
*Demographic information for study participants*

Factor	Total Sample (n=36)	Factor 1 (n=6)	Factor 2 (n=8)	Factor 3 (n=7)	Factor 4 (n=4)	Multiple loading (n=6)	Non-loading (n=5)
<b>Gender</b>							
Male (%)	32 (89)	6 (100)	8 (100)	5 (72)	2 (50)	6 (100)	5 (100)
Female (%)	4 (11)	0	0	2 (28)	2 (50)	0	0
<b>Age</b>							
Mean (SD)	39.97 (13.08)	37 (12.94)	41.5 (15.3)	41.29 (15.5)	39.5 (12.79)	36 (10.6)	44 (12.9)
Range	23-65	24-53	22-65	24-63	26-54	23-53	26-61
<b>Ethnicity</b>							
Asian (%)	3 (8.3)	1 (16.7)	1 (12.5)	0	0	1 (16.7)	0
Black (%)	13 (36.1)	2 (33.3)	3 (37.5)	2 (28.6)	1 (25)	3 (50)	2 (40)
White (%)	16 (44.4)	2 (33.3)	2 (25)	5 (71.4)	3 (75)	2 (33.3)	2 (40)
Mixed (%)	3 (8.3)	0	2 (25)	0	0	0	1 (20)
Other (%)	1 (2.8)	1 (16.7)	0	0	0	0	0
<b>Education level</b>							
Primary (%)	1 (2.8)	1 (16.7)	0	0	0	0	0
Secondary (%)	7 (19.4)	1 (16.7)	2 (25)	1 (14.3)	1 (25)	2 (33.3)	0
Further (%)	14 (38.9)	2 (33.3)	3 (37.5)	4 (57.1)	0	1 (16.7)	4 (80)
Higher (%)	13 (36.1)	2 (33.3)	2 (25)	2 (28.6)	3 (75)	3 (50)	1 (20)
Other (%)	1 (2.8)	0	1 (12.5)	0	0	0	0
<b>Marital Status</b>							
Single (%)	29 (80.6)	5 (83.3)	6 (75)	5 (71.4)	3 (75)	5 (83.3)	5 (100)
Divorced (%)	2 (5.6)	0	0	1 (14.3)	1 (25)	0	0
Separated (%)	3 (8.3)	1 (16.7)	2 (25)	0	0	0	0
Widowed (%)	1 (2.8)	0	0	1 (14.3)	0	0	0
Married (%)	1 (2.8)	0	0	0	0	1 (16.7)	0
<b>Religion</b>							
Christianity (%)	15 (41.7)	2 (33.3)	1 (12.5)	5 (71.4)	0	4 (66.7)	3 (60)
Islam (%)	4 (11.1)	0	2 (25)	1 (14.3)	0	1 (16.7)	0
Sikhism (%)	2 (5.6)	0	2 (25)	0	0	0	0
Judaism (%)	1 (2.8)	0	0	0	1 (25)	0	0
None (%)	9 (25)	4 (66.7)	1 (12.5)	1 (14.3)	2 (50)	0	1 (20)
Agnostic (%)	1 (2.8)	0	0	0	1 (25)	0	0
Other (%)	2 (5.6)	0	2 (25)	0	0	1 (16.7)	0
Rather not say (%)	2 (5.6)	0	0	0	0	0	1 (20)
<b>First contact NHS</b>							
Total (years)	362.83	38.42	125.25	28.16	34	81	56
Range	2month-41 years	5month-13 years	3month-41 years	2month-14years	1-15years	4years -30 years	3 years-20 ears
Mean (SD)	10.67 (10.08)	6.4 (4.74)	17.89 (16.01)	4.69 (5.17)	8.5 (5.8)	14 (9.9)	11 (7.5)
<b>No. admissions</b>							
Total	175	17	50	22	30	26	35*
Range	1-23	1-9	2-20	1-8	1-23	1-10	1-15*
Mean (SD)	4.86 (5.47)	2.83 (3.13)	6.25 (6.39)	3.14 (2.54)	7.5 (10.5)	4 (3.2)	7 (6.2)*
<b>Duration psychosis experience</b>							
Total (years)	285.33	37.42	62.25	24.16	13.5*	91	57
Range	2 month-30 years	5month-13 years	3month-20 years	2month-14 years	6 month-10 years*	4 years-30 years	1 year-20 year
Mean (SD)	8.92 (7.86)	6.24 (4.85)	10.38 (7.85)	4.03 (5.15)	4.5 (4.92)*	15 (10)	11 (8.4)
<b>Diagnosis</b>							
Schizoaffective disorder (%)	1 (2.8)	0	0	0	1 (25)	0	0
Schizophrenia (%)	15 (41.7)	2 (33.3)	5 (62.5)	1 (14.3)	1 (25)	3 (50)	1 (20)
Psychosis (%)	1 (2.8)	0	0	0	0	0	1 (20)
Schizotypal PD (%)	1 (2.8)	1 (16.7)	0	0	0	0	0
Drug induced psychosis (%)	1 (2.8)	1 (16.7)	0	0	0	0	0
Bipolar (%)	1 (2.8)	0	0	0	0	1 (16.7)	0
Anxiety (%)	1 (2.8)	0	0	0	1 (25)	0	0
Multiple Diagnoses (%)	6 (16.7)	0	1 (12.5)	3 (42.9)	0	1 (16.7)	1 (20)
No Diagnosis (%)	5 (13.9)	0	2 (25)	1 (14.3)	1 (25)	0	1 (20)
Not reported/ Unknown (%)	4 (11.1)	2 (33.3)	0	2 (28.6)	0	1 (16.7)	1 (20)
<b>Symptom</b>							
Paranoia/ unusual beliefs (%)	18 (50)	3 (50)	2 (25)	3 (42.9)	3 (75)	3 (50)	4 (80)
Hearing voices (%)	14 (38.9)	3 (50)	3 (37.5)	2 (28.6)	3 (75)	2 (33.3)	1 (20)
Seeing things that arent there (%)	13 (33.3)	1 (16.7)	2 (25)	3 (42.9)	3 (75)	3 (50)	1 (20)
Disorganised thinking (%)	19 (52.8)	4 (66.7)	3 (37.5)	5 (71.4)	3 (75)	1 (16.7)	3 (60)
Negative symptoms (%)	24 (66.7)	5 (83.3)	2 (25)	6 (85.7)	3 (75)	4 (66.7)	4 (80)
No. participants reporting symptoms (%)	28 (77.8)	5 (83.3)	4 (50)	7 (100)	3 (75)	4 (66.7)	5 (100)

Note. \* based on estimates as incomplete data provided

## **3.2 Statistical analysis**

The Q-sorts of 36 participants were intercorrelated and analysed using the computer software PQ method (Schmolck, 2002). A principal component analysis and varimax rotation were employed which resulted in the extraction of four factors explaining 38% of the study variance. Twenty-five of the 36 participant's Q-sorts loaded significantly on one of the four factors. Factor loadings of 0.36 or above were significant at the  $p < 0.01$  level. The factors are presented in the order of extraction by PQ method, which after rotation is non-meaningful.

### **3.2.1 Examination of assumptions required for Q-methodology**

Kaiser-Guttman Criteria:

The Kaiser-Guttman criteria suggests that all factors should have an Eigenvalue of 1.0 or more (Guttman, 1954; Kaiser, 1960, 1970). The Eigenvalues of the four-factor solution were all above 1.0, (Factor 1: 4.84; Factor 2: 4.13; Factor 3: 2.36; Factor 4: 2.32), therefore justifying the inclusion of all four factors.

Humphrey's rule:

Humphreys rule suggests that the cross product of a factor's two highest loadings should be greater than twice the standard error (Brown, 1980). For this study, twice the standard error was calculated to be 0.27 and this criterion was satisfied for all four factors.

Factor loadings:

Factor loadings are presented in numbers depicting the strength of the association between a Q-sort and a factor. A statistically significant factor loading was calculated to be 0.3511 at the  $p < 0.01$  level. As the PQ Method program (Schmolck, 2002)

provides loadings in whole numbers (a loading of 0.3511 appears as 35), this level was rounded up to 0.36 to ensure statistical significance for each loading. Statistically significant factor loadings were flagged and contributed to the creation of the factor arrays (see Appendix J for rotated factor matrix demonstrating factor loadings for each factor, loadings marked with an X are statistically significant).

### **3.2.2 Factor extraction**

Factor extraction took place at both a statistical and theoretical level (Brown, 1980; McKeown & Thomas, 2013). As such a number of different factor solutions were considered and explored. Statistical considerations involved assessing the significance of factor loadings, and an evaluation of the Kaiser-Guttman criteria (Guttman, 1954; Kaiser, 1960, 1970) and Humphrey's rule (Brown, 1980).

Additionally, the number of Q-sorts, and therefore participants, that were included in each solution was considered (Watts & Stenner, 2012).

Theoretical consideration involved the use of abduction theory where the aim was to extract a factor solution that made both theoretical and statistical sense (Brown 1980; Peirce, 1931; Watts & Stenner, 2012). Both a four and five factor solution were considered as these solutions met the statistical criteria detailed above and provided a good fit between the amount of variance explained and the number of Q-sorts included in the solution. The four-factor solution provided viewpoints that were theoretically distinct in what they portrayed about participants views on recovery. The five-factor solution, although statistically stronger, provided a weaker distinction between viewpoints, (in that two of the factors appeared to share a common perspective in relation to recovery) and therefore made less theoretical sense in relation to expressing the differing viewpoints that were held among participants about recovery. From this process, the four-factor solution appeared to represent the

best fit between statistical and theoretical strength, being inclusive of a larger number of Q-sorts and expressing meaningful and distinct viewpoints in relation to the subject matter of recovery from psychosis.

### **3.3 Factor interpretations**

The process of factor interpretation revealed the four distinct viewpoints that were held among participants about what was important to them in their recovery from psychosis. The interpretations of each of the four factors are described below. In brackets are the item numbers from the Q-set statements (e.g. Item 3, 5, 6; see Appendix A for list of numbered Q-set items) which contributed to the factor along with the corresponding ranking, indicating the items position in the factor array (e.g. +4, -2, +1; see Appendix K for table of factor arrays).

#### **3.3.1 Factor 1: Stability, independence, and “keeping a roof over your head”**

Factor 1 explains 9% of the study variance and has an Eigenvalue of 4.84. The Q-sorts of six participants loaded significantly on this factor. Their ages ranged from 24-53 with a mean age of 37 (SD 12.94). All participants were male, two participants described themselves as White British, two as Black African, one as Indian and one as “Other”. One participant reported nine hospital admissions, the other five participants reported between 1-3 admissions, with the average number of admissions being 2.8. This group had one of the lowest average number of hospital admissions (3), but the second highest average duration of psychosis experiences (6 years).

This factor consisted of people who felt that the ability to maintain stable living arrangements and to support themselves or their family financially was most important to recovery. Participants spoke of the importance of having “a roof over your head before you can do anything” (pp. 13) and how both finances and

employment were necessary to maintain this. Participants described worrying about their housing situation and the impact that not having stable living arrangements would have on their lives. For example, one participant stated, “I worry about whether I can keep looking after myself and I need a secure residence to have, because if I don’t know where I will be from day to day there is no point in trying” (pp. 26). Another participant spoke of the impact that not having secure housing would have on their ability to carry out independent study. As a result, this group felt that the most important forms of support were from the government and by gaining access to skills, education, or employment courses. For this group, their primary focus was first and foremost on being able to maintain a stable living environment. Therefore, feeling in control of their personal and living circumstances and being able to look after themselves was important, as it afforded them the ability to function independently in their daily lives, which was valued among this group (Items 1, 9, 19, 12, 42, 28, 29, 39 44: How much the government supports people with my difficulties, +5; How much control I have over my circumstances [money, living, employment etc.], +5; How able I am to support myself and/or my family financially, +5; How stable my living arrangements are, +4; How suitable my housing is [outside of hospital], +4; How able I am to look after myself [e.g. daily tasks] , +4; How able I am to cope with my mental health experiences myself, +3; How much support I get with financial problems, +3; How easily I can access employment/education/skills courses, +3).

This group viewed the reduction of mental health experiences as important to their recovery. However, their primary concern was the impact that their mental health experiences had on their day-to-day lives. As such this group were less concerned about societal or relational factors, and instead aimed to reduce symptoms for the

purpose of restoring their ability to function independently and uphold their personal responsibilities. For this group the reduction of mental health experiences enhanced their ability to maintain employment and bring in an income, allowing them to look after themselves and/or their family, and to keep a roof over their head (Items 41, 7, 28, 13, 2, 37: How much distress my mental health symptoms/voices cause me, +4; How much my mental health experiences affect my memory & concentration, +3; How able I am to cope with my mental health experiences myself, +3; How much my mental health experiences affect my mood/emotions, +2; How often my mental health experiences happen, +1; How much my mental health affects my ability to work, +2). A further barrier to recovery for this group was their use of drugs and alcohol. It's possible that this group used substances as a means to manage their mental health experiences or the associated distress. However, they recognised that their use of substances further impacted their mental health and their ability to function in day-to-day life and as such, reducing drug and alcohol intake was seen to be an important step towards recovery. Reducing substance use was rated more importantly by this group when compared with the other three groups (Item 49: How able/supported I am to reduce my drug/alcohol intake, +2).

Due to their reported struggles with maintaining secure housing, and the concerns they raised about the impact that unstable living arrangements may have on lives, it is possible that experiences of insecure living arrangements and financial difficulties were more common among this group and as such it's possible that these individuals came from more economically deprived backgrounds. Having a secure place to live is a basic human need and as stated by one participant "If my housing isn't secure it would make it hard for me to progress in life" (pp. 23). For these individuals being able to meet their basic needs became their primary focus and the maintenance of

these factors were paramount in achieving recovery. Additionally, those who experience social deprivation are more likely to experience difficulties with substance misuse (Daniel et al., 2009). A number of individuals reported difficulties with substance use and being able to reduce this was seen as important to their recovery.

Despite their comparatively low duration of engagement with mental health services, individuals in this group felt that to reduce the impact of their mental health experiences, gaining support from services was important for recovery. Interestingly, their average number of years in contact with mental health services was similar to the average number of years duration of psychosis. This factor therefore represents a group of people who were willing to access support from services when needed. The type of support that this group valued as most important was medication. Medication was rated more importantly by this group when compared with other groups.

Additionally, this group consisted of those who valued feeling in control of their circumstances and as such being involved in decisions relating to their treatment and care was considered important. Furthermore, it's possible that their focus on symptom reduction meant that medication was considered an acceptable form of treatment, possibly seeing it as a 'quick fix' in enabling them to get back to their normal level of functioning. Comparatively, other forms of support such as talking therapy were seen to be less important (Items 3, 48, 36, 16: How much my medication helps me, +3; How involved I am in my treatment and care, +2; How supported I feel by mental health services, +1; How much therapy helps me, -1). Further to this, in comparison to the more practical or medical forms of support through finance and housing, or receiving medication, this group viewed religion and relational factors such as receiving support from family or having positive relationships with others as less important to their recovery (Items 6, 8, 11, 26, 31, 32, 45, 20, 5, 30, 34, 38: How

much my religion/spirituality helps me to cope, -5; How much my religious/spiritual beliefs are respected by others, -5; How positively others view me, -5; How able/supported I am to manage feelings of loneliness and isolation, -4; How positive I view my relationships to be, -4; How much I'm able to reduce feeling a burden to others, -4; How much support I get from family/loved ones, -3; How involved my family/loved ones are in my treatment/care, -3; How supported/able I am to socialise with others, -2; How much I feel part of a community/society, -2; How well society understands my mental health difficulties, -1; How much staff treat me with dignity and respect, -1).

This factor represents a group whose primary focus in recovery centred around being able to maintain stable living and financial arrangements. Due to their reported struggles, it's likely these individuals experienced some level of social or economic deprivation, and as such this group felt that the most important forms of support were from the government, or through access to education/skills courses. This group valued feeling in control and being able to function independently.

### **3.3.2 Factor 2: Hope, optimism and enhancing wellbeing**

This factor explained 11% of the study variance and had an Eigenvalue of 4.13. The Q-sorts of eight of the participants loaded significantly on this factor. Their ages ranged from 22-65 with a mean age of 42 years (SD 15.3). All participants were male. Two described their ethnicity as White British, two as Black African, one as Black Caribbean, one as Indian, and two as Mixed. This group comprised the longest average duration of psychosis experience (10 years), the longest contact time with the NHS (18 years) and the second highest average number of hospital admissions (6). The number of hospital admissions for this group ranged from 2-20.

This factor consisted of people who reported that enhancing the positive aspects of mental wellbeing were the most important factors to recovery, and were the only group to view reduction of mental health symptoms as the least important factors. This group had the longest average number of years' duration of psychosis. As a result of the chronicity of their mental health experiences, these individuals may have adopted a view of recovery that aligns with the personal model of recovery endorsing "living well with" symptoms, rather than a need for complete symptom remission (Anthony, 1993). As such this group consisted of those who rejected medical conceptualisations of mental health and recovery.

For this group, intrapersonal factors such as how they felt about themselves and their future were integral to recovery. Many of the participants spoke about the importance of having self-worth and how experiencing mental health difficulties or being in hospital could impact on this. For example, one participant stated, "Upon entry to hospital your confidence has taken a bashing and it's important that your self-worth and purpose is reinstated" (pp.4). For this group maintaining hope and optimism were key factors in their recovery and many engaged with religious practices or spirituality to help them cope (Items 53, 4, 14, 54: How much I believe things can get better, +5; How much I feel my life has purpose, +5; How confident I am in my skills and abilities, +4; How much self-worth I feel, +2). These individuals felt their religion was a personal experience and were less concerned about how their spiritual practices were viewed by others (Item 34, 38: How much my religion/spirituality helps me to cope, +5; How much my religious/spiritual beliefs are respected by others, -4). Their spirituality supported them in maintaining a sense of purpose and self-worth, which helped them to feel more hopeful and optimistic in their journey to recovery. This group were less concerned about social evaluation. The personal benefits they got

form their spirituality appeared to protect them against the impact of negative social attitudes and stigma around mental health. Participants spoke of how “you should not worry what other people think or view you as” (pp. 21) or how “the only thing that matters is how you are judged by your God” (pp. 30) (Items 20, 30: How positively others view me, -3; How well society understands my mental health difficulties, -2).

Along with religion, this group engaged in wellbeing enhancing activities such as maintaining a good diet, exercise, and involvement with hobbies, as additional strategies to foster their sense of purpose and self-worth during recovery (Items 25, 17: How often I exercise and eat well, +3, How much I enjoy my activities/hobbies in the community, +1).

For participants in this group having a balance between time alone and self-coping versus seeking relational support from others was seen to be important. Participants in this group felt that positive relationships with peers and staff, and having support from family were important factors in recovery (Items 40, 26, 32, 31, 5: How much others respect my right to be alone, +4; How positive I view my relationships to be, +4; How much staff treat me with dignity and respect, +3; How much support I get from family/loved ones, +2; How much I feel part of a community/society, +2).

Research suggests that the experience of psychosis is strongly linked with poor social outcomes (Harrison et al., 1996). It’s possible, that due to their long-standing difficulties with psychosis, the importance this group placed on relational factors, represented what they believed to be important for recovery, but not necessarily things they felt they had.

This factor represented a group of people who rejected medical conceptualisations of mental health. Two members of this group reported that they did not have mental

health difficulties and another reported a diagnosis but stated that he did not agree with it. For this group, the experience of being an inpatient in a mental health hospital, driven by a model of psychiatry, may have led to disagreements between them and staff, in relation to understanding their experiences or in their treatment and care. One participant mentioned he had lost trust with the doctors due to the multiple diagnoses he had received and it's possible that this factor comprises a group of people who may be labelled by staff as "lacking insight". Therefore, feeling that staff treat them with dignity and respect was particularly important for this group. In addition, their rejection of the medical model, meant that treatments such as medication were not seen as helpful to recovery and instead this group valued intrapersonal factors such as self-belief and have a sense of purpose (Items 3, 53, 4: How much my medication helps me, -4; How much I believe things can get better, +5; How much I feel my life has purpose, +5).

Due to the duration of their mental health experiences, this group were more familiar with the experience of needing support from others, compared with those whose difficulties had a more recent onset. As such they were less concerned about feeling a burden to others. One participant stated, "I shouldn't be feeling a burden on others because quite often people are put in a position where they need help from others" (pp. 4) (Item 45: How much I'm able to reduce feeling a burden to others, -3). This group had long standing difficulties, therefore it's likely that the social impact of their experiences meant these individuals were also more used to spending time on their own, perhaps due to social isolation or the experience of multiple hospital admissions. As a result, feelings of loneliness and boredom were also less concerning for this group, (Items 8, 35: How able/supported I am to manage feelings of loneliness and isolation, -3; How able I am to manage feelings of boredom, -1).

This group comprised the longest average duration of contact with the NHS (18 years) and the highest average number of admissions (6). Their view of recovery was focused around enhancing hope and optimism through personal coping and relationships. As such they tended to sort factors relating to support from services toward the middle of the distribution. However, the chronicity of their mental health experiences and frequency of service use, meant that these individuals acknowledged support from services was necessary at times, however they viewed it as less helpful to their recovery than intrapersonal coping (Items 36, 16, 33: How supported I feel by mental health services, 0; How much therapy helps me, 0; How understanding staff are towards me, 0). This factor consisted of those who saw recovery in a non-symptomatic manner, instead valuing practices that enhance wellbeing and hope. Despite the duration of their psychosis experiences, this group were the only group that felt that factors relating to their mental or physical health symptoms and diagnosis were the least important to recovery. A large proportion of this group felt that either they had no symptoms or they reported experiencing their symptoms as positive. For example, one participant spoke of his voices as being “nice most of the time”, and reported that he saw colours which he experienced as positive (Items 2, 3, 7, 41, 18, 52, 37, 23, 15, 13: How often my mental health experiences happen, -5; How much my mental health experiences affect my memory & concentration, -5; How much distress my mental health symptoms/voices cause me, -5; How much my medication helps me, -4; How much my diagnosis is explained to me, -3; How much the impact of my physical health issues can be reduced, -3; How much my mental health affects my ability to work, -2; How much my mental health experiences affect my mood/emotions, -1; How much I believe I am more than my diagnosis/illness, -1; How much the side effects of medication can be reduced, -1).

This group consisted of those who had long term experience of mental health difficulties. They rejected medical conceptualisations of mental health and felt that reduction of ‘symptoms’ was not important for recovery. Instead these individuals valued intrapersonal factors such as maintaining hope and optimism, and found religion/spirituality to be a particularly important coping mechanism. For this group it’s likely that the chronicity of their mental health experiences impacted on their social networks, however this group felt that social relationships and support from others were important factors in recovery.

### **3.3.3 Factor 3: Emotional change through self-management and social support**

This factor explained 10% of the study variance and had an Eigenvalue of 2.36. The Q-sorts of seven of the participants loaded significantly on this factor. One participant’s Q-sort loaded negatively on this factor, meaning that this participant’s view was negatively associated with this factor. Five participants were male and two were female. Their ages ranged from 22-67, with a mean age of 42. Six of the seven participants in this group reported a relatively recent onset of psychosis experiences of four years or less, one participant reported having experienced issues with psychosis for 14 years. This group reported the shortest duration of experience of psychosis (4 years), the shortest time in contact with the NHS for mental health (5 years) and the joint lowest average number of admissions (3).

This factor consisted of people who valued self-management and coping with their experiences without the input of mental health services. Due to the relatively recent onset of psychosis experiences for the majority of participants in this group, it is likely that this factor represents a group of people with early stage psychosis. This was the only group where 100% of the participants reported experiencing symptoms and participants viewed being able to reduce the impact of mental and physical health

symptoms and enhance their sense of purpose and self-belief as important factors in their recovery (Items 7, 37, 14, 41, 27, 18, 13, 23, 4, 53, 54: How much my mental health experiences affect my memory & concentration, +5; How much my mental health affects my ability to work, +4; How confident I am in my skills and abilities, +4; How much my mental health affects my personal freedoms and rights, +4; How much my mental health experiences affect my mood/emotions, +3; How much I feel my life has purpose, +3; How much I believe things can get better, +3; How much the impact of my physical health issues can be reduced, +2; How much the side effects of medication can be reduced, +1; How much self-worth I feel, +1; How much distress my mental health symptoms/voices cause me, 0). For this group being able to manage without the need for engagement with services was important. They valued self-management and utilizing their own resources, such as through exercise or religion, to help them cope with their experiences (Items 28, 34, 44, 25: How able I am to cope with my mental health experiences myself, +5; How often I exercise and eat well, +5; How able I am to look after myself [e.g. daily tasks], +4; How much my religion/spirituality helps me to cope, +2). One participant wrote “exercise helps release endorphins and provides a sense of achievement” (pp. 16) and another spoke of how their religion helps them to cope “I believe that God and me personally can overcome anything” (pp.32). Individuals in this group valued feeling in control of their circumstances and being able to function independently of formal forms of support (Items 44, 9: How able I am to look after myself (e.g. daily tasks), +4; How much control I have over my circumstances [money, living, employment etc.], +3). This group comprised those who were adjusting to the recent onset of their psychosis experiences. As such these individuals were motivated to maintain a sense of control and find their own coping mechanisms to help them in their recovery.

In contrast to accessing formal avenues of support, such as from mental health services, this group saw the value of gaining support from family and loved ones and recognised the value of maintaining social relationships in helping them to recover (Items, 31, 11: How much support I get from family/loved ones, +3; How supported/able I am to socialise with others, +2). Positive relationships with others were viewed by individuals in this group as important in aiding recovery, and individuals felt that spending time with others was more helpful to recovery than being alone. One participant stated, “as a society we enjoy seeing each other through the good as well as the bad times” (pp.16) (Items 26, 46, 40: How positive I view my relationships to be, +2; How much private time I have to myself, -4; How much others respect my right to be alone, -3). Individuals recognised relational factors as impacting on their recovery and felt that feelings of loneliness and being a burden would hinder their recovery (Items 45, 8: How much I’m able to reduce feeling a burden to others, +1; How able/supported I am to manage feelings of loneliness and isolation, 0). Research suggests that the experience of psychosis has a significant impact on social functioning, and that being able to achieve “social recovery” is an often reported, yet little achieved aim for service-users (Fowler et al., 2017). It’s possible that the increased focus on relational factors for this group, was in response to the impact their experiences of psychosis had on their ability to function socially and maintain social roles. As such being able to reduce the social impact of their experiences may be an important goal for this group.

This group had the lowest average number of years’ experience of psychosis (4 years) and the least time in contact with the NHS (5 years). Due to their recent onset of psychosis experiences, this group felt less reliant on services and instead value was placed on self-management and relational support. In contrast, access to, and support

from mental health services, were seen as some of the most unimportant factors in recovery (Items 3, 32, 47, 36, 16, 10, 33, 52, 24: How comfortable the hospital ward/environment is, -5; How many activities there are for me to do in hospital, -4; How understanding staff are towards me, -4; How much my diagnosis is explained to me, -4; How much therapy helps me, -3; How supported I feel by mental health services, -2; How available hospital/ward staff are to support me, -2; How much staff treat me with dignity and respect, -1; How much my medication helps me, -1). Likely stemming from their limited use of services, this group were less concerned about psychiatric perspectives of mental health, such as gaining an understanding of their diagnosis. Instead these individuals felt that having a view of themselves beyond mental health labels was important (Items 15, 52: How much I believe I am more than my diagnosis/illness, +2; How much my diagnosis is explained to me, -4). For this group mental health services appeared to present more of a barrier than a facilitator to recovery. Participants felt that reducing the degree to which their mental health impacted on their freedom and rights, such as through involuntary hospitalisation and restricted leave, was a key factor in their recovery (Items 47: How much my mental health affects my personal freedoms and rights, +4).

This group consisted of those who were experiencing early stage psychosis. They represent a group of people who were still adjusting to their experiences and making sense or meaning of what was happening to them. As such they were less willing to accept medical labels and saw accessing support from mental health services as a barrier to recovery rather than a facilitator. Instead their motivation was around trying to find their own coping mechanism and they placed value on getting back to, or maintaining, their usual social roles and relationships.

### **Negatively loading Q-sort: Psychosis as a gift from God**

One participant loaded negatively on this factor, meaning this participant's view opposed that of the rest of the group. This participant was male aged 63 and reported one year's experience of psychosis and one hospital admission. This suggests this participant was also experiencing his first episode of psychosis, but later in life. It's possible the difference in age between this participant and the rest of those in the factor, contributed to his difference in experience of psychosis and recovery. For the majority of the group, reducing mental health symptoms through self-coping was seen as paramount for recovery. For this participant however, the reduction of symptoms and the negative impact of symptoms on work, freedom and cognitive abilities were seen to be the most unimportant to factors to recovery (Items 7, 28, 27, 37, 13: How much my mental health experiences affect my memory & concentration, -5; How able I am to cope with my mental health experiences myself, -5; How much my mental health affects my personal freedoms and rights, -4; How much my mental health affects my ability to work, -4; How much my mental health experiences affect my mood/emotions, -3). This participant reported hearing voices and seeing things that weren't there, however he described these experiences as "a gift from God" (pp.33). This participant understood his mental health experiences to be associated with his religion and as such felt their presence to be a positive experience. He disputed that his experiences were part of a mental health problem, and therefore the reduction or ability to cope with "mental health symptoms" was not important to him. In response to items from the Q-set that were relating to mental health symptoms, he reported "I am not a mental case, if you have a religion, that is the only reason" (pp. 33).

However, this participant's current experience was that of being an inpatient in a mental health hospital. As such his focus on what was important to him was directed towards his current environment. For this participant, the comfort of his surroundings and having things to do, along with maintaining positive relationships with staff and peers were rated as important. (Items 20, 24, 10, 33, 36, 47, 32: How positively others view me, +5; How comfortable the hospital ward/environment is, +5; How many activities there are for me to do in hospital, +4; How understanding staff are towards me, +4; How supported I feel by mental health services, +2; How available hospital/ward staff are to support me, +2; How much staff treat me with dignity and respect, +1). As this participant's conceptualisation of his experience was of a religious gift, he felt he did not need to be in hospital and therefore was motivated to return to his usual life. He reported wanting to get back to his community and described an ambition to become involved in charity work. As such, other factors that were important to him were related to his life outside of hospital (Items 5, 22, 39, 17, 19, 42: How much I feel part of a community/society, +3; How easily I can access meaningful activities in the community, +3; How easily I can access employment/education/skills courses, +2; How much I enjoy my activities/hobbies in the community, +1; How able I am to support myself and/or my family financially, +1; How stable my living arrangements are, +1).

#### **3.3.4 Factor 4: Symptom reduction through mental health support**

This factor explained 8% of the study variance and had an Eigenvalue of 2.32. The Q-sorts of four participants loaded significantly on this factor. Two of this group were male and two were female. Their ages ranged from 26-54 with a mean age of 40. Three of the sample reported being White British and one Black Caribbean. Only one member of this group followed a religion (Judaism). And 75% of the sample were

educated to university level. This group consisted of those who reported the most symptoms per participant, the highest average number of admissions (7.5), the second highest time in contact with the NHS (9 years) but the second lowest average duration of psychosis experience (5 years).

This factor consisted of those who felt that reducing the impact of mental health symptoms and receiving support through mental health services were the most important factors in recovery. For this group the presence of mental and physical health symptoms along with side effects from medication impacted heavily on recovery. This factor represents a group of people who experienced acute and distressing episodes of psychosis and as such the reduction of mental health experiences and distress was most important to them in recovery (Items 28, 41, 7, 13, 2, 18, 23: How much distress my mental health symptoms/voices cause me , +5; How able I am to cope with my mental health experiences myself, +5; How much my mental health experiences affect my memory & concentration, +4; How much my mental health experiences affect my mood/emotions, +2; How often my mental health experiences happen, +1; How much the impact of my physical health issues can be reduced, +1; How much the side effects of medication can be reduced, 0). This group represented people who felt recovery was almost solely related to the reduction of symptoms through mental health support, which is reflected in their service use data. As such these individuals may view mental health in line with medical models of understanding, perhaps seeing mental health difficulties as an “illness like any other” (Longdon & Read, 2017). It’s possible that their heavy use of mental health services may have contributed to their adoption of this model of explanation. Participants in this group viewed their symptoms as burdensome and felt that their mental health experiences impacted on other areas of their life, such as their ability to work, and

therefore reducing the impact of mental health symptoms was rated as important by this group (Items 27, 37: How much my mental health affects my ability to work, +3; How much my mental health affects my personal freedoms and rights, +1). This group also reported the highest number of symptoms per person. Their symptom focused nature meant that understanding more about their diagnosis was helpful to them, suggesting that this group were more willing to accept their diagnoses, and were more on board with psychiatric conceptualisations of mental health. This group also viewed societal views of mental health as important to recovery. They valued social acceptance and viewed their mental health status as having a social impact.

Research has suggested that medical conceptualisations of mental health experiences as illnesses, leads to increased levels of stigma and negative social attitudes (Longdon & Read, 2017; Read, Haslam, Magliano, 2013). It's possible that their medicalised view of mental health leaves them more susceptible to self-stigma or the expectation of stigma from others and this may contribute to the importance they place on societal understandings of mental health (Items 52, 30: How much my diagnosis is explained to me, +4; How well society understands my mental health difficulties, +3).

For this group, gaining support from mental health services was viewed as integral to recovery and individuals were open to a variety of types of support, such as therapy, medication or psychoeducation (Items 36, 3, 16, 52: How supported I feel by mental health services, +5; How much my diagnosis is explained to me, +4; How much therapy helps me, +4; How much my medication helps me, +1). Participants felt support from services was both helpful and necessary to manage their experiences. One participant reported feeling worried that their symptoms would return were they to go home and felt that staying in hospital would be more beneficial. Further to this, this group were sensitive to the quality of support they received and considered

aspects of care such as how safe they felt in hospital, and having positive relationships with staff, as important to recovery (Items 33, 47, 21, 24, 32: How available hospital/ward staff are to support me, +3; How safe I feel in hospital, +3; How much staff treat me with dignity and respect, +2; How understanding staff are towards me, +1; How comfortable the hospital ward/environment is, +1).

Additionally, they valued the amount of involvement that both they and their family had in their treatment and care (Items 48, 6: How involved I am in my treatment and care, +4; How involved my family/loved ones are in my treatment/care, +3).

For this group the least important factors were those related to drug and alcohol intake or religion. Only one participant described themselves as religious. (Items 34, 38, 49: How much my religious/spiritual beliefs are respected by others, -5; How much my religion/spirituality helps me to cope, -5; How able/supported I am to reduce my drug/alcohol intake, -5). Perhaps due to their heavy focus on symptom reduction and their medical conceptualisation of mental health, this group placed less value on relationships in the recovery process (Items 26, 5, 11, 20, 31: How positive I view my relationships to be, -3; How much I feel part of a community/society, -2; How supported/able I am to socialise with others, -1; How positively others view me, -1; How much support I get from family/loved ones, -1). Similarly, their heavy focus on mental health services for supporting symptom reduction and recovery, meant that this group felt self-coping mechanisms such as engaging in activities or setting goals were less important (Items 17, 50, 10, 22, 25: How much I enjoy my activities/hobbies in the community, -4; How supported I am to set goals for myself, -4; How many activities there are for me to do in hospital, -3; How often I exercise and eat well, -3; How easily I can access meaningful activities in the community, -2). Additionally, they placed less importance on practical forms of support such as

through finance or education (Items 29, 39: How much support I get with financial problems, -4; How easily I can access employment/education/skills courses).

This factor represents a group of people who experienced acute and distressing episodes of psychosis. They reported high use of mental health services and felt that the reduction of mental health experiences through support from services were the most important factors to them in recovery. This group adopted a medicalised view of mental health and its possible that this, coupled with their desire for social acceptance, left them more susceptible to the impact of negative social evaluation or stigma around mental health.

### **3.4 Distinguishing and consensus statements**

The table of distinguishing and consensus statements was inspected. Distinguishing statements were used to inform the interpretation process (see Appendix L for distinguishing statements for each factor). Only one statement was considered a consensus statement across all factors (Item 43: How much I feel I have equal opportunities compared to others), meaning this item was ranked similarly across all four factors. The remaining consensus statements demonstrate some similarity in ranking across multiple factors, but where there was still some level of difference based on how the item was ranked in one or more factors (see Appendix M for consensus statements ordered by consensus to disagreement).

For this study, consensus statements allowed an understanding of which aspects of recovery participants held similar views about across factors and whether these aspects of recovery were viewed to be important or unimportant (see Table 8 for consensus statements). Table 8 demonstrates the top five consensus statements that were rated as either important or unimportant across factors (statements where the

consensus represented a neutral viewpoint [i.e. mostly -1, 0, +1] have not been included but can be found in Appendix M).

Table 8:

*Top five consensus statements rated as important and unimportant*

<b>Consensus statements rated as important</b>	<b>Factors</b>			
	1	2	3	4
44 How able I am to look after myself (e.g. daily tasks)	4	1	4	0
48 How involved I am in my treatment and care	2	1	1	4
9 How much control I have over my circumstances (money, living , employment etc.)	5	2	3	2
28 How able I am to cope with my mental health experiences myself	3	2	5	5
1 How much the government supports people with my difficulties	5	3	0	2
<b>Consensus statements rated as unimportant</b>				
22 How easily I can access meaningful activities in the community	0	-2	-3	-2
38 How much my religious/spiritual beliefs are respected by others	-5	-4	-5	-5
10 How many activities there are for me to do in hospital	-1	0	-4	-3
20 How positively others view me	-5	-3	-5	-1
43 How much I feel I have equal opportunities compared to others*	-3	-1	-2	-2

*Note.* \*consensus statement across all four factors

The consensus statements that were rated as important demonstrate that participants across three factors (Factors 1, 2, and 3) valued self-management. Additionally, having some level of choice or control in their circumstances, both financially and in mental health care was endorsed across all factors. Endorsed items are those sorted between +1 to +5, indicating that participants felt these items were important to recovery. Further to this having support from the government was also endorsed by participants across three factors (Factors 1, 2, and 4). These findings are in line with what may be expected from a majority male sample (89%), as research suggests that men are more likely to value control and less likely to seek help from others when compared with women (Mackenzie, Gekoski, & Knox, 2006; Möller-Leimkühler, 2002; Yousaf, Grunfeld, & Hunter, 2015). The qualitative data supports these findings as many participants commented about issues with finance, housing or employment during the task. Similarly, participants often spoke of how important it was for them to be independent and not rely on others. One participant spoke of the

lack of support he had received from his family from a young age and how this necessitated that he be independent and able to look after himself.

In contrast, having access to activities in the community was negatively endorsed by participants across three factors (Factors 2, 3, and 4). Negatively endorsed items are those sorted between -1 to -5, indicating participants felt these items were less important or unimportant to recovery. Having activities to do in hospital was also negatively endorsed by 3 factors (Factors 1, 3, and 4). This suggests that for this sample, access and engagement in activities was seen to be less important to recovery. Similarly, participants across all factors felt that how much their religious beliefs were respected by others, how positively other people viewed them, and having equal opportunities were less important or unimportant to them in their recovery. These items were negatively endorsed by participants across all four factors.

The qualitative data collected during the study provides some additional insights into these consensus statements. A number of participants commented on their religion being a personal thing and reported that even when they felt religion was an important coping mechanism, whether others respected it or not was unimportant to them. For example, one participant stated, “religion is personal and so it doesn’t matter if others respect it” (pp. 21). Another participant spoke of how the lack of support he had received from others meant that he cared little about what others thought of him “left home at 15 without help from family. Don’t care what family think about my mental problems” (pp.13). Another stated “I don’t need anyone to accept me to be who I am” (pp. 19). Having equal opportunities to others (Item 43) was the only consensus statement ranked significantly similar across all factors. This statement was ranked as unimportant, however participants comments during the task suggest there may be

alternative explanations for the positioning of this statement. For example, one participant commented, “equal opportunities are important but they are a myth, there is no such thing as equal opportunities” (pp. 36). This participant positioned having equal opportunities as unimportant due to this reasoning. It is therefore possible that other participants shared this viewpoint, suggesting that although this item was ranked as unimportant across all factors, participants reasoning may reflect that they felt that this was unachievable, rather than unimportant.

#### **3.4.1 Exploration of qualitative feedback**

Participants were given the opportunity to provide feedback on the task. They were asked whether there was anything that was important to recovery that was missing from the Q-set statements and whether they had any general feedback about the task.

#### **3.4.2 Additional factors important to recovery not included in the Q-set**

Thirty-three of the 38 participants did not identify any additional items of importance to recovery that were not included in the Q-set. However, five participants suggested additional items that they felt were important to recovery and should be included. One participant commented that due to the side effects of medication they felt the introduction of new medications was important for recovery “I have suffered bad side effects from many different mental health medications given to me, there is a need for new safer and more effective medications” (pp.4). Another participant commented that the happiness of their children was an important factor in their recovery “My children developing into happy adults” (pp.35). One participant felt that issues related to home treatment, care plans and support after discharge were important in their recovery and were not included in the Q-set. One participant felt that “chance, fate, fortune, and luck” (pp.36) were important factors in recovery. Finally, issues to do

with how mental health is portrayed in the media were considered by one participant who commented “my illness doesn’t get enough publicity media wise” (pp. 3).

### **3.4.3 Feedback on the task**

During the task many participants commented verbally that they found completing the task to be a positive experience and that it helped them to think more about recovery and what was important to them. Participants also reported that they appreciated being given the opportunity to express their views about recovery and the care and support they had received. Additionally, some participants commented that they struggled with the sustained concentration which was required for the task. All participants were encouraged to stop or take breaks if they found the task difficult. One participant decided to stop without completing the task due to this reason. Seven participants provided written feedback about their experience of completing the task. Their comments are detailed below:

*“Some cards don’t stay in the same place – their importance may change over time”*  
(pp.36).

*“I enjoyed the research interview as I was helped to understand myself better and give my views which is important to me”* (pp. 4).

*“Many a grey area with many of the statements”* (pp. 35).

*“It was good and got my brain working again. I got to do something productive and it also helps people acknowledge the good people are doing taking care of people”*  
(pp.21).

*“I can’t think and describe all my psychological system in a few minutes”* (pp.17).

*“I hope I could be helpful”* (pp.24).

*“Made me think what’s important and not important” (pp.26).*

## Chapter 4: Discussion

### Chapter outline:

This chapter explores the views that service-users who experience psychosis hold about what is important to them in recovery. The four recovery factors identified are discussed in light of previous research and psychological theory. The consensus statements of pertinent recovery factors, along with discussion around the qualitative feedback from the task, are explored. Clinical implications and suggestions for future research are presented. Following which, the strengths and limitations of the current study are discussed, and the chapter concludes with a personal reflective account of the research process.

### 4.1 Discussion of findings

This study aimed to explore the views of an inpatient population of service-users about factors that promote recovery from psychosis using a Q-methodology design. Analysis revealed four distinct viewpoints that were present relating to factors that promote recovery. These were: *Stability, independence, and “keeping a roof over your head”*; *Hope, optimism and enhancing wellbeing*; *Emotional change through self-management and social support*; and *Symptom reduction through mental health support*. These results suggest that service-users hold different views about what is important to them in recovery. An exploration of these views in light of previous research along with suggestions for clinical implications and future research will be discussed.

#### 4.1.1 Factor 1: Stability, independence and “keeping a roof over your head”

Factor 1 represents a group of individuals for whom the most important factors in recovery were related to meeting basic needs for housing, money and employment.

This group valued stability, independence, and self-control. Being able to uphold their personal responsibilities to provide for themselves and/or their family, along with maintaining a safe and secure place to live was paramount for recovery. As such, the main sources of support for this group were from the government and through access to skills and employment courses. This group were willing to access support from mental health services, however their preference for treatment was through medication rather than therapy or psychoeducation. Additionally, they valued support in reducing drug and alcohol intake, suggesting that this group may experience difficulties with substance use. Through their desire to maintain independence, it is possible that this group used substances as a self-coping strategy to manage the impact of their mental health experiences, which were also considered to impact on recovery.

The literature review completed as part of this study, along with a systematic review exploring recovery from psychosis in a broader population, indicates a number of factors that contribute to additional challenge during recovery, such as discrimination, substance misuse, and social disadvantage (Wood & Alsawy, 2017). The impact of these barriers is demonstrated by Spaniol et al. (2002) who found that African-American's from disadvantaged backgrounds, with co-morbid substance use, and an earlier onset of psychosis, had the greatest struggles in recovery. Participants represented by this factor had the second longest duration of psychosis experiences, were likely to experience issues with substance use, and four of the six were from Black, Asian or minority ethnic backgrounds. In addition, the importance this group placed on accessing support with housing, finance and being able to maintain stability within their personal circumstances, suggests this factor may represent those who

experience some level of social deprivation, and may therefore have the most difficulty in recovery.

For this group issues around finance, employment and housing were considered to have the most impact on recovery. This group's view of recovery likely aligns with a functional recovery model, where the main aims are around obtaining and maintaining security with finance, housing and employment (Whitley & Drake, 2010). Research suggests that poorer mental health is linked with increased difficulty with issues relating to welfare rights (Balmer, Pleasence, & Buck, 2010; Read, 2004, 2010). Additionally, poverty is suggested as both a causal and maintaining factor in psychosis (Read, 2004, 2010; Wilkinson & Pickett, 2010). Mediating factors in this relationship are linked to discrimination, lack of power, access to resources and social status (Read, Johnstone, & Taitimu, 2013).

In the UK over the past decades, the philosophy that has underpinned discourses around social deprivation and mental health is attributed to a "treatment first" approach. This approach theorises that treating mental health difficulties as the first step, will lead to individuals developing their own capacities to alleviate social issues, through being "well enough" to get a job or access the support they need, affording them the ability to become contributing members of society (Padgett et al., 2006; Slade, 2012). Contrasting with this is the "housing first" approach, which originated in the US and has recently been implemented in the UK. This approach advocates that having a secure place to live should come first, irrespective of adherence to treatment plans (Slade, 2012; Slade et al., 2014; 'The Principles of Housing First', 2017). This model has been used to target homelessness however the underlying philosophy is applicable to other areas of social injustice. A similar approach has been developed for supporting service-users into employment. The "Individual Placement and

Support” programme offers an alternative to traditional employment initiatives (such as pre-vocational training) and research supports it as more effective in relation to employment rates (Bond, Drake, & Becker, 2008; Burns et al., 2007). However, these approaches have yet to be implemented on a broad scale in the UK therefore more work is needed in researching, developing, and integrating them into standard care practices.

For individuals in this group, getting support to meet their basic needs of housing and finance first, may be far more effective in helping them achieve recovery than viewing these as separate or “additional” needs. Slade et al. (2014) argues for “everyday solutions for everyday problems” and suggests that having a place to live, should be the “base from which people with severe mental illness can achieve numerous recovery goals and improve quality of life”. Additionally, the provision of specialist employment support for people with “severe mental illness” was set out as an area for development in NHS England’s “Priorities for mental health” document (Parsonage, Grant, & Stubbs, 2016). Along with this, the Centre for Mental Health has suggested that specialist welfare support should be available to those with mental health difficulties, suggesting this would both support recovery and reduce inpatient admission numbers (Parsonage, 2013). As such the first line of treatment for this group may be around gaining support with employment, benefits, and housing, along with supporting access to skills and educational courses, prior to engagement with mental health services or traditional pathways to recovery.

Mental health policy for inpatient care posits that stressors outside the hospital, such as difficulties with housing and finance, can influence conflict and incidents occurring within the ward. The Safewards Model suggests that to reduce incidents that arise in response to external circumstances, staff should be involved and have

knowledge of service-user's lives outside of hospital, and offer support in areas such as accessing benefits (Bowers, 2014). However, benefit support remains a difficult area. Changes to the welfare system, such as alterations in eligibility criteria for Personal Independence Payments (PIP), and austerity measures, means accessing appropriate financial support has become an increasingly difficult task, and these changes have been shown to directly impact on people's mental health, hitting the poorest hardest (McGrath, Griffin, & Mundy, 2015; Parsonage, 2013). Suggestions are made around the introduction of the Universal Basic Income or the provision of Personal Budgets as methods to address the financial difficulties of those most in need, however more research is needed in considering the feasibility and implications of such interventions (Alakeson & Perkins, 2012; McGrath et al., 2016). As such, to best support these individuals toward recovery, change is required at both a political and structural level and not just an individual one.

On a personal level however, this group valued medication as a form of support from mental health services. This was favoured in comparison to therapy or psychoeducation. It's possible that this group viewed medication as a "quick fix" enabling them to maintain some functionality in order to hold down a job, or maintain independence. Additionally, this group recognised reducing their self-medication, through drug and alcohol intake, as being helpful toward recovery. This finding is supported by previous research which suggests that substance abuse is commonly reported among individuals with psychosis and presents an additional barrier to recovery (Connell et al., 2015; Laithwaite & Gumley, 2007; Spaniol et al., 2002; Tan et al., 2014).

This group valued feeling in control of their experiences and it is possible that both medication and substances were used as a means to control mental health

experiences. Research has implicated substance use in the onset of psychosis experiences, but additionally many people use substances as a mean to cope (Dudley, Siitarinen, James, & Dodgson, 2009; Laithwaite & Gumley, 2007). This factor may therefore represent those who experience co-morbid psychosis and substance misuse difficulties. This “dual-diagnosis” has been linked with additional struggles during recovery and research suggests that 43% of inpatients experience these difficulties (Drake et al., 2006; Weaver, Charles, Madden, & Renton, 2002). However a recent survey indicated that 38% of those with dual-diagnoses were not receiving substance use support (Strathdee et al., 2002). There has been some debate as to whether co-morbid mental health and substance use difficulties are best treated separately or through an integrated approach, with the Department of Health recommending integrated care as more effective (DoH, 1991, 2002a). However, this recommendation is not reflected in current practice (DoH, 2002b). Therefore, working towards developing a more integrated approach to care may be helpful in supporting this group toward recovery.

The view of recovery expressed by participants in this factor pertains to addressing difficulties in areas related to social deprivation and functional recovery. Previous research has criticised the dominant model of recovery adopted by services as being individualistic and side-lining issues relating to social inequality (Harper & Speed, 2012). The view of recovery expressed by this group highlights the need for mental health services to adopt a model of recovery that incorporates issues relating social disadvantage, and addresses these issues as integral to recovery rather than as additional factors. The view of recovery held by this group may therefore align with the social justice model of recovery suggested by “Recovery in the bin” which highlights issues relating to the social and political determinants of mental health

(Recovery in the Bin, 2016). This group's focus on being able to meet their basic needs suggests that changes need to occur at a societal level and not just an individual one (Boyle, 2003; Slade & Longden, 2015). Johnson (2017) has argued that the social domain "remains the poor relative in the bio-psycho-social triad". Therefore, the development of social interventions and research evaluating their effectiveness is much needed to support recovery for individuals who face these challenges (Johnson, 2017).

#### **4.1.2 Factor 2: Hope, optimism and enhancing wellbeing**

The participants in this factor had the longest duration of psychosis experiences and the longest time in contact with mental health services. For this group factors related to hope, optimism and improving self-worth were seen to be some of the most important to recovery, whereas the reduction of mental health experiences was viewed as unimportant. For this group, engaging with religion or spirituality along with wellbeing enhancing activities such as exercise were viewed as important for recovery. This group were willing to access support from services however, their preference was to manage their experiences through self-coping or relational support. Many of this group reported either; they didn't have a mental health difficulty; they didn't experience any symptoms; or they viewed their experiences to be positive. Therefore, the view of mental health and recovery held by this group likely contrasts somewhat with "clinical" models of recovery or medical conceptualisations of mental health (Slade et al., 2008). These models focus primarily on the experience of symptoms, and are often endorsed by medically trained staff. As such, it is likely that this group's conceptualisation of their experiences contrasts with that of some staff teams who align with these models. The psychological understanding of staff has been recognised in inpatient policy as a modifying factor in service-user-staff conflict

(Bowers, 2014). Therefore, an appreciation of differing conceptualisations of experience by staff, along with a psychological understanding of the impact of imposing one's own framework of understanding, is important to minimise difficulties resulting from contrasting views.

Although it's possible that this group's rejection of medical models of mental health presented a challenge to professionals, it appears that the alternative ways in which this group made sense of their experiences, served to protect them from concerns relating to stigma and negative social evaluation by others. These findings are in agreement with previous research which suggests that holding medical conceptualisations of mental health leads to: negative attitudes from the public, increased expectation of negative attitudes from others, and increased self-stigma (Brohan et al., 2010; Longdon & Read, 2017). The participants in this group tended to challenge their diagnoses, and some disputed that they had mental health difficulties completely. For this group, receiving information or having their diagnoses explained was not considered important for recovery. Previous research has suggested that some service-users cope with the negative impact of diagnosis through finding alternative meanings or keeping their diagnosis a secret, and for others the rejection of diagnosis or medical conceptualisations of experience forms an important part of the recovery process (Mora-Rios, Ortega-Ortega, & Natera, 2016; Nixon et al., 2010b; Thornhill et al., 2004). These conceptualisations are linked with hopelessness, a lack of agency, disempowerment, and an enforced identity as a "patient" (Pitt et al., 2007; Pitt, Kilbride, Welford, Nothard, & Morrison, 2009; Thornhill et al., 2004). Thornhill et al. (2004) found narratives of "escape" among individuals who have experience of both psychosis and psychiatric hospitalisation. For these individuals, recovery was viewed through a lens of needing to escape from unwanted labels,

enforced identities and imprisonment (through psychiatric hospitalisation), which were experienced to negatively impact recovery. This group had the longest duration of psychosis and contact with mental health services. It's likely that experiences of being labelled and feelings of hopelessness associated with diagnosis and long-term treatment, were more pertinent for these service-users. Therefore, the narratives of escape reported by participants in Thornhill et al. (2004) may be shared by participants in this group.

The most important factors for recovery for this group were around maintaining hope, improving self-worth and having a sense of purpose. This group felt that utilizing their spirituality or religion and engaging in wellbeing enhancing activities (such as through exercise and healthy eating) were important in helping them to move towards recovery and enhance intrapersonal strengths. This group's view of recovery may align with a "personal" model emphasising factors such as hope, optimism and enhancing self-worth (Anthony, 1993). Previous research supports hope as an important factor in recovery and some research has suggested that regaining a sense of hope may be the first step to recovery from psychosis (Noiseux & Ricard, 2008; Schrank, Stanghellini, & Slade, 2008; Spaniol et al., 2002; Tooth et al., 2003).

The question then posed is: how can hope be fostered within the current system? Spandler and Stickley (2011) propose that in creating environments that stimulate a sense of hope, compassion is key. However, they argue that the current conditions of today's society are far from compassionate, especially for those who experience difficulties with mental or physical health. They suggest that operations of neoliberalism within society engenders selfishness, competition, and the pursuit of capitalist aims, whilst creating a view of those who need support as irresponsible and a burden (Gillies, 2005; Jensen & Tyler, 2015). This "compassion deficit" is also

apparent in services, where staff are overworked and unable to provide the care they feel is needed, which is echoed in service-user's negative accounts of care (Koekkoek, van Meijel, Schene, & Hutschemaekers, 2009; Spandler & Stickley, 2011; Tooth et al., 2003). Coupled with this is the linguistic conceptualisations of service-user's whose views oppose that of the medical model, as "lacking insight" (Kirmayer, Corin, & Jarvis, 1998; White, Bebbington, Pearson, Johnson, & Ellis, 2000). The value this group placed on being treated with dignity and respect emphasises the importance of compassion between staff and service-users. Positive relationships and treating service-users with compassion, dignity, and respect is highlighted in the Accreditation for Inpatient Mental health Services policy for acute wards (AIMS; Royal college of Psychiatrists, 2017). Experiences of being labelled as "ill" or "lacking insight" likely contrasts with these values. The acceptance of medical labels may also pose a social challenge. This group valued their relationships in recovery and felt that being part of a community was important. The concept of insight in mental health is complex. However, holding alternative conceptualisations of experience may not reflect a lack of insight but an attempt by service-users to preserve their social status (Johnson & Orrell, 1995). Perceptions of experience are also culturally and religiously responsive (Kirmayer et al., 1998). Therefore, there are likely multiple reasons for this group's conviction in rejecting these labels. The creation of truly compassionate services and systems of support that recognise and appreciate service-user's individual needs and subjective conceptualisations of their experiences, is therefore an essential component in supporting recovery for this group.

This group highlighted religion as an important factor for recovery. This finding is supported by previous research suggesting service-users, especially those in inpatient

settings, view religion as a helpful coping mechanism in recovery from psychosis (Nixon et al., 2010b; Noiseux & Ricard, 2008; Pieper & Uden, 2012; Spaniol et al., 2002; Thornhill et al., 2004; Tooth et al., 2003). Religion and spirituality have been linked with enhancing wellbeing and are implicated in transformative experiences of psychosis (Heffernan, Neil, Thomas, & Weatherhead, 2016; Nixon, Hagen, & Peters, 2010a). Meaning-making is an important part of the process of recovery from psychosis (Connell et al., 2015; Lam et al., 2011; Tan et al., 2014; Thornhill et al., 2004). Research suggests that religion and spirituality help PWP to make sense, and give meaning to their unusual experiences and suggestions are made that spirituality and religion be more deeply integrated into models of care (Cooke, 2017; Heffernan et al., 2016; Murphy, 2000). Mental health policy recognises the role of spirituality in recovery and recommendations advise that inpatient hospitals complete spirituality assessments (DoH, 2002; National Institute of Mental Health, 2003). However these policies are infrequently adhered to in inpatient settings (Healthcare Commission, 2008; Perkins & Rinaldi, 2007). Additionally, few models incorporate religion in a truly integrative manner, and it's suggested that clinicians struggle to talk about religion with service-users (Huguelet et al., 2011; Slade, 2012). For this group, spirituality was the most important factor to recovery and therefore spirituality assessments on admission and incorporating religious beliefs into treatment approaches may support this group in their journey to recovery.

This group valued relational support and considered positive relationships and feeling part of a community to be important in recovery. Previous research exploring recovery from psychosis has suggested positive relationships play an important role (Connell et al., 2015; Laithwaite & Gumley, 2007; Noiseux & Ricard, 2008; Tooth et al., 2003). However evidence suggests that psychosis is linked with diminished social

network, lack of social support and poor social outcomes, with this presentation being described as characteristic of PWP, especially for long-term service-users (Gayer-Anderson & Morgan, 2013; Harrison et al., 1996; Henderson, 1980). Additionally the smaller social networks of those with psychosis tend to consist of fewer friends and more staff (Macdonald, Hayes, & Baglioni, 2000). Participants in this group had the longest duration of psychosis experiences. Research indicates that long term service-users have smaller social networks than those whose experiences are of a shorter duration (Brugha, Wing, Brewin, MacCarthy, & Lesage, 1993; Koenders, Mooij, Dekker, & Kikkert, 2017). Deficits in social functioning are suggested to contribute to the reduction in social networks (Brugha et al., 1993; Fowler et al., 2017). This group also had the second highest average number of admissions. Previous research indicates that social network size decreases with an increased number of admissions, with those with smaller networks at an increased likelihood of being admitted (Becker et al., 1997; Fraser, Fraser, & Delewski, 1985). Further to this, due to the stigma around psychosis, service-users often experience social exclusion and discrimination, which is an increasing problem for those experiencing long-term difficulties (Perry, Henry, Sethi, & Grisham, 2011). Therefore, this group's desire to feel part of a community may reflect the presence of long-standing social difficulties and as such, the relational factors they viewed to be important for recovery may represent their desires for social inclusion and support. Therefore, interventions targeting social functioning and social inclusion will be important for supporting this group toward recovery (Fowler et al., 2017).

#### **4.1.3 Factor 3: Emotional change through self-management and social support**

Factor 3 represents service-users experiencing early stage psychosis. They had both the shortest duration of psychosis, and time in contact with mental health services.

These individuals placed value on self-management strategies to reduce their mental health experiences, and tended to view engagement with mental health services as a barrier to recovery. In agreement with those in factor 2, individuals in this group reported that religion and spirituality were helpful to recovery and were also less accepting of mental health labels. This group placed value on positive relationships and being able to socialise with others in the recovery process. Their view of recovery may therefore align with a social model which emphasises social support and inclusion (Mezzina et al., 2006).

This group recognised mental health experiences as impacting on their recovery. For these service-users, reducing mental health experiences and enhancing a sense of purpose and self-worth was best achieved through engaging in self-coping strategies. These findings are supported by previous research which implicates self-management and finding one's own coping strategies as important in recovery from psychosis (Laithwaite & Gumley, 2007; Lam et al., 2011; Nixon et al., 2010b; Noiseux & Ricard, 2008; Spaniol et al., 2002; Tan et al., 2014; Thornhill et al., 2004; Tooth et al., 2003). Noiseux and Ricard (2008) spoke of participants "discovering the keys to wellbeing" which were seen to be personalised coping mechanisms discovered by the PWP, which supported them in improving their ability to manage their experiences and enhance self-worth. The individuals in this factor were adjusting to their recent onset of psychosis and thus may represent those who are still in the process of finding useful coping strategies and discovering "the keys" to recovery.

This group preferred to cope with their mental health experiences without accessing mental health services. They were rejecting medical labels and placed value on social engagement. These findings are in line with previous research suggesting those who hold psychosocial conceptualisations of their experiences tend to prefer informal

sources of support and self-coping (Angermeyer, Matschinger, & Riedel-Heller, 1999; Ortega & Alegría, 2002). In agreement with those in Factor 2, this group thought it was important to see themselves beyond their diagnosis and due to the value they placed on social factors, it's possible they were conscious of the social impact of accessing services or accepting a diagnosis. Research has suggested that stigma and shame around diagnosis, along with denial and lack of information, provides a barrier to accessing support in the early phases of psychosis and to recovery (Clement et al., 2015; Harris, Collinson, & das Nair, 2012; Larsen, Johannessen, & Opjordsmoen, 1998; Perry et al., 2011; Schulze & Angermeyer, 2003). Early intervention services view psychosis as a phased process of which the “psychotic breakdown” is only one part of the process. These services are built on the premise that early intervention can prevent these experiences progressing (Johannessen, Koa, Larsen, & Langeveld, 2013). Longer “durations of untreated psychosis” have been linked with worse recovery outcomes and therefore more research exploring the barriers to accessing services and alternative methods of support, will aid in supporting this group toward recovery (Johannessen, Koa, Larsen, & Langeveld, 2013).

There is much research to support the role of social relationships in recovery from psychosis (Connell et al., 2015; Lam et al., 2011; Nixon et al., 2010b; Spaniol et al., 2002; Tooth et al., 2003; Wood & Alsawy, 2017). However, research also suggests that experiences of psychosis often have a big impact on social functioning, and social recovery outcomes are often reported to be poor (Fowler et al., 2017; Harrison et al., 1996). Interventions targeting social recovery are therefore an increasingly important focus for this group and are a specific focus for early intervention services. However due to the severity of the impact on social functioning and the poor recovery

rates reported in this area, it suggested that more needs to be done to target social functioning in the prodromal phase of psychosis (Fowler, 2009; Hodgekins et al., 2015; NICE, 2014).

One participant loaded negatively on this factor, meaning that his view opposed the view held by the rest of those in factor 3. This participant shared some similarities with those in both factor 2 and 3 in that his religion played a big part in his experiences. However, in contrast with those in Factor 3, who used religion mainly as a coping mechanism, for this participant religion also provided a framework through which he made sense of his experiences. Thus, the most important factor for him was having his religious beliefs respected by others. This participant reported seeing things that others don't and hearing voices, however his ability to make sense of these experiences as being a religious gift, meant that their presence was felt to be positive. In contrast with the rest of those in Factor 3 this individual felt support from services was important. Using the standard medical or even psychological frameworks with individuals who hold such views are therefore likely to be ineffective. Again, this highlights the importance of flexibility within services and how imposing one's model of understanding onto service-users who don't share the same view, or labelling them as lacking insight, may be counterproductive or even damaging. Religious conceptualisations of psychosis are not uncommon and as stated, the incorporation of spiritual and religious frameworks into treatment approaches may prove useful in engaging those who make sense of their experiences in this way (Murphy, 2000; Nixon et al., 2010a).

#### **4.1.4 Factor 4: Symptom reduction through mental health support**

This factor represented those who experienced acute and distressing episodes of psychosis. For this group their primary focus was to reduce mental health experiences

through support from mental health services. In contrast with much of the research on recovery, these individuals placed much less value on social, functional and intrapersonal factors (Bonney & Stickley, 2008; Jacob, 2015; Law & Morrison, 2014; Wood et al., 2013) . However this group's preference for more formal forms of support is in line with research suggesting that those who view mental health through a medical model are less likely to endorse self-help (Pattyn, Verhaeghe, Sercu, & Bracke, 2013). This group conceptualised their experiences through a medical framework, and this view is likely shared by a large proportion of ward staff. Their shared understanding may therefore contribute to their view of mental health services as both helpful and important for recovery. This groups view of recovery likely aligns with "clinical recovery" model, emphasising symptom remission (Slade et al., 2008). This contrasts with what is commonly reported in recovery literature; that few service-users view recovery primarily in relation to symptom reduction, and their preferred methods of support contrast with research suggesting that services should move away from reduction of symptoms as a primary focus (Law & Morrison, 2014). This raises some important issues, as drives to replace medical models of mental health or diagnostic systems, inevitably alienates some service-users who find these models helpful.

These individuals placed high value on social acceptance. Their medicalised conceptualisations of mental health may lead them to being more susceptible to perceptions of stigma from others or to experiences of self-stigma (Longdon & Read, 2017). This is an important consideration as stigma poses a significant barrier to recovery and is reportedly more of an issue with diagnoses such as schizophrenia (Schulze & Angermeyer, 2003). Research suggests that labelling experiences as mental illnesses leads to treatment compliance but increases stigma, which is

reflected in this groups acceptance of a range of treatment options from services (Xu et al., 2016). Indeed, there is evidence to suggest that some service-users find mental illness labels and medical models of mental health helpful (Cooke, 2017). Service-user research has indicated that diagnoses can be useful in supporting access to treatment and giving a name to experiences (Pitt et al., 2009). However, despite these benefits, research indicates that even when medical labels are experienced positively, the associated experiences of social exclusion remain (Pitt et al., 2009).

What appears most pertinent is to reduce the stigma around mental health, whichever model of understanding is preferred. Anti-stigma campaigns have been driven by medical models focusing on “an illness like any other” approach to mental health (Longdon & Read, 2017). These models, although reducing blame, and improving attitudes towards psychiatric treatment, have led to increased stigma and negative attitudes towards those with mental health difficulties (Albee & Joffe, 2004; Longdon & Read, 2017; Read & Cain, 2013; Schomerus et al., 2012; Silton et al., 2011). Therefore, to reduce stigma, new approaches must be developed which focus on social inclusion.

This group were accepting of treatment within mental health services and reported medication, psychological therapy and psycho-education as important to recovery. They valued choice and involvement in their treatment, and therefore having a range of different options and a collaborative approach may be useful for this group. The provision of a range of treatments for inpatient service-users; including group, psychology, medication and psychosocial interventions is highlighted in the AIMS criteria for acute services (Royal College of Psychiatrists, 2017). Knowledge about diagnosis was also valued by this group. Considering the links between psychoses and stigma, it may be increasingly important for psychiatrists to be mindful of the

impact of diagnosis for service-users. Therefore, explaining diagnosis along with exploring the meaning and potential impacts for service-users will be important. Further to this, sensitivity around how prognosis is described will be paramount in reducing stigmatising attitudes of non-recovery associated with psychosis (Pitt et al., 2009).

#### **4.1.5 Discussion of consensus statements**

The consensus statements viewed by participants across factors as important to recovery were related to desires for independence and control. Across factors participants felt that being able to look after, and cope with their experiences by themselves was important to recovery. This study involved a majority male sample and these findings are in line with previous research indicating that men tend to value independence and control in the recovery process (Schön, 2013). Additionally, these factors may relate to the importance of empowerment and self-agency which are commonly reported as central to recovery (Bjornestad et al., 2017; Pitt et al., 2007; Wood & Alsawy, 2017). Further to this, across all factors participants valued support from the government and being in control of their circumstances (related to housing, employment and finances). This suggests that these issues are particularly pertinent to this group and highlights the need for models of care that incorporate the socio-political determinants of mental health and the need for policy change which addresses issues relating to social disadvantage (Harper & Speed, 2012; Slade & Longden, 2015; Wood & Alsawy, 2017) .

#### **4.1.6 Discussion of qualitative feedback**

The qualitative feedback suggests that the majority of participants found the task to be a positive experience. However, a few participants struggled with the sustained

concentration required. To accommodate for this, participants were encouraged to stop or take breaks if they found the task difficult. This feedback is discussed in the limitations of the study.

In response to being asked whether there was anything missing from the Q-set, some participants commented on additional factors they felt were important to recovery.

One participant suggested that service support following discharge was important. It has been suggested that service-users are at an increased risk of a number of negative outcomes following discharge, these include: suicide, homelessness, and readmission (D'Ercole, Struening, Curtis, Millman, & Morris, 1997; Gunnell et al., 2008; Herman, Susser, Jandorf, Lavelle, & Bromet, 1998; Høyer, Mortensen, & Olesen, 2000).

Continuity of care following discharge and transition to outpatient services is important to protect against these risks, however it is suggested that only 50% of service-users make a successful transition (Boyer, 1997). As such continued care for service-users is an important consideration to promote recovery following discharge.

Another participant suggested that luck or fate played a part in recovery, and another felt that the way mental health is portrayed in the media was important to recovery. Statements concerning public perception were included in the Q-set however these were not linked specifically to the media. Research suggests the media plays a role in public perception of psychosis, often being linked with increased stigma and negative attitudes. Therefore this may be an important consideration in understanding service-user's views about factors that impact their recovery (Manago, Pescosolido, & Olafsdottir, 2018). These points are discussed further in terms of the strengths and limitations of this study.

## 4.2 Summary of clinical implications and future research

The findings from this study indicate that service-users hold different perspectives about recovery. At the heart of these findings is the need for services to be flexible and compassionate toward supporting service-user's individual conceptualisations of their experiences (Spandler & Stickley, 2011). The four viewpoints expressed suggest that some service-users find accessing support from mental health services helpful whereas for others, there are significant barriers. Participants in factor 1, 2 and 4 all expressed that support from mental health services was helpful to recovery, whereas those in factor 3 considered support from services as unimportant to recovery. For those advocating mental health service support, participants in each factor differed in terms of which type of support was preferred. Those in factor 1 preferred medication; factor 2 preferred therapy; and factor 4 were open to both these forms of support and psychoeducation. In line with current policy, this highlights the need for a range of treatment options to be available to service-users and for service-users to have choice in this process (Royal Collage of Psychiatrists, 2017). For those in factor 3 it's likely there were significant barriers to accessing services, therefore future research exploring these along with efforts to address the stigma associated with mental health will prove helpful in supporting this group in recovery. Targeted assessments and interventions in inpatient services may help to address these issues once service-users are admitted, however feelings of stigma and shame may act as a barrier to accepting continued support once in the community (Clement et al., 2015; Harris et al., 2012; Xu et al., 2016). Additionally, non-statutory services such as the *Hearing Voices Network* or *Mind*, which may be associated with less stigma, could provide alternative avenues of support for this group.

The findings from this study indicate a need to reconsider anti-stigma campaigns. It is suggested that current campaigns focusing on mental health as “an illness like any other illness” have been ineffective in reducing stigma (Albee & Joffe, 2004; Longdon & Read, 2017; Schomerus et al., 2012; Siltan, Flannelly, Milstein, & Vaaler, 2011). Research indicates that psychosocial explanations of mental health may be more effective, however at their heart these campaigns must have a focus on social inclusion (Longdon & Read, 2017). Further research exploring the impact of alternative explanations of mental health on stigma, along with the impact on access to services will be important in supporting recovery for service-users.

Participants in each group also differed in terms of what they prioritised as targets for care. For example, those in factor 1 preferred support in accessing employment, housing, and addressing issues relating to finance or substance use; in factor 2 and 3 self-coping strategies or relational support was preferred; whereas only those in factor 4 saw support from mental health services as being the most important form of support. This highlights the need for a range of services to be available to service-users and for clinicians to tailor their approaches to supporting service-users who hold different views about recovery.

The findings from this study highlight the varying ways that service-users conceptualise their difficulties. Some service-users conceptualised their experiences through a medical model, were accepting of diagnosis, and aligned with a clinical model of recovery (Slade et al., 2008). For others, their views aligned more with a personal model of recovery, focusing on enhancing intrapersonal strengths (Anthony, 1993). Whereas for others, recovery was understood in line with functional or social models (Mezzina et al., 2006; Whitley & Drake, 2010). In addition, some service-users conceptualised their experiences through a religious framework. Clinicians must

therefore be sensitive to service-user's subjective conceptualisations of their experience and offer support in line with these frameworks of understanding (Heffernan et al., 2016). Research indicates service-users make sense of their experiences in many ways, and what is helpful for some may not be for others (Cooke, 2017). Clinicians must be mindful of the impact of imposing their own frameworks of understanding onto service-users, and efforts made towards exploring the meaning service-users give to their experiences will be helpful in this respect. The psychological understanding of staff has been identified as a modifying factor in reducing incidents on psychiatric wards (Bowers, 2014). Therefore, additional psychological training for non-psychology staff groups may be beneficial in reducing tensions caused by contrasting frameworks of understanding between staff and service-users on inpatient wards, therefore supporting recovery.

The findings from factor 1 also indicate that changes need to occur at a socio-political level in addressing issues relating to social disadvantage. It is argued that the dominant model of recovery adopted by mental health services aligns with a personal recovery approach and these models have been criticised for their lack of focus on the social and political determinants of mental health (Harper & Speed, 2012). Whilst alternatives to this model taking a more holistic approach to recovery, inclusive of political and/or societal influences on mental health exist, groups advocating for social change, argue more needs to be done (McGrath et al., 2016). Such models include the Power Threat Meaning Framework, the Dimensional model of recovery; the culturally responsive model of recovery; and the Unrecovery Star (Jacobson & Farah, 2012; Recovery in the Bin, 2016; recoveryinthebin, 2018a; Whitley & Drake, 2010). The social justice group "Psychologists for Social Change" suggest that change must happen at a socio-political level to properly address these issues and

create systems and services that promote economic and social equality conducive to a “mentally healthy” society (Psychologists for Social Change, 2017; McGrath et al., 2015; McGrath et al., 2016).

On a smaller scale, the Safewards Model suggests that staff on inpatient wards should have knowledge of, and provide support with, service-user’s external circumstances (Bowers, 2014). Staff should take an active role in assessing external pressures, such as with housing and finance, and offer support to minimise potential stressors and support recovery. Early assessment of welfare issues on admission and provision specialist welfare and employment support should therefore be provided for all inpatients (Parsonage, 2013; Parsonage et al., 2016).

Both the “Housing First” and “Individual Placement and Support” models have shown promise in offering a more effective means of supporting service-users who experience difficulties with housing and employment (Bond et al., 2008; Burns et al., 2007; ‘The Principles of Housing First’, 2017). However, these programs have not yet become widespread in the UK. Therefore, more needs to be done in developing and integrating these approaches into care practices, along with research assessing and addressing the barriers to implementation. Propositions are also made in regard to the introduction of the Universal Basic Income or Personal Budgets as methods to address the financial hardship experienced by service-users. However more research is required to considering the feasibility and implications of such interventions (Alakeson & Perkins, 2012; McGrath et al., 2016).

Support with substance use was reported by service-users in this study as important to recovery. Integrated treatment approaches have been suggested as best practice for supporting those with dual-diagnosis (DoH, 2002a). Improved training for staff and

improved communication links between services will therefore be important in meeting these aims (Johnson, 1997; Schulte, Meier, & Stirling, 2011; Weaver et al., 2003).

Finally, research suggests that psychosis is linked with poor social recovery and participants in this study highlighted relationships as playing an important role. Developing interventions that target social functioning, particularly in the prodromal phase of psychosis may therefore be useful in supporting service-users toward recovery (Fowler et al., 2017).

### **4.3 Study strengths**

The current study is the first study to use Q-methodology to explore recovery from psychosis in an inpatient sample. There is a lack of recovery research conducted in inpatient settings and as such the voices of these service-users are often not heard. The participants in this study likely represent some of the most marginalised and in need of support and therefore more research exploring the unique experiences and views of this client group will be beneficial in developing services that are better able to meet their needs.

A strength of the current study is the use of Q-methodology. A large proportion of the research exploring recovery from psychosis uses an interview design. Q-method allows the incorporation of a larger sample of service-users and as such the range of different views identified are likely more representative of those held by this population. One of the strengths of Q-method is its ability to discern both similarity and difference. The four views uncovered by this study represent distinct opinions held by service-users allowing the appreciation of subjectivity and difference, which may be less easy to achieve with other exploratory methods or a smaller sample.

Further to this, in accordance with other research utilising Q-methodology with PWP, a large proportion of participants reported completing the task to be a positive experience (Dudley et al., 2009; Wood et al., 2013). Q-method allows the exploration of views in a fashion that is less intrusive or demanding from participants than methods such as interviews. The flexibility in the application of Q-method allows participants to engage in a manner they feel comfortable. For some the task sparked conversation and thought about their experiences which they shared with the researcher, whilst others preferred to complete the task more independently. Q-method is therefore a more inclusive method and may be less likely to deter certain groups of people, as may be the case with interviews.

Another strength of this study is the range of sources used to inform the Q-set development. Sources such as previous literature, questionnaires, service-user accounts, policy documents, mental health websites etc. were explored to generate a Q-set that depicted a broad and inclusive perspective of recovery. Only five participants commented on aspects of recovery they felt were missing from the Q-set therefore demonstrating the validity of final statements used in the task. This is important as poorly developed Q-sets that do not accurately reflect the range of opinions held intrinsically limit participants in the views they can express with their Q-sort (Watts & Stenner, 2012). Additionally, the methodological rigor involved in the structured approach to Q-set development and the consistency with which the task was carried out with each participant adds to the validity and reliability of this study (Watts & Stenner, 2012).

#### **4.3.1 Study limitations**

One of the limitations for this study was the lack of service-user involvement in the research process. Service-user involvement in research has become an increasing

focus over recent years and is implicated in all aspects of research (DoH, 2006; National Institute for Health Research, 2010). Previous studies using Q-methodology have involved service-user researchers in the process of developing themes and consulted service-user advisory groups for collaboration of the final Q-set (Wood et al., 2013). Additionally previous studies have conducted interviews with service-users in order to identify themes relevant to the topic domain which can then be used toward developing the Q-set (Papworth & Walker, 2008; Wood et al., 2013). Involvement of service-users in this process has two benefits: one that it improves the validity of the eventual Q-set by obtaining information from primary sources, and two, that service-users themselves take an active role in the research process, thus creating a more collaborative process (Barber, Beresford, Boote, Cooper, & Faulkner, 2011). Unfortunately, due to time pressure the current study did not include service-user interviews to inform the Q-set, which could impact upon the validity of the statements. However, a vast array of sources was consulted during Q-set development to ensure a broad and representative picture of recovery from psychosis was obtained. Additionally, the validity of the Q-set was consolidated by participants as the majority commented that there was nothing missing.

Another limitation of the current study was the length of time the Q-sort took for participants to complete. It has been reported that Q-sorting requires a high level of cognitive processing, however previous research utilizing Q-method with participants who experience psychosis has reported it to be a useful and acceptable method (Dudley et al., 2009; Tubergen & Olins, 1978; Wood et al., 2013). These studies were both completed with outpatient samples. As such it's likely the difficulties a minority of participants experienced in the current study, were resultant from the severity of their mental health experiences. Although the materials were piloted, those involved

in this process were lay persons, and it was not a requirement that they be representative of the target population. Service-user involvement in future research and piloting may prove useful in avoiding such problems. Additionally, it was considered that a smaller Q-set may have reduced the burden on participants, however concerns around omission of important items during Q-set development made decisions around creation of a smaller Q-set a challenge.

A further limitation for this study was that it did not meet the recruitment target of 40 participants. Failure to meet this quota was mostly relating to time pressures. In Q-method a sample size of between 40-60 is standard practice, however studies have been completed with far fewer participants, and this number is more a rule-of-thumb than an absolute boundary (Stainton Rogers, 1995; Stephenson, 1953; Watts & Stenner, 2012). The importance in Q-method is to reveal the viewpoints that are present among the sample, rather than to generalise the findings to a larger population. Generalisations in Q-method can be made but these are on theoretical rather than statistical grounds (Brown, 2009; Watts & Stenner, 2012). The current study involved 36 participants in the analysis, and this was considered to be an adequate number to meet the study aims of revealing the distinct viewpoints that were held among this group in relation to recovery.

The study sample consisted of 89% male. Practical difficulties in gaining access to female wards during the study meant that the researcher only had access to male wards for the majority of the recruitment period. Research suggests that men and women view recovery differently, with women tending to value gaining meaning and understanding, whereas for men being in control, independence and regaining roles such as through employment are seen to be more important (Schön, 2013). This research supports findings from the current study, where there was a heavy focus on

independence and self-coping across factors. It's likely that the inclusion of more females may have led to different or additional viewpoints being expressed. However research indicates a higher incidence of non-affective psychosis in males (Kirkbride et al., 2012). Some research indicates men are more likely to be hospitalised than women, with other research suggesting that men have longer periods of admission and higher relapse rates (Haro et al., 2008; Romans & Seeman, 2006; Uggerby, Nielsen, Correll, & Nielsen, 2011; Usall et al., 2001; Usall, Ochoa, Araya, & Marquez, 2003). As such, although the sample is clearly biased towards male opinion, it's likely that the demographics of the sample are representative of the population under study.

The four-factor solution accounted for 38% of the study variance. Therefore, it is noted that a proportion of the variance is not explained by the four factors. However, an acceptable level of variance explained is suggested to be anything upwards of 35% (Kline, 1994). Additionally, 11 participants' data did not load significantly on one of the factors, or loaded significantly on multiple factors, which indicates that there are additional viewpoints held by participants about recovery that are not accounted for by the four-factor solution. The aim in Q-method however is to uncover the main and distinct viewpoints that are present among the group, as such a limitation of the method is that it is rarely inclusive of every participant's viewpoint.

A final limitation of the study was in relation to the collection of demographic data. Collection of a greater range of demographic data such as employment history, or details relating to voluntary or involuntary admission status, may have added to the richness of the interpretations. However, due to the amount of time participants spent completing the task, adding further demands on participants was avoided.

Additionally, collection of data from participants was done on a self-report basis. As

such some details such as relating to number of years involvement with services may not be completely accurate. However, as this study was based around obtaining service-user views, collection of data through any other method was felt to contradict these aims.

#### **4.4 Personal reflective account**

Q-methodology is a “difficult and time-consuming” method which consists many stages (Watts & Stenner, 2012). The process of Q-set development is often considered to take up a relatively large proportion of the process (Curt, 1994). As such a large amount of work is required prior to the recruitment stage. Coupled with this, the process of recruitment in inpatient settings brings about its own challenges. Practical obstacles such as having access to a suitable room, the availability of staff and service-users, and factors relating to participant eligibility, meant that the process of recruitment was also very time consuming. The changeable nature of acute inpatient wards means that participants may often only remain on ward for short periods of time, may be on leave, or engaged with other staff, as such opportunities to speak with those deemed suitable are limited. These difficulties meant that more time than expected was spent developing the Q-set and recruiting, which resulted in the study not achieving its recruitment target and additionally left less time for write up.

However, conducting research in an inpatient setting meant that the researcher could gain a realistic perception of the experience of acute inpatient wards. Being immersed in this environment for a considerable amount of time allowed a realistic appreciation of the nature of this setting, and the experiences for both service-users and staff. This was considered to benefit the research process in comparison with conducting research about inpatient’s experiences once they have been discharged or in an off-site location, where the direct experience of this environment is lost. This experience

allowed direct observation of some of the unique challenges that arise in these settings which likely aided the interpretation process through allowing a greater understanding of service-users experiences. One particular observation was the under resourced and overburdened nature of the staff teams, who work in increasingly unpredictable and chaotic environments. The researcher was thoughtful about the impact that this has on service-user's experiences of hospitalisation and the extent to which the resources are available to foster an environment that is responsive to the differing recovery needs expressed by service-users. A large number of participants expressed gratitude in having the opportunity to talk with the researcher about their experiences and have their opinions listened to and acknowledged, which although felt a strength for the study, sadly gave the impression that these experiences were rare.

At times the research process also posed an emotional challenge. During the Q-sort task participants sometimes spoke of difficulties within their living circumstances, negative experiences of care, or past experiences of trauma. The researcher was sensitive to these conversations and utilised clinical skills where participants spoke of distressing experiences. On a personal level, these discussions highlighted the immense challenges often experienced by this client group, and through working in a research capacity it was sometimes difficult to not be able to offer some ongoing support. The emotional content of these conversations brought about a sense of great sadness but also a shared frustration at the failings of the current system in supporting people whose past and current experiences reflect such adversity. At times this frustration was coupled with a shared sense of powerlessness in reflecting on the complexity of service-users lives and the systems involved in maintaining such distress. However, through gaining a deeper understanding of the experiences and

challenges faced by these people, the process of completing this research fostered a greater sense of compassion and motivation to continue working to support these individuals and to challenge the systems that serve to maintain such distress.

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## Appendices

### Appendix A

#### Q-set statements with corresponding numbers for each statement

Q-set no.	Q-set statements
1	How much the government supports people with my difficulties
2	How often my mental health experiences happen
3	How much my medication helps me
4	How much I feel my life has purpose
5	How much I feel part of a community/society
6	How involved my family/loved ones are in my treatment/care
7	How much my mental health experiences affect my memory & concentration
8	How able/supported I am to manage feelings of loneliness and isolation
9	How much control I have over my circumstances (money, living, employment etc.)
10	How many activities there are for me to do in hospital
11	How supported/able I am to socialise with others
12	How suitable my housing is (outside of hospital)
13	How much my mental health experiences affect my mood/emotions
14	How confident I am in my skills and abilities
15	How much I believe I am more than my diagnosis/illness
16	How much therapy helps me
17	How much I enjoy my activities/hobbies in the community
18	How much the impact of my physical health issues can be reduced
19	How able I am to support myself and/or my family financially
20	How positively others view me
21	How safe I feel in hospital
22	How easily I can access meaningful activities in the community
23	How much the side effects of medication can be reduced
24	How comfortable the hospital ward/environment is
25	How often I exercise and eat well
26	How positive I view my relationships to be
27	How much my mental health affects my personal freedoms and rights
28	How able I am to cope with my mental health experiences myself
29	How much support I get with financial problems
30	How well society understands my mental health difficulties
31	How much support I get from family/loved ones
32	How much staff treat me with dignity and respect
33	How understanding staff are towards me
34	How much my religion/spirituality helps me to cope
35	How able I am to manage feelings of boredom
36	How supported I feel by mental health services
37	How much my mental health affects my ability to work
38	How much my religious/spiritual beliefs are respected by others
39	How easily I can access employment/education/skills courses
40	How much others respect my right to be alone
41	How much distress my mental health symptoms/voices cause me
42	How stable my living arrangements are
43	How much I feel I have equal opportunities compared to others
44	How able I am to look after myself (e.g. daily tasks)
45	How much I'm able to reduce feeling a burden to others
46	How much private time I have to myself
47	How available hospital/ward staff are to support me
48	How involved I am in my treatment and care
49	How able/supported I am to reduce my drug/alcohol intake
50	How supported I am to set goals for myself
51	How much I understand why this is happening to me
52	How much my diagnosis is explained to me
53	How much I believe things can get better
54	How much self-worth I feel

## Appendix B

### Participant information sheet (PIS)

#### Factors that promote recovery: The views of patients experiencing psychosis on an acute psychiatric ward.

<b>INFORMATION FOR PARTICIPANTS</b>
-------------------------------------

This information sheet is to let you know about a research study that you may be eligible to take part in. Before you decide, it is important that you understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. This should take about 10 minutes. You can also talk to others about the study if you wish, and please ask us if there is anything that is not clear.

This study has been reviewed by an NHS ethics committee to ensure that the rights, safety, dignity and well-being of everyone that takes part in this study are protected.

#### Principal Investigators

XXXXXX

Supervised by:

XXXXX

#### What is the purpose of the study?

This study is being conducted as part of the researcher's Doctorate in Clinical Psychology.

Research has suggested that people who experience mental health difficulties such as psychosis view their recovery in many different ways. Some see recovery as being related to not having symptoms anymore and others see recovery as being able to get back to activities that they enjoy and things that they did prior to becoming unwell. We know that people hold different ideas about what recovery means, but what this study is interested in, is what factors people feel are important in helping them to feel better or move towards recovery. Previous research has suggested an important role for staff in hospitals in helping patients to engage socially or to feel safe. This study aims to develop this understanding and to provide a better understanding of what factors patients feel are most important in helping them to recover.

**Why have I been given this information?**

This research study is looking for people who experience psychosis who are willing to complete a brief task where they will be asked to sort different statements relating to their recovery needs in order of most to least important to them.

**Do I have to take part?**

No. Taking part in this research study is voluntary therefore it is up to you to decide whether or not to take part. You should not feel under any pressure to take part. If you do decide to take part, you will be asked to sign a consent form. Even after signing this form you will still be free to withdraw at any time and without giving a reason. This will not affect any care you may receive in the future.

**What will happen to me if I take part?**

You can meet a researcher for this study at a convenient time for you to discuss the study in more detail. The researcher will talk through the study in detail with you, explaining the reasons for running this study and answering any questions you may have. You will be given time to make your decision. If you are interested in taking part you will be asked to sign a consent form.

If you take part we will ask you to meet with the researcher where you will be asked to fill out a few forms relating to demographic information and to sign a consent form. After this we will arrange a time to meet once more to complete the card sort task.

.

**What will I have to do?**

This research involves the use of 'Q-methodology' which is a research tool that allows the incorporation of a large range of patient views in order to produce groups of patients who share similar ways of thinking about a particular issue. Q-methodology involves a card sort task where participants are asked to sort cards in order from most to least important. Each of the cards contains a statement relating to factors that may contribute to recovery, for example 'How much support I get from loved ones'. The researcher will talk you through each stage of the task and you will have opportunities to ask questions if there is anything you do not understand. Once you have finished the card sort task you will then be asked to provide a brief reason for the order you have chosen (this is optional). This task is about getting an understanding of individual patient's views and experiences and therefore there is no wrong or right order and individual responses will not be fed back to staff members. It is hoped that this task will help us to see which factors are most important to patients in order to help us to guide service delivery in a way that meets patient's needs.

**Timings:**

It is expected that filling out demographic information forms should take about 10 minutes and the card sort task should take about 30-40 minutes.

**Will taking part in the study cost me anything?**

No. The study will only involve your time.

**Who will know I am participating in the study?**

Other people involved in your care such as your Consultant Psychiatrist, Clinical Psychologist, Care Coordinator and GP (if consented) will be informed.

**Will my information be kept confidential and anonymous?**

All the information you give will be strictly confidential so it will not be shared with anyone else other than the research team. However there are two reasons why this confidentiality may be broken. Study documents may be looked at by individuals from the University of Essex, from North East London Foundation Trust, or other authorities for monitoring and auditing purposes, and this may well include access to personal information. Also, if during the course of the study, there were concerns about your safety or the safety of others, a member of your clinical team will be contacted to ensure the safety of yourself and others.

The results of this research study and any published versions will also be anonymous; your name will not be quoted. Direct quotes based on what is said during the session may be used in the write up. Every effort will be made to anonymise quotes used, however complete anonymity cannot be guaranteed.

All completed forms will be stored in a locked filing cabinet at the University of Essex. Forms will also be kept separate to any documents with personal information on them (such as your name). All electronic data (such as the order chosen for the card sort task) will be stored on a password protected computer which only the research team will have access to. All data and personal information from this study will be kept for five years after the study has finished so the study can be written up for publication in a research journal.

**What are the advantages and disadvantages of taking part?**

Taking part in this research will help us to understand patient's views about what is important to their recovery. We hope that this research will help us to structure services in a way that is helpful to patients and their recovery. You may find it an enjoyable experience being involved in such work. You will also be given £10 as compensation for your time.

It is possible that thinking about your personal experiences could sometimes lead to feeling upset. The researchers will be sensitive to your needs as they have experience working with people with upsetting or distressing emotions. You will have

the opportunity to talk about any concerns you have at the end of the task and you are free to withdraw from the research study at any point.

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

This project does not have any medical interventions such as asking to take a new medication. You will only be asked to complete some forms and a card sort task. There is no 'right and wrong' to this, 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 researcher 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 speak to the researcher who will do their best to answer your questions (xxxxx).

### **Formal Complaints**

If you wish to make a formal complaint or 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: [XXXXX](#)

### **Independent Advice**

If you would like independent advice about taking part in research please contact:

Patient Advice and Liaison Service (PALS), XXXXX.

### **What do I need to do now?**

If you would like to take part, please complete the tear of sheet below and hand it to a staff member who will then pass your details on to the researcher (XXXXX). The researcher will then contact you to discuss the study further.

Alternatively if you have any further questions please CONTACT XXXXX (see email on first page).

---

I ..... (Participant name) would like to take part in the above study.

I give consent for my contact details to be passed on to the researcher and to be contacted by xxxxx (researcher) to discuss participation in this study.

Signed:.....

Telephone/email:

.....

## Appendix C

### Consent form

# CONSENT FORM

Participant Identification Number for this study: .....

**Title of Project:**

**Factors that promote recovery: The views of patients experiencing psychosis on an acute psychiatric ward**

**Name of Researcher: XXXXXXXXX**

**Name of Participant:**

**Please initial box**

1. I confirm I have read and understand the participant information sheet (PIS) dated \_\_\_\_\_.(version \_\_)   
for the above study, have been given a copy to keep and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without   
giving any reason, without my medical care or legal rights being affected.
3. I consent to taking part in the research study which will involve a card sort task where I   
will be asked to rate statements from most to least important to my recovery.
4. I understand that data collected during the study may be looked at by individuals from the University   
of Essex, 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 data.
5. I consent to being contacted about the results of the study (optional).
6. I consent to my GP being informed about my participation in this research study (optional)
7. I consent to a copy of this consent form being kept with my medical notes

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 copy for participant; 1 for researcher; 1 to be kept with medical notes

**Appendix D**

**Contact details sheet for participants**

**Contact Detail Form**

**Participant Name:** .....

**If you would like to be contacted following completion of the research with a written summary of the project and findings please provide an email address or address below**

**Address:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix E

### Demographic information sheet

#### Factors that promote recovery: The views of patients experiencing psychosis on an acute psychiatric ward

##### Demographic information & Symptom checklist

<b>Participant No</b>		<b>Gender</b>	<input type="checkbox"/> Male	<input type="checkbox"/> Female
<b>Age</b>				
<b>Schooling</b>	<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary		
	<input type="checkbox"/> Further	<input type="checkbox"/> Higher		
<b>Marital Status</b>	<input type="checkbox"/> Single	<input type="checkbox"/> Married	<input type="checkbox"/> Common law	<input type="checkbox"/> Separated
	<input type="checkbox"/> Divorced	<input type="checkbox"/> Widowed		
<b>Ethnicity</b>				
<b>Asian/Asian British</b>		<b>Mixed</b>		<b>Other</b>
<input type="checkbox"/> Bangladeshi <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Any other Asian background		<input type="checkbox"/> White & Asian <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> Any other mixed background		<input type="checkbox"/> Chinese <input type="checkbox"/> Any other ethnic group Specify _____
<b>Black/Black British</b>		<b>White</b>		
<input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black background		<input type="checkbox"/> British <input type="checkbox"/> Irish <input type="checkbox"/> Any other White background		
<b>Religious Beliefs</b>				
<input type="checkbox"/> Buddhism <input type="checkbox"/> Christianity <input type="checkbox"/> Islam		<input type="checkbox"/> Sikhism <input type="checkbox"/> Hinduism <input type="checkbox"/> Judaism		<input type="checkbox"/> Atheism <input type="checkbox"/> Jainism <input type="checkbox"/> Other, _____
<b>The following to be filled out from participant:</b>				
<b>First contact with NHS</b>	__/__/----	<b>First issues with psychosis</b>	__/__/----	
<b>Number of Hospital Admissions</b>				
<b>Primary Diagnosis (if any)</b>	<input type="checkbox"/> Schizophrenia <input type="checkbox"/> Acute and transient psychotic disorder <input type="checkbox"/> Schizoaffective disorder <input type="checkbox"/> Persistent delusional disorder <input type="checkbox"/> Other   Specify code _____			
<b>Experiences of psychosis</b>	<input type="checkbox"/> Paranoia <input type="checkbox"/> Voices <input type="checkbox"/> Unusual beliefs/delusions <input type="checkbox"/> visual hallucinations <input type="checkbox"/> Flattened affect <input type="checkbox"/> Avolition <input type="checkbox"/> Alogia <input type="checkbox"/> disorganised thinking Please specify experiences/ additional symptoms: _____ _____			

**Appendix F****Blank distribution grid**

+5							
+4							
+3							
+2							
+1							
0							
-1							
-2							
-3							
-4							
-5							

## Appendix G

### Post task feedback sheet

#### Feedback sheet

Once you have completed the card sort task please answer the following questions based on your reasons for placing the cards in the order you have.

1. Please explain your reasons for selecting the top three statements as most important to your recovery.

---

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---

---

2. Please explain your reasons for selecting the last three statements as least important to your recovery.

---

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---

3. If there is anything that is important to your recovery that was not listed in the statements please write it below.

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---

4. If you have any further comments or feedback regarding the task or the research process please add them below.

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## Appendix H

### National Research Ethics Committee approval letter



Health Research Authority

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

25 May 2017

#### Letter of HRA Approval

Study title:	Factors that promote recovery: The views of patients experiencing psychosis on an acute psychiatric ward.
IRAS project ID:	205433
REC reference:	17/EE/0140
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.

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 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/>.

IRAS project ID	205433
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**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 205433. Please quote this on all correspondence.

Yours sincerely



Copy to:



## Appendix I

### NHS local trust research and development ethics approval email

Dear XXXXX,

Study title: Factors that promote recovery: The views of patients experiencing psychosis on an acute psychiatric ward.  
IRAS project ID: 205433  
Sponsor: University of Essex

I am writing to confirm capacity and capability for the above titled research to proceed at XXXX Trust.

This confirmation is based on the HRA approval letter dated 25<sup>th</sup> May 2017 and the attached Statement of Activities and corresponding appendix B. The study is considered to be commencing at XXXX today 28<sup>th</sup> July 2017.

I have the pleasure of attaching you letter of access to this email. You should inform XXXXX (XXXX Research Data Manager) when your study has completed so that we can provide you with a close out monitoring form for return. I have copied XXXX in here for your convenience and interim monitoring purposes.

Should you have any other queries regarding the research here at XXXXX please do feel free to contact me. We wish you every success with your work here at the Trust.

Kind regards,

Research and Development Administrator  
Research and Development Department  
XXXXXXXX

## Appendix J

### Rotated factor matrix

Table of factor loadings for each Q-sort on each factor. Loadings demonstrate the extent to which each Q-sort is associated with each factor. Factors loadings >0.36 were significant and are marked with an X indicating a defining Q-sort. Defining Q-sorts contribute to the creation of factor arrays.

QSORT	Loadings			
	1	2	3	4
1 3M41WBSZ	0.0514	0.4731	0.4763	0.0809
2 4M67WBSZ	-0.0141	0.5452X	-0.1239	0.0958
3 5M24BADK	0.5885X	-0.0251	0.0144	-0.0560
4 6M49BBSZ	0.1762	0.1960	0.2707	-0.1172
5 7M49WBSZ	0.3649X	0.0139	-0.0710	0.1039
6 8F32WBSZ	0.1794	-0.2328	0.0337	0.6655X
7 9M47WBNR	0.0323	0.6042X	0.2107	-0.0671
8 10F32WOM	0.0388	0.3115	0.4740X	0.2827
9 11M58BCS	-0.1727	0.6314X	-0.0279	0.1104
10 12M38BCS	-0.2519	-0.1855	0.1916	-0.1259
11 13M43AIN	0.7916X	-0.0698	0.2401	0.3115
12 14M26WOP	0.1287	0.0476	0.3106	0.1473
13 15M39WBM	0.2016	-0.3876	0.5146	0.0276
14 16M33WOM	0.1639	-0.0819	0.6413X	-0.0890
15 17M53OOS	0.4533X	0.1252	-0.0714	0.2308
16 18M28BBS	0.3732	-0.3298	0.5718	0.0455
17 19M26MOS	0.0726	0.5777X	-0.1385	-0.1925
18 20M40AIS	-0.2638	0.3806X	-0.0180	-0.0072
19 21M22BAN	0.2067	0.5309X	0.0272	-0.1902
20 22M61WBS	0.1827	-0.1025	0.0971	-0.1325
21 23M24BAS	0.6417X	0.0026	0.1608	0.2558
22 24M35BAD	-0.1521	-0.0580	0.4169X	-0.0519

23	25M34BCS	0.4818	-0.0387	0.2275	-0.4581
24	26M29WBD	0.6195X	0.0016	0.2326	-0.1007
25	27M26WBS	0.3146	-0.2137	-0.0034	0.5215X
26	28M23BCN	0.0110	-0.0564	0.3974	0.6396
27	29M44MOM	-0.1918	-0.2876	0.2149	0.0580
28	30M29BAm	-0.0158	0.6827X	0.1509	-0.0545
29	31M53APB	-0.0823	0.4116	0.4715	0.1071
30	32F24BCM	-0.2954	0.1271	0.5418X	0.1601
31	33M63WBN	-0.2039	0.2558	-0.3706X	-0.2081
32	34M46BCN	0.2473	-0.0784	-0.0696	0.7007X
33	35M45MWS	0.0345	0.6073X	0.3509	-0.0153
34	36M39WOM	0.2494	0.1072	0.4164X	0.2756
35	37M54WBA	-0.0693	0.1100	0.0893	0.5132X
36	38M63WBD	0.0617	0.2035	0.6241X	-0.1385

% expl.Var.      9      11      10      8

## Appendix K

### Table of factor arrays for all 4 factors

Numbers indicate where Q-set statements are positioned on the Q-sort grid e.g. +5 is 'most important'.

Q-set no.	Q-set statements	Factors			
		1	2	3	4
1	How much the government supports people with my difficulties	5	3	0	2
2	How often my mental health experiences happen	1	-5	-1	1
3	How much my medication helps me	3	-4	-1	1
4	How much I feel my life has purpose	0	5	3	-1
5	How much I feel part of a community/society	-2	2	-3	-2
6	How involved my family/loved ones are in my treatment/care	-3	1	0	3
7	How much my mental health experiences affect my memory & concentration	3	-5	5	4
8	How able/supported I am to manage feelings of loneliness and isolation	-4	-3	0	0
9	How much control I have over my circumstances (money, living, employment etc)	5	2	3	2
10	How many activities there are for me to do in hospital	-1	0	-4	-3
11	How supported/able I am to socialise with others	-2	0	2	-1
12	How suitable my housing is (outside of hospital)	4	3	0	-1
13	How much my mental health experiences affect my mood/emotions	2	-1	3	2
14	How confident I am in my skills and abilities	0	4	4	-3
15	How much I believe I am more than my diagnosis/illness	-3	-1	2	-1
16	How much therapy helps me	-1	0	-3	4
17	How much I enjoy my activities/hobbies in the community	0	1	-1	-4
18	How much the impact of my physical health issues can be reduced	1	-3	2	1
19	How able I am to support myself and/or my family financially	5	0	-1	-2
20	How positively others view me	-5	-3	-5	-1
21	How safe I feel in hospital	-2	0	0	3
22	How easily I can access meaningful activities in the community	0	-2	-3	-2
23	How much the side effects of medication can be reduced	0	-1	1	0
24	How comfortable the hospital ward/environment is	-3	1	-5	1
25	How often I exercise and eat well	-1	3	5	-3
26	How positive I view my relationships to be	-4	4	2	-3
27	How much my mental health affects my personal freedoms and rights	0	-2	4	1
28	How able I am to cope with my mental health experiences myself	3	2	5	5
29	How much support I get with financial problems	3	3	0	-4
30	How well society understands my mental health difficulties	-1	-2	-3	3
31	How much support I get from family/loved ones	-3	2	3	-1
32	How much staff treat me with dignity and respect	-1	3	-1	2
33	How understanding staff are towards me	1	0	-4	1
34	How much my religion/spirituality helps me to cope	-5	5	2	-5
35	How able I am to manage feelings of boredom	-2	-1	1	-4
36	How supported I feel by mental health services	1	0	-2	5
37	How much my mental health affects my ability to work	2	-2	4	3
38	How much my religious/spiritual beliefs are respected by others	-5	-4	-5	-5
39	How easily I can access employment/education/skills courses	3	-4	-2	-2
40	How much others respect my right to be alone	-2	4	-3	0
41	How much distress my mental health symptoms/voices cause me	4	-5	0	5
42	How stable my living arrangements are	4	4	-1	0
43	How much I feel I have equal opportunities compared to others	-3	-1	-2	-2
44	How able I am to look after myself (e.g. daily tasks)	4	1	4	0
45	How much I'm able to reduce feeling a burden to others	-4	-3	1	2
46	How much private time I have to myself	-4	1	-4	-3
47	How available hospital/ward staff are to support me	2	-2	-2	3
48	How involved I am in my treatment and care	2	1	1	4
49	How able/supported I am to reduce my drug/alcohol intake	2	-4	1	-5
50	How supported I am to set goals for myself	1	0	0	-4
51	How much I understand why this is happening to me	0	-1	-2	0
52	How much my diagnosis is explained to me	-1	-3	-4	4
53	How much I believe things can get better	1	5	3	0
54	How much self-worth I feel	0	2	1	0

## Appendix L

### Distinguishing statements for each factor

Tables showing distinguishing statements for each factor. For each factor numbers to the right represent Z scores comparing how each item is ranked in that factor compared to the other three. Statements shown demonstrate those that have been ranked significantly differently by participants in that factor compared with the other three factors. Scores marked with an \* are significant at the  $p < 0.01$  level. In each factor numbers to the left demonstrate the Q-sort value in the factor array (where the item was positioned on the factor array Q-sort distribution grid).

#### Factor 1 distinguishing statements:

( $P < .05$  ; Asterisk (\*) Indicates Significance at  $P < .01$ )

Both the Factor Q-Sort Value (Q-SV) and the Z-Score (Z-SCR) are Shown.

No. Statement	No.	Factors							
		1		2		3		4	
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR
19 How able I am to support myself and/or my family financially	19	5	1.84*	0	0.23	-1	-0.69	-2	-0.53
9 How much control I have over my circumstances (money, living	9	5	1.82*	2	0.86	3	0.79	2	0.49
1 How much the government supports people with my difficulties	1	5	1.51	3	0.94	0	0.09	2	0.57
12 How suitable my housing is (outside of hospital)	12	4	1.50	3	0.90	0	0.16	-1	-0.28
3 How much my medication helps me	3	3	1.12*	-4	-1.48	-1	-0.50	1	0.29
39 How easily I can access employment/education/skills courses	39	3	1.04*	-4	-1.36	-2	-0.70	-2	-0.59
14 How confident I am in my skills and abilities	14	0	-0.12	4	1.15	4	1.38	-3	-0.88
52 How much my diagnosis is explained to me	52	-1	-0.15*	-3	-0.94	-4	-1.45	4	1.22
21 How safe I feel in hospital	21	-2	-0.62	0	0.11	0	0.00	3	1.18
31 How much support I get from family/loved ones	31	-3	-0.93	2	0.60	3	1.24	-1	-0.27
15 How much I believe I am more than my diagnosis/illness	15	-3	-0.94	-1	-0.26	2	0.70	-1	-0.25
6 How involved my family/loved ones are in my treatment/care	6	-3	-0.94*	1	0.37	0	0.02	3	0.99
24 How comfortable the hospital ward/environment is	24	-3	-1.00	1	0.51	-5	-1.59	1	0.23

#### Factor 2 distinguishing statements:

( $P < .05$  ; Asterisk (\*) Indicates Significance at  $P < .01$ )

Both the Factor Q-Sort Value (Q-SV) and the Z-Score (Z-SCR) are Shown.

No. Statement	No.	Factors							
		1		2		3		4	
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR
4 How much I feel my life has purpose	4	0	0.01	5	1.98*	3	1.16	-1	-0.33
34 How much my religion/spirituality helps me to cope	34	-5	-2.28	5	1.85*	2	0.71	-5	-2.21
53 How much I believe things can get better	53	1	0.38	5	1.66*	3	0.96	0	0.10
26 How positive I view my relationships to be	26	-4	-1.18	4	1.37*	2	0.66	-3	-0.79
40 How much others respect my right to be alone	40	-2	-0.70	4	1.07*	-3	-1.15	0	-0.15
25 How often I exercise and eat well	25	-1	-0.56	3	1.03	5	1.67	-3	-0.77
12 How suitable my housing is (outside of hospital)	12	4	1.50	3	0.90	0	0.16	-1	-0.28
54 How much self-worth I feel	54	0	-0.06	2	0.87	1	0.36	0	-0.03
5 How much I feel part of a community/society	5	-2	-0.85	2	0.75*	-3	-1.21	-2	-0.65
31 How much support I get from family/loved ones	31	-3	-0.93	2	0.60	3	1.24	-1	-0.27
46 How much private time I have to myself	46	-4	-1.30	1	0.55*	-4	-1.31	-3	-0.87
19 How able I am to support myself and/or my family financially	19	5	1.84	0	0.23	-1	-0.69	-2	-0.53
13 How much my mental health experiences affect my mood/emotion	13	2	0.68	-1	-0.37*	3	1.20	2	0.69
27 How much my mental health affects my personal freedoms and r	27	0	0.15	-2	-0.57*	4	1.61	1	0.30
37 How much my mental health affects my ability to work	37	2	0.84	-2	-0.73*	4	1.33	3	1.18
52 How much my diagnosis is explained to me	52	-1	-0.15	-3	-0.94	-4	-1.45	4	1.22
20 How positively others view me	20	-5	-1.63	-3	-0.99	-5	-1.88	-1	-0.38
18 How much the impact of my physical health issues can be redu	18	1	0.20	-3	-1.16*	2	0.57	1	0.48
39 How easily I can access employment/education/skills courses	39	3	1.04	-4	-1.36	-2	-0.70	-2	-0.59
3 How much my medication helps me	3	3	1.12	-4	-1.48*	-1	-0.50	1	0.29
49 How able/supported I am to reduce my drug/alcohol intake	49	2	0.67	-4	-1.51	1	0.41	-5	-2.21
7 How much my mental health experiences affect my memory & con	7	3	0.92	-5	-1.53*	5	1.95	4	1.32
2 How often my mental health experiences happen	2	1	0.38	-5	-1.70*	-1	-0.41	1	0.46
41 How much distress my mental health symptoms/voices cause me	41	4	1.47	-5	-2.27*	0	-0.20	5	1.98

### Factor 3 distinguishing statements:

(P < .05 ; Asterisk (\*) Indicates Significance at P < .01)

Both the Factor Q-Sort Value (Q-SV) and the Z-Score (Z-SCR) are Shown.

No. Statement	No.	Factors							
		1		2		3		4	
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR
7 How much my mental health experiences affect my memory & con	7	3	0.92	-5	-1.53	5	1.95	4	1.32
25 How often I exercise and eat well 25	25	-1	-0.56	3	1.03	5	1.67	-3	-0.77
27 How much my mental health affects my personal freedoms and r	27	0	0.15	-2	-0.57	4	1.61*	1	0.30
31 How much support I get from family/loved ones 31	31	-3	-0.93	2	0.60	3	1.24	-1	-0.27
4 How much I feel my life has purpose 4	4	0	0.01	5	1.98	3	1.16*	-1	-0.33
53 How much I believe things can get better 53	53	1	0.38	5	1.66	3	0.96	0	0.10
34 How much my religion/spirituality helps me to cope 34	34	-5	-2.28	5	1.85	2	0.71*	-5	-2.21
15 How much I believe I am more than my diagnosis/illness 15	15	-3	-0.94	-1	-0.26	2	0.70*	-1	-0.25
11 How supported/able I am to socialise with others 11	11	-2	-0.73	0	-0.14	2	0.66*	-1	-0.25
26 How positive I view my relationships to be 26	26	-4	-1.18	4	1.37	2	0.66*	-3	-0.79
35 How able I am to manage feelings of boredom 35	35	-2	-0.57	-1	-0.38	1	0.42*	-4	-1.64
29 How much support I get with financial problems 29	29	3	0.99	3	0.95	0	0.21*	-4	-1.15
41 How much distress my mental health symptoms/voices cause me	41	4	1.47	-5	-2.27	0	-0.20*	5	1.98
2 How often my mental health experiences happen 2	2	1	0.38	-5	-1.70	-1	-0.41*	1	0.46
3 How much my medication helps me 3	3	3	1.12	-4	-1.48	-1	-0.50	1	0.29
36 How supported I feel by mental health services 36	36	1	0.54	0	0.07	-2	-0.74*	5	1.37
51 How much I understand why this is happening to me 51	51	0	0.08	-1	-0.40	-2	-0.94	0	0.19
16 How much therapy helps me 16	16	-1	-0.33	0	-0.00	-3	-1.12*	4	1.23
33 How understanding staff are towards me 33	33	1	0.20	0	0.19	-4	-1.28*	1	0.20
10 How many activities there are for me to do in hospital 10	10	-1	-0.41	0	-0.26	-4	-1.44	-3	-0.69
52 How much my diagnosis is explained to me 52	52	-1	-0.15	-3	-0.94	-4	-1.45	4	1.22
24 How comfortable the hospital ward/environment is 24	24	-3	-1.00	1	0.51	-5	-1.59	1	0.23

### Factor 4 distinguishing statements:

(P < .05 ; Asterisk (\*) Indicates Significance at P < .01)

Both the Factor Q-Sort Value (Q-SV) and the Z-Score (Z-SCR) are Shown.

No. Statement	No.	Factors							
		1		2		3		4	
		Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR	Q-SV	Z-SCR
36 How supported I feel by mental health services 36	36	1	0.54	0	0.07	-2	-0.74	5	1.37*
16 How much therapy helps me 16	16	-1	-0.33	0	-0.00	-3	-1.12	4	1.23*
52 How much my diagnosis is explained to me 52	52	-1	-0.15	-3	-0.94	-4	-1.45	4	1.22*
21 How safe I feel in hospital 21	21	-2	-0.62	0	0.11	0	0.00	3	1.18*
30 How well society understands my mental health difficulties 3	30	-1	-0.46	-2	-0.93	-3	-0.94	3	1.11*
6 How involved my family/loved ones are in my treatment/care 6	6	-3	-0.94	1	0.37	0	0.02	3	0.99
3 How much my medication helps me 3	3	3	1.12	-4	-1.48	-1	-0.50	1	0.29
31 How much support I get from family/loved ones 31	31	-3	-0.93	2	0.60	3	1.24	-1	-0.27
20 How positively others view me 20	20	-5	-1.63	-3	-0.99	-5	-1.88	-1	-0.38
14 How confident I am in my skills and abilities 14	14	0	-0.12	4	1.15	4	1.38	-3	-0.88
50 How supported I am to set goals for myself 50	50	1	0.55	0	-0.01	0	0.30	-4	-1.04*
29 How much support I get with financial problems 29	29	3	0.99	3	0.95	0	0.21	-4	-1.15*
17 How much I enjoy my activities/hobbies in the community 17	17	0	-0.10	1	0.26	-1	-0.31	-4	-1.48*
35 How able I am to manage feelings of boredom 35	35	-2	-0.57	-1	-0.38	1	0.42	-4	-1.64*
49 How able/supported I am to reduce my drug/alcohol intake 49	49	2	0.67	-4	-1.51	1	0.41	-5	-2.21

## Appendix M

### Factor Q-Sort values for statements sorted by consensus vs. disagreement

Q-set statements ordered from consensus to disagreement (from top to bottom). Consensus statements are those that were ranked similarly by participants in each factor. Numbers in each factor column represent factor Q-sort values.

No.	Statement	No.	Factor Arrays			
			1	2	3	4
43	How much I feel I have equal opportunities compared to other	43	-3	-1	-2	-2
23	How much the side effects of medication can be reduced	23	0	-1	1	0
48	How involved I am in my treatment and care	48	2	1	1	4
54	How much self-worth I feel	54	0	2	1	0
22	How easily I can access meaningful activities in the communi	22	0	-2	-3	-2
38	How much my religious/spiritual beliefs are respected by oth	38	-5	-4	-5	-5
51	How much I understand why this is happening to me	51	0	-1	-2	0
10	How many activities there are for me to do in hospital	10	-1	0	-4	-3
11	How supported/able I am to socialise with others	11	-2	0	2	-1
9	How much control I have over my circumstances (money, living	9	5	2	3	2
28	How able I am to cope with my mental health experiences myse	28	3	2	5	5
1	How much the government supports people with my difficulties	1	5	3	0	2
13	How much my mental health experiences affect my mood/emotion	13	2	-1	3	2
44	How able I am to look after myself (e.g. daily tasks)	44	4	1	4	0
20	How positively others view me	20	-5	-3	-5	-1
15	How much I believe I am more than my diagnosis/illness	15	-3	-1	2	-1
53	How much I believe things can get better	53	1	5	3	0
50	How supported I am to set goals for myself	50	1	0	0	-4
8	How able/supported I am to manage feelings of loneliness and	8	-4	-3	0	0
33	How understanding staff are towards me	33	1	0	-4	1
21	How safe I feel in hospital	21	-2	0	0	3
17	How much I enjoy my activities/hobbies in the community	17	0	1	-1	-4
32	How much staff treat me with dignity and respect	32	-1	3	-1	2
12	How suitable my housing is (outside of hospital)	12	4	3	0	-1
18	How much the impact of my physical health issues can be redu	18	1	-3	2	1
6	How involved my family/loved ones are in my treatment/care	6	-3	1	0	3
47	How available hospital/ward staff are to support me	47	2	-2	-2	3
35	How able I am to manage feelings of boredom	35	-2	-1	1	-4
5	How much I feel part of a community/society	5	-2	2	-3	-2
46	How much private time I have to myself	46	-4	1	-4	-3
36	How supported I feel by mental health services	36	1	0	-2	5
27	How much my mental health affects my personal freedoms and r	27	0	-2	4	1
37	How much my mental health affects my ability to work	37	2	-2	4	3
31	How much support I get from family/loved ones	31	-3	2	3	-1
40	How much others respect my right to be alone	40	-2	4	-3	0
30	How well society understands my mental health difficulties	30	-1	-2	-3	3
16	How much therapy helps me	16	-1	0	-3	4
42	How stable my living arrangements are	42	4	4	-1	0
24	How comfortable the hospital ward/environment is	24	-3	1	-5	1
29	How much support I get with financial problems	29	3	3	0	-4
2	How often my mental health experiences happen	2	1	-5	-1	1
39	How easily I can access employment/education/skills courses	39	3	-4	-2	-2
45	How much I'm able to reduce feeling a burden to others	45	-4	-3	1	2
4	How much I feel my life has purpose	4	0	5	3	-1
14	How confident I am in my skills and abilities	14	0	4	4	-3
3	How much my medication helps me	3	3	-4	-1	1
19	How able I am to support myself and/or my family financially	19	5	0	-1	-2
52	How much my diagnosis is explained to me	52	-1	-3	-4	4
25	How often I exercise and eat well	25	-1	3	5	-3
26	How positive I view my relationships to be	26	-4	4	2	-3
49	How able/supported I am to reduce my drug/alcohol intake	49	2	-4	1	-5
7	How much my mental health experiences affect my memory & con	7	3	-5	5	4
41	How much distress my mental health symptoms/voices cause me	41	4	-5	0	5
34	How much my religion/spirituality helps me to cope	34	-5	5	2	-5