

**UNDERSTANDING RECOVERY IN PSYCHOSIS**

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of  
Doctor of Philosophy  
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## **List of abbreviations**

AMOS- Analysis of Moment Structures (statistical software package)

BG- Biogenetic (used in reference to biogenetic causal explanations of psychosis).

BHS- Beck Hopelessness Scale

CBT- Cognitive Behaviour therapy

CDSS- Calgary Depression Scale for Schizophrenia

CFI- Cumulative Fit Index

CHIME- Connectedness, Hope, Identity, Meaning and Empowerment

CMHT- Community Mental Health Team

COMPARE- Cognitive behavioural therapy or medication for psychosis- a randomised evaluation.

DLA- Disability Living Allowance

DSM- Diagnostic and Statistical Manual of Mental Disorders

EFA- exploratory factor analysis

EI- Early Intervention

EPMA- Emotional Processing and Metacognitive Awareness

ESM- Experience Sampling Method

FAIR- Free Access to Involvement in Research

FI- Family interventions

GAF- Global assessment of functioning

GP- General Practitioner

IACT- Investigating Attention Control Training

IAT- Implicit Association Test

ICD- International Classification of Disorders

IMR- Illness management and recovery

IMRS- Illness management and recovery scale

LR- Likelihood Ratio

MHSIP- Mental Health Statistics Improvement Programme

NHS- National Health Service

NICE- National Institute for Health and Care Excellence

NIHR- National Institute for Health Research

NIMHE- National institute for Mental Health in England

NRES- National Research Ethics Service

PANSS- Positive and Negative Syndrome Scale

PRI- Psychosis Recovery Inventory

PROM- Patient Reported Outcome Measure

PRU- Psychosis Research Unit

PS- Psychosocial (used in relation to psychosocial causal explanations)

PSP- Personal and Social Performance Scale

PSYRATS- Psychotic Symptom Rating Scales

QPR- Questionnaire about the Process of Recovery

RAQ- Recovery Attitudes Questionnaire

RAS- Recovery Assessment Scale

RMSEA- Root-Mean-Square Error of Approximation

RPI- Recovery Process Inventory

RSQ- Recovery Styles Questionnaire

SCAN- Schedule for Clinical Assessment in Neuropsychiatry

SE- Standard Error

SERS- Self Esteem Rating Scale

SOFAS- Social Occupational Functioning Assessment Scale

SPSS- Statistical Package for the Social Sciences

SRMR- Standardised Root Mean Square Residual

STARS- Staff Attitudes to Recovery Scale

STORI- Stages of Recovery Instrument

SURG- Service User Reference Group

TEAMS- Think Effectively About Moodswings

WHO- World Health Organisation

## **Abstract**

The University of Manchester

**Candidate:** Heather Law

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**Thesis title:** Understanding recovery in psychosis

This thesis explored conceptualisations of recovery, associated psychological factors and predictors, measurement of subjective recovery, and attitudes towards recovery. A multi-method approach was utilised, including reviewing evidence from the existing literature, cross-sectional, survey and longitudinal designs, and a computer based implicit association task. Chapter 1 provided a review of the literature, followed by an overview of the methodology employed throughout this thesis in chapter 2. Chapter 3 (study 1) included a user informed review of existing recovery measures. The Recovery Assessment Scale appeared to be the most valid and acceptable measure currently in use, although the Questionnaire about the Process of Recovery (QPR) received particularly positive feedback from service users, but lacked further psychometric validation. Consequently, chapter 4 (study 2, N=335) went on to explore the psychometric properties of the QPR. Exploratory factor analysis suggested a one factor model with high internal consistency, test re-test reliability and convergent validity. Recommendations for the use of the QPR in routine clinical practice was discussed. Chapter 5 (study 3, N=381) utilised the Delphi method to consult a large sample of service users about their views on recovery. A high level of consensus (>80%) was reached for a number of items on defining recovery, factors which help and hinder recovery and factors which show recovery. Implications for clinical practice and future research are discussed. Chapter 6 (study 4, N=110) examined longitudinal predictors of recovery. Negative emotion, positive self-esteem, hopelessness, and to a lesser extent symptoms and functioning predicted subjective recovery. Psychosocial factors and negative emotion appear to be the strongest longitudinal predictors of subjective recovery. Chapter 7 (study 5, N=146) used an online survey and computer task to explore attitudes towards recovery in health professionals and the general public. Explicit attitudes towards recovery were generally positive, with health professionals having significantly more positive attitudes than the general public group. Positive attitudes towards recovery were predicted by greater knowledge of recovery and a preference for psychosocial causal models of psychosis. Implications for focussing on psychosocial causal explanations in recovery training and awareness programmes for health professionals and the general public are discussed. This thesis has advanced our understanding of recovery by reaching consensus about what recovery means to individuals with experiences of psychosis, evaluating tools for measuring recovery and determining some of the key psychological processes and predictors of recovery, including causal beliefs, locus of control and negative emotion. These findings appear to fall into four main themes: conceptualising and defining recovery, measurement of recovery, relationships between psychological processes and recovery, and facilitating recovery. Further research is needed to explore recovery across the continuum of psychosis and investigate recovery focussed interventions which target the key psychological processes identified throughout this thesis.

## **Declaration**

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification at this or any other university or institute.

## **Data**

Data for study 2 and 4 was collected as part of the Recovery Research Programme (RP-PG-0606-1086 - full title: Psychological approaches to understanding and promoting recovery from psychosis). The author was responsible for management of the research studies within this programme of work and contributed to data collection by management of research assistants and recruitment strategies. The author was independently responsible for design, analysis and write up of these studies. Data for the remaining studies was collected by the author for the purpose of this thesis.

## **Published work**

This thesis is submitted in alternative format with five papers. Each of the five papers has been submitted to peer-reviewed journals to maximise dissemination. Study 1 has been published in the *Journal of Mental Health*. Study 2 has been reviewed by *Schizophrenia Research*, changes have been requested and submitted. Study 3 is in press at *Schizophrenia Bulletin*. Study 4 has been submitted to *British Journal of Psychiatry*. Study 5 has been submitted to *Psychology and Psychotherapy: Theory, Research and Practice*.

## **Authorship and collaborator contributions**

The author's supervisor, Professor Anthony P. Morrison, has overseen the design, conduct and write up of each of the studies within this thesis, and is therefore listed as an author on each paper. Study 1 was conducted in collaboration with two service users who are therefore included as authors on this paper. Study 3 developed a measure originally designed by Dr. Sandra Neil, who acted as a consultant on this study and is

therefore included as an author. Professor Richard Bentall had input into the design and write up of study 4 and is therefore included as an author on this paper. Statistical support was provided by Professor Graham Dunn on study 2 and Dr Nick Shryane on study 4, so they are included as authors on the respective papers.

### **Analysis and write up**

The analysis of data reported throughout this thesis has been carried out by the candidate, under the supervision of Professor Anthony P. Morrison with support from statisticians at the University of Manchester. The candidate led the write up of each study, preparing drafts for comment from the supervisors and co-authors.

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## **The Author**

I began working in the National Health Service in 2007 as a research assistant in the forensic service at the young person's directorate. I went on to work as an assistant psychologist at Hindley Young Offender Institution, working with young people with mental health difficulties. In 2010, I was offered a position at the Psychosis Research Unit (PRU). The position was research coordinator for the Recovery Research Programme, which included being a trial manager for two randomised controlled trials (RCT's) along with managing a number of other studies. As part of this role, I was responsible for management of up to 7 research assistants and a service user researcher. I also chaired the Recovery Service User Reference Group (SURG). I completed this role alongside completion of this thesis.

I am now working as trial manager for the TEAMS study (Think Effectively About Mood Swings), COMPARE study (Cognitive therapy Or Medication for Psychosis: A Randomised Evaluation) and IACT study (Investigating Attention Control Training) at the Psychosis Research Unit (PRU). I continue to manage research assistants, a service user researcher and chair the PRU Service User Reference Group (SURG).

## **Chapter 1: Introduction and literature review**

This chapter begins by describing what we mean by the term psychosis and outlining this concept from both a biomedical and psychological perspective. It examines the most recent data on the prevalence of psychosis related disorders and symptoms, and explores the current approaches to intervention and treatment from the perspectives of the medical and psychological models.

This introduction sets the foundation for a more detailed exploration of the field of psychosis from a recovery perspective. Firstly, the relatively new concept of recovery from psychosis and the recent upsurge in literature in this field is discussed. This includes an examination of a variety of qualitative and quantitative studies investigating recovery from psychosis, and discussion around the views of service users and health professionals such as psychiatrists and psychologists. Secondly, the recovery approach and its application for mental health in the context of the NHS and recovery-oriented services is discussed.

Finally the rationale for the current research is summarised and the aims of the study are outlined.

### **1.1. Definitions of Psychosis**

Historically, it is believed the term psychosis was first coined in 1845 by the psychiatrist Baron Ernst von Feuchtersleben in his textbook "Principles of Medical Psychiatry" and was used as an umbrella term to include "idiocy, fixed delusion, mania and fatuity" (1996). The origins of the word are thought to be from the Greek word "*psyche*" meaning mind or soul, and "*osis*" meaning abnormal condition. In the contemporary literature, psychosis is used more generally to refer to experiences including hallucinations, delusions and paranoia. In the current medical literature, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), defines psychosis as "restricted to delusions or prominent hallucinations, with the hallucinations occurring in the absence of insight into their pathological nature" (American Psychiatric Association, 2000).



From the medical perspective, psychotic experiences are usually viewed as symptoms of psychiatric disorders in which the individual is believed to have a loss of contact with reality. Schizophrenia is the disorder most commonly associated with psychotic symptoms and was originally described by Kraepelin in the compendium of psychiatry as "dementia praecox" (Kraepelin, 1883). Kraepelin's research indicated that the disorder begins during the late teens to early adulthood and was characterised by progressive deterioration which was irreversible, hence the name "dementia praecox" or "premature dementia". Kraepelin stated that psychiatric disorders could be classified by their symptoms and the neurobiological aetiologies could be inferred from these symptom profiles. It is believed that this approach to diagnostic classification formed the cornerstones of modern psychiatry.

In 1911, Bleuler noted that dementia praecox was not always characterised by early onset or by a progressive and irreversible deterioration. In fact, Bleuler's research showed that many of his patients actually showed improvement in symptoms and some appeared to have recovered completely (Warner, 2004). Bleuler went on to describe the central characteristic of the disorder to be a splitting of the personality and therefore used the term schizophrenia rather than dementia praecox.

The term schizophrenia is still used today, although the concept of a splitting of the personality is no longer relevant. The DSM-IV-TR (American Psychiatric Association, 2000) lists five subtypes of schizophrenia: paranoid, disorganised, catatonic, undifferentiated and residual. All of these subtypes must meet the three diagnostic criteria for schizophrenia: i) the presence of two or more characteristic symptoms such as hallucinations, delusions, disorganised speech and behaviour or negative symptoms such as blunted affect or avolition; ii) social or occupational dysfunction iii) a duration of at least six months disturbance including one month of symptoms. The DSM-IV also lists various other disorders in which psychotic experiences or symptoms can be present, including bipolar disorder and personality disorders.

When diagnosing psychotic disorders, one of the essential criteria is the presence of positive symptoms such as hallucinations and delusions. The DSM-IV-TR (American Psychiatric Association, 2000) characterises

hallucinations as “a sensory perception that has the compelling sense of reality of a true perception but that occurs without external stimulation of the relevant sensory organ”. It goes on to define delusions as “a false personal belief based on an incorrect inference about external reality and firmly sustained in spite of what usually constitutes incontrovertible and obvious proof or evidence to the contrary”. It is interesting to note the inherent difficulties in objectively determining “incontrovertible and obvious proof” in relation to an individual’s “personal belief” and critics have therefore argued that definitions of delusions in particular are not “acceptable” (David, 1999) and in practice, psychiatrists are expected to make subjective decisions to classify these experiences and symptoms.

It is perhaps easy to see why the medical model and its classification of these experiences as symptoms of mental disorders has been heavily criticised in recent years and the diagnosis of schizophrenia in particular has been the subject of much debate. It has been argued that this classification is at best “scientifically meaningless” (Bentall, 2003) and others have suggested it is “a harmful concept” (Romme, 2005). Research into schizophrenia has failed to show validity in terms of aetiology, symptoms and treatment outcomes (Bentall, 2003) and campaigners have called for the abolition of the schizophrenia label (Hammersley, 2006).

### **1.2. Prevalence of psychosis**

Schizophrenia is the most common psychotic disorder (National Institute for Health & Clinical Excellence, 2010), affecting twenty-four million people worldwide (World Health Organisation, 2010). Many textbooks and policy documents report that around 1% of the population will develop schizophrenia over the lifetime (British Psychological Society, 2000), although a recent systematic review indicated the point prevalence is more like four per 1000 (Saha, Chant, Welham, & McGrath, 2005), with estimates in the literature varying from 3.4 to 5.5 per 1000 persons (Goldner, Hsu, Waraich, & Somers, 2002). Prevalence estimates of bipolar disorder also average at 1%, with estimates ranging from 0.3-1.5% (National Institute for Health & Clinical Excellence, 2006), and although bipolar disorder is not primarily a psychotic disorder, between

10 and 20% of people with bipolar disorder exhibit psychotic symptoms including thought disorder, hallucinations and delusions (National Institute for Health & Clinical Excellence, 2006). Similarly, major depressive episodes with psychotic features are thought to affect 0.35% of the population (Perala et al., 2007) and borderline personality disorder is estimated to affect 0.7% of the population, with transient psychotic symptoms often being present in this client group (National Institute for Health & Clinical Excellence, 2009).

More general prevalence figures for psychosis vary depending on which psychiatric diagnoses are included, the methodology for both data collection and diagnosis used, and the nature of the population being studied. Recent research suggests that the lifetime prevalence for all psychotic disorders in the DSM-IV is 3.06%, or 3.48% if register diagnosis of non-responders is included (Perala et al., 2007). The current Adult Psychiatric Morbidity Study (The NHS Information Centre for health and social care, 2009) explored the prevalence of "psychotic disorder", as diagnosed by the Schedule for Clinical Assessment in Neuropsychiatry (SCAN), and "probable psychosis", as determined by SCAN and/or the psychosis screening questions, in the general population in England. Prevalence figures from this study were 0.4% for psychotic disorder in the past year, and 0.5% for probable psychosis in the past year.

The literature also suggests psychotic experiences occur within the general population. Between 10 and 25% of the general population report that they have experienced hallucinations (Johns & Van Os, 2001), whilst unusual beliefs and delusions are experienced by 3.3 and 8.7% (van Os, Hanssen, Bijl, & Ravelli, 2000; Van Os, Hanssen, Bijl, & Vollebergh, 2001). Similarly, paranoid thoughts have been found to occur regularly in almost a third of the population (Freeman et al., 2005). Many studies of psychotic symptoms in non-patient samples have been conducted within student populations. Prevalence of psychosis within these samples range from 30% to as high as 70% (Stip & Letourneau, 2009). Based on general population studies such as these, it has been suggested that experiences of psychosis occur on a continuum of normality (British Psychological Society, 2000) and that it is only when distress occurs as a result of these experiences that we label them as symptoms of illness (Johns & Van Os, 2001).

### **1.3. Approaches to understanding and treating psychosis**

The medical model puts neurobiology at the cause of psychotic disorders such as schizophrenia. The origins of schizophrenia are proposed to be organic; a result of genetics, infection or virus, brain abnormalities or deregulation of neurotransmitters. Historically, treatments for this "disease of the brain" included radical and often inhumane procedures such as lobotomy or electro convulsive therapy (Warner, 2004), and until the 1950's, schizophrenia was generally treated and managed within large asylums (National Institute for Health & Clinical Excellence, 2010).

In contemporary psychiatry, antipsychotic medication is seen as the primary treatment for schizophrenia (National Institute for Health & Clinical Excellence, 2010). Pharmacological treatments have been shown to be effective for both acute psychotic episodes and relapse prevention over time (National Institute for Health & Clinical Excellence, 2010). However, as with most treatments, there are considerable limitations to the efficacy of antipsychotic medication. Firstly, these medications have a high incidence of side effects ranging from lethargy, weight gain and sexual dysfunction to the more severe and potentially disabling movement disorders such as parkinsonism and dystonia (National Institute for Health & Clinical Excellence, 2010). Despite considerable advances in reducing these side effects in the so-called second-generation antipsychotics, the result is that many service users do not take their medication (Allison et al., 1999). Secondly, up to 40% of service users continue to experience moderate to severe psychotic symptoms, showing a poor response to antipsychotic drugs (Kane et al., 1996). Finally, recent research suggests that recovery from psychosis is possible without medication (Harrow, Grossman, Jobe, & Herbener, 2005).

On the whole, a purely medical model of understanding and treating psychosis could be seen to be a reductionist approach and may lead to pessimism about the possibility of recovery from symptoms (Jones & Hayward, 2004). Also, service users themselves report a need to explore the effects of their psychotic symptoms on their social, cultural and occupational lives, rather than a focus purely on symptoms and a

reduction of such symptoms through medication (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007c).

Psychological approaches to schizophrenia on the other hand, have a more holistic approach to the origins of psychotic disorders, listing numerous factors involved in both the development and maintenance of psychosis. Cognitive theories propose that our behavioural and emotional responses to particular stimuli or events are governed by the way we interpret those stimuli and events (Beck, 1976). Based on this model, cognitive psychologists often take a symptom based approach to understanding psychosis (Garety & Freeman, 2013). For example, it is suggested that auditory hallucinations, are internally generated events which are misattributed to external sources (Baker & Morrison, 1998). Chadwick and Birchwood (1997; 1994) suggest that beliefs about power, identity and meaning behind auditory hallucinations influence the way the individual reacts to the voice. A belief in the power of the voice can lead to appraisals involving a lack of control and a need to comply with voices. Similarly, the meaning and identity of a voice will impact on reactions to that voice.

Bentall and colleagues (1994) propose that persecutory delusions are a protective device; negative events are blamed on others, which is an attribution defence to prevent negative thoughts about the self from reaching consciousness. Based on this understanding, persecutory delusions are seen to be the results of a protective device against negative emotion and low self-esteem. In contrast with this, Garety and Freeman (1999; 2013) suggest that disturbances in reasoning and affective process contribute to persecutory delusions. Rather than the defensive role suggested by Bentall et al., (1994), this model emphasises the direct (non-defensive) role of emotion in the development and maintenance of delusions. In particular this model highlights a key role for worry and depression; persecutory thoughts are viewed as an extension of anxiety and depressive concerns about self-worth. However, both these models highlight a key role for negative emotion.

In addition to these symptom specific models, there are also more general cognitive models of psychosis which incorporate many of the same themes. Morrison (2001) suggests that anomalous experiences are

a normal and common intrusion into awareness which, if perceived as unacceptable or misinterpreted, are viewed as psychotic phenomena. Life experiences and beliefs about the self and others contribute to how individuals make sense of these intrusions and consequently how they feel and react to these intrusions.

Similarly, Garety et al., (2001) suggest that positive symptoms develop either through cognitive and affective changes, or via affective disturbances alone (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Garety et al., (2001) posit that emotional changes occur within the context of psychosis like experiences. These emotional changes can feed into the way such experiences are processed, influencing their content and maintaining their occurrence. This model highlights that emotion plays a central role in the development and maintenance of psychosis (Garety et al., 2001) and suggests that negative emotion and low self-esteem play a central, normal, direct and non-defensive role in the development of psychosis. Further research has supported this claim that low mood and low self-esteem contributes to the development and maintenance of psychosis (Barrowclough et al., 2003; Krabbendam et al., 2005; Smith et al., 2006).

Another psychosocial factor which can influence the development of psychosis is traumatic life events. The integrative model of trauma and psychosis (Morrison, Frame, & Larkin, 2003) suggests that intrusive memories resulting from traumatic life events can be correctly identified as symptoms of post-traumatic stress disorder if the link between these intrusions and the history of personal trauma is made. However, these intrusions are often dissociative in nature and/or involve a vivid reliving of events and consequently, if this link between idiosyncratic life events and the intrusions is not made, they may be viewed as psychotic phenomena. Evidence also suggests that the experience of psychosis is, in itself, a traumatic life event and receiving a diagnosis and being in contact with or admitted to services can also be traumatic (Morrison, Bowe, Larkin, & Nothard, 1999; Morrison et al., 2003). Service users have reported that the way they are treated by mental health services and society in general play a huge part in what is considered to be their 'illness' (Tooth, Kalyanasundaram, Glover, & Momenzadah, 2003).

Read et al., (2014; 2001) developed the traumagenic neurodevelopmental model after highlighting similarities in the structural and functional abnormalities of children who have experienced trauma and adults diagnosed with schizophrenia. The model brings together biological and psychological processes, proposing that trauma in early life leads to neurodevelopmental changes in the brain heightening sensitivity to stress, which is often found in individuals with a diagnosis of schizophrenia.

The majority of academics and clinicians from various backgrounds now agree that there is likely to be some interaction of both biological and psychosocial factors in the development and maintenance of psychosis, although the weighting of importance between these factors is still debated between the medical and psychological paradigms. Often the stress vulnerability model of psychosis is cited (Zubin & Spring, 1977), whereby biological factors such as genetics and neural abnormalities can predispose an individual to be vulnerable to psychotic experiences, and stressful or traumatic life events can trigger psychotic symptoms in these individuals. A recent review highlighted the potential for integrating cognitive approaches to understanding psychosis with neurobiological frameworks (Garety, Bebbington, Fowler, Freeman, & Kuipers, 2007). Garety and colleagues suggest that research into interactions between genes, environment, cognition and emotion could be key to furthering our understanding of psychosis and treatment approaches.

Psychological treatments for psychosis are a relatively new concept with psychoanalysis gaining popularity in the 1950s (Fromm-Reichmann, 1950) and the advent of social skills training in the 1970s which was based on learning theory and behaviour modification techniques (Shepherd, 1978). Soon after, family interventions and psychoeducation became widespread, most probably as a result of the "care in the community" movement, when services moved away from institutional care.

Family interventions (FI) aim to improve social functioning and supportive relationships by targeting behaviour of family members which in turn impacts on symptoms (Barrowclough & Tarrier, 1990; Kavanagh, 1992; Kuipers, Birchwood, & McCreadie, 1992). Research has suggested

that treatment effects appear to be limited to the duration of the intervention, meaning that FI would need to be continued for benefits to be maintained (Kuipers, Bebbington, Pilling, & Orbach, 1999). However, there is a growing evidence base for the use of FI's and NICE guidelines recommend offering them in routine practice (National Institute for Health & Care Excellence, 2014)

In contrast, the effects of cognitive behavioural therapy (CBT) are believed to be maintained after therapy finishes (Kuipers et al., 1998; Sensky et al., 2000). One of the biggest innovations in psychological therapy was the introduction of CBT in the late 1970s. Originally developed as a treatment for depression, (Beck, Rush, Shaw, & Emery, 1979) CBT aims to reduce the distress associated with psychotic symptoms by normalising and making sense of the individuals experiences. There is a wealth of literature on the effectiveness of CBT, which is beyond the scope of this review. However, the recently updated NICE guidance for schizophrenia advocates the provision of CBT to service users experiencing psychotic symptoms, and includes a systematic review of the relevant trials which confirm the effectiveness of CBT for both symptom reduction, decrease in duration of hospital admissions and in rehospitalisation rates (National Institute for Health & Care Excellence, 2014). It has been suggested that the future of CBT for psychosis is to tailor interventions to take into account the growing role of emotion in the development and maintenance of psychosis (Birchwood & Trower, 2006).

#### **1.4. Definitions of Recovery**

The concept of recovery has seen an upsurge in both literature and interest over recent years, particularly from service users themselves, as well as those commissioning and providing mental health services. It can be conceptualised as a "social movement" rather than a model of services based on scientific evidence (Warner, 2010), and it has brought a new sense of optimism and enthusiasm to the care and treatment of individuals experiencing severe and enduring mental health problems.

Recovery orientated practice can be traced back to the early 19<sup>th</sup> Century, when the Quaker movement led to the opening of the



residential home "the Retreat" in York (Roberts & Wolfson, 2004). Unlike the harsh environments of the mental institutions of the time, the Retreat did not use physical restraint or punishment, nor did it advocate the use of the "physical treatment practices" of the era. Instead the focus was on moral and psychological treatment and work orientated rehabilitation. It is only in the past 20 years or so in the UK, that the recovery approach has again come to the forefront of the minds of mental health professionals, mainly as a result of service users publishing their own personal accounts of recovery (Social Care Institute for Excellence, 2007)

Despite this relatively recent reawakening of interest in the concept of recovery and the increasing use of the word within mental health services and the academic literature, there is still no universally accepted and unambiguous definition of recovery. The word has a completely different meaning to service users compared with clinicians and academics. Generally the term recovery implies a cure or healing after illness or injury and a return to the normal condition. However, based on this connotation, few people with severe mental illness would ever be fully recovered (Whitwell, 2005).

Clinicians advocating the biomedical model define recovery in terms of the absence of symptoms, decreases in duration of hospital admissions and reduced rate of rehospitalisation (National Institute for Health & Clinical Excellence, 2010). In psychiatry the gold standard for research into recovery is longitudinal studies demonstrating significant improvements in symptoms and other deficits to the degree that they could be considered within the normal range (Schrank & Slade, 2007). Andreasen et al (2005) posit that recovery is seen as "a long term goal of remission".

Various studies have attempted to describe the criteria for recovery from the medical perspective. For example, Liberman et al., (2002) suggest that recovery from schizophrenia can be defined by, over a period of at least two consecutive years:

- Symptom remission ( $\leq 4$  on the positive and negative symptom items of the Brief Psychiatric Rating Scale)
- full- or part-time involvement in work or school

- independent living without supervision by family or surrogate caregivers
- not fully dependent on financial support from disability insurance
- having friends with whom activities are shared on a regular basis.

Similarly, Torgalsboen (1999) suggests that for an individual to be in recovery from schizophrenia, they must:

- have had a diagnosis of schizophrenia at an earlier time,
- currently not meet the diagnostic criteria for schizophrenia
- not currently be on antipsychotic medication (or be on minimal dosage),
- have been out of hospital for a minimum period of five years
- Demonstrate psychosocial functioning within the normal range as assessed by the Global Assessment Scale.

Bellack (2006) argues that whilst the biomedical approach to defining recovery from physical illness may be acceptable, using the same paradigm to define recovery from mental illness is inadequate. Severe and enduring mental illness may remit and relapse and can result in significant changes in functioning from prior to the onset of illness; however, individuals can have a return to an acceptable level of functioning.

Contrary to these relatively rigid biomedical approaches to defining recovery, the service user movement in conceptualising recovery has moved away from these professional classifications towards self-definition. Service users view recovery as something very different to clinicians (Bellack, 2006) and are not limited to purely considering recovery as the absence of symptoms, disability or reduction in the use of mental health services (Social Care Institute for Excellence, 2007). There is a strong belief that recovery is different for everyone and that it is a complex process rather than an outcome or end point.

Many service users have been encouraged to write about their personal experiences of recovery and this has furthered our understanding of what exactly we mean by recovery from a service user perspective. It is

difficult to succinctly and accurately define recovery from this perspective, because it can mean something different to each individual. Many of these service user accounts have common themes which, when brought together, are helping to illustrate the multifaceted and dynamic process that is recovery. These themes are discussed in more detail later in this chapter, but include internal factors (such as hope, empowerment and acceptance), external factors (such as support networks) and the concept of recovery as a journey, a process and a transformation (Leete, 1989; Mead & Copeland, 2000; Pitt et al., 2007c; Ralph, 2000; Ridgeway, 2001).

In contrast with the more purist biomedical definitions which limit the possibility of recovery to only those with a complete remission of symptoms and a return to the premorbid state, these service user informed conceptualisations propose that there is the potential for all individuals to recover to some extent (Davidson, 2003). This has prompted a need for further research to identify the factors which constitute recovery, and even more importantly to uncover what can be done to facilitate the process.

### ***1.5. Review of the literature on psychosis and recovery***

So far, this chapter has concentrated on defining the key terms used in this thesis, as well as introducing the key theoretical paradigms for exploring psychosis and recovery. Based on this introduction to the field, the remainder of this review examines the extant literature on recovery from psychosis from the perspectives of service users, clinicians, academics and service commissioners. This includes autobiographical and anecdotal accounts from those with first hand experience of recovery from psychosis; qualitative and descriptive studies by leading researchers and service user led research groups, as well as longitudinal and quantitative studies. A summary of the relevant governmental policy behind the drive for recovery oriented services, and a critical review of measures of recovery from psychosis are incorporated.

To identify relevant studies, a search of the internet and appropriate databases (PsychINFO, MEDLINE, Health and Psychosocial Instruments, EMBASE and the British Nursing Index and Archive), was conducted.

Reference lists from key articles were hand searched to identify any additional literature. Key terms were selected to include psychosis and recovery and their common alternatives (see table 1) as well as the terms used to refer to service users, mental health services themselves and recovery measures. Initially, a general search of any articles with keywords from column one and two were included. This was further refined by selecting keywords from columns three and four, dependent on the specific nature of the articles being searched for. The truncation tool (\$) was used with some terms and keywords from the same column were combined using the “or” function.

**Table 1: literature search key words**

Key Terms 1	Key terms 2	Key terms 3	Key terms 4
Schizophren\$	Recover\$	Service user	Service\$
Psychosis	Recovery model	User / user led	Measure
Psychotic	Recovery oriented	Patient	Outcome
Mental\$		Client	Tool
		personal	Scale

The articles and papers identified are reviewed in terms of their key findings and implications, as well as their limitations. Their relevance to and influence on this thesis are discussed and summarised in the rationale for the present study.

### *1.5.1 Autobiographical and anecdotal accounts*

As discussed earlier, much of the recent interest in the concept of recovery from psychosis arose in the 1980’s as a result of a number of service users publishing personal accounts of their experiences. One of the most commonly cited accounts is that of Patricia Deegan (1988), who was diagnosed with schizophrenia as a teenager, and told that she would be “sick” for the rest of her life. She went on to train as a clinical psychologist and to publish her autobiographical account of recovering from psychosis. She describes the “three cornerstones of recovery- hope,

willingness, and responsible action” and how recovery is not an “end point or result” but “a process, a way of life”.(Deegan, 1988)

Similarly, Ezzo Leete (1989) shared her personal account of living with psychosis for over 20 years and her experience of recovery. She too describes the need to take personal control of her life, to develop ways of coping with vulnerabilities whilst focussing on her strengths and assets. Most importantly, she emphasises that “illness can be overcome”.

More recently, Mead and Copeland (2000) described their experience of psychosis and recovery and highlight the importance of hope, personal responsibility, education, advocacy and peer support. They describe how they were originally told that their illness was incurable but that with the help of medication for the rest of their lives they would be “ok”. They commend the more recent optimism and normalisation of experiences of psychosis and how people “can and do get well”. They also describe recovery as a choice, and that it is up to the individual to decide when they are ready to start this process.

Several authors have attempted to extrapolate common themes from user accounts of recovery from psychosis. Ralph (2000) found four factors which are common to personal accounts of recovery: internal factors including awakening, insight and determination; self managed care and coping; external factors such as support of others; and empowerment or internal strength.

Similarly, Ridgeway (Ridgeway, 2001) analysed four of the earliest published personal accounts, including that of Deegan (1988) described above, and again found several commonalities including: hope; acceptance and understanding; engagement and active participation; active coping; a purposeful and complex journey; and the need for external support.

### *1.5.2 Qualitative studies of recovery*

Qualitative studies supplement the work of first person accounts by enhancing our understanding of the concept of recovery, still using the service user perspective whilst building a more scientific evidence base than single case accounts. Several researchers have investigated recovery from psychosis using this approach.

For example, Smith (2000) conducted semi-structured interviews with 10 participants who had been diagnosed with either schizophrenia, bipolar disorder or major depression. The author used a software package to analyse the transcribed interviews and identified five themes. The first theme was concerned with what recovery means to them. Participants reported that recovery is a long process which is about control over symptoms, but also about other complex aspects of life such as support, self respect and goals along the recovery journey. The second theme was "turning points toward recovery" which encompassed what was considered to be the first stage of recovery. Participants explained that this began with acceptance of their illness, determination and desire for change, followed by help-seeking behaviours. After this initial phase, participants described the third theme as factors which were critical to recovery. This included medication, support, activities, control and independence, determination and a positive outlook. The fourth theme followed on from this with barriers to recovery: stigma, symptoms, finances, limited access to services and responses to life pressures. Finally participants identified ten strategies for recovery which included many of the earlier themes such as acceptance and support as well as taking care of yourself.

As with most qualitative investigations, this study is limited by a small and homogenous sample, and consequently it may not be appropriate to generalise the findings to other individuals from other cultures or educational backgrounds. Similarly, this study was not specific to people with experience of psychosis and included a diagnosis of bipolar disorder and major depression. Further investigation of the nature of recovery in these different samples would have been beneficial. However, as many of the themes identified compare with those described earlier, it would appear that the study has face validity.

In a similar study, Spaniol, Wewiorski, Gagne & Anthony (2002) conducted semi-structured interviews with twelve participants who had been diagnosed with schizophrenia or schizoaffective disorder, and who had just taken part in a two year study of psychiatric rehabilitation. The authors followed up these individuals for four years with open ended interviews every four to eight months. Analysis of the interviews revealed four phases to recovery: being overwhelmed with disability; struggling

with disability; living with disability; and finally living beyond disability. They described recovery as developmental, with the need to work through three basic tasks: finding explanations for their experiences; managing their 'disability'; and engaging in meaningful and productive roles. As with the previous study, the authors acknowledge that a complete model and understanding of recovery cannot be gained from the limited sample of 12, but acknowledge the similarities between the themes identified in this study and those extrapolated from other service user accounts. They also call for more research of a similar nature, using a prospective, longitudinal approach.

Forchuk, Jewell, Tweedell and Steinnagel (2003) also used a relatively small sample of ten individuals and conducted interviews before and during treatment with clozapine or risperidone. This is one of the few qualitative studies to examine experiences of recovery during the initial year of their pharmacological treatment. In common with the themes identified by Smith (2000) and Spaniol et al (2002), this study found that recovery was described as a process, beginning with improvements in personal thoughts and feelings and extending to reconnections with the environment and other people. Recovery is described as involving the mental, physical, emotional and spiritual aspects of the self into their experiences. Unlike other studies, this investigation also found that the individual's thinking moved from being focussed on the internal self to the larger world.

Many of the service user accounts and qualitative studies have emphasised the importance of social support, yet little is known about the experiences of families of individuals in recovery from mental illness. Tweedell, Forchuk, Jewell and Steinnagel (2004) attempted to address this gap in knowledge by interviewing nine families, with a member who had a chronic mental illness, on five separate occasions over the course of a year. The families described the huge impact the illness had on them, including social, emotional and financial problems but that the process of recovery had allowed them to see positive outcomes including improved interpersonal relationships. This study highlights the important role the family can play in the process of recovery and the difficulties families face when providing this key supporting role.

Building on this notion of the importance of family and support networks, Noiseux and Ricard (2008) used a grounded theory inspired approach to analyse interviews conducted with sixteen individuals living with schizophrenia, five family members and twenty health care professionals. Analysis revealed seven categories: "perceiving schizophrenia as a 'descent into hell'; igniting a spark of hope; developing insight; activating the instinct to fight back; discovering keys to well-being; maintaining a constant equilibrium between internal and external forces; and, finally, seeing light at the end of the tunnel". As with the other qualitative studies and personal accounts, the authors conclude that recovery is a non-linear process concerned with the sense of self as well as the balance between internal and external factors. As with any qualitative analysis, the authors of this study note that the themes which are extrapolated are largely dependent of the subjective views of the researcher. However this study paid particular attention to providing a detailed account of the rigorous methodology used and to describing the data coding and analysis.

Another study which used the grounded theory approach was conducted using direct interviews as well as audio taped therapy sessions. As with the previous study by Noiseux and Ricard (2008), Dilks, Tasker and Wren (2010) also included health care professionals in the study, conducting a total of 23 interviews with clients and psychologists. Themes identified included functioning in the social world, managing the impact of psychosis and getting caught up in the experience of psychosis.

There has been little research specifically focussing on mental health professionals and their views and attitudes towards recovery. This is clearly an important area of work still to be undertaken, because if NHS services are to be truly recovery focussed, training and professional competencies need to address the understanding of and barriers to the concept of recovery in mental health care.

One such study conducted focus groups with twelve trainee psychiatrists (Ng, Pearson, & Chen, 2008) to discuss how they define recovery specifically from schizophrenia; whether or not they think a full recovery is possible and what health care professionals should discuss with patients in relation to recovery. A thematic analysis was conducted on



the focus group transcripts and generated a central theme that recovery is complex but important. Four other themes were identified: 1) that absence of relapse is the pre-requisite for recovery; 2) recovery means different things to different people; 3) recovery is an important item to discuss with patients and carers; 4) recovery is possible even when symptoms are present. This study used a small sample of Chinese psychiatrists and the findings can therefore not be generalised to other categories of mental health professionals and other cultures. The authors note that replication of their study, and similar studies would be beneficial to the training of mental health care professionals.

Similarly, Cleary and Dowling (2009) adopted a descriptive approach to survey 153 health care professionals about their knowledge and views towards recovery. Generally respondents were positive about the adoption of a recovery approach, but were less familiar with the non-linear nature of the recovery process. Respondents placed greater emphasis on symptom management and treatment compliance and were less comfortable with encouraging therapeutic risk taking. The authors note the importance of this type of research to inform the mental health workforce and unify the attitudes of service users and the professional tasked with their care. Often, the people most able to educate professionals about the process of recovery are the service users who are experts by experience.

None of the qualitative studies so far have involved service users directly in the design and conduct of the research, which could be considered to be a great disadvantage when investigating the process of recovery. However, in 2007 a service user led research project conducted seven interviews which were analysed using interpretive phenomenological analysis (Pitt et al., 2007c). Themes emerging from this data again included the idea of recovery being a complex and personal process involving rebuilding life, rebuilding self and hope for a better future. These main themes were broken down into several subthemes which included understanding, empowerment, social support, active participation and personal transformation amongst other key concepts. Again, these themes are consistent with the literature and the authors encourage more research in this field and specifically more quantitative studies to confirm these findings and strengthen the evidence base.

### *1.5.3 Quantitative studies of recovery*

Adding to the qualitative investigations and personal accounts of recovery, quantitative studies have begun to expand our knowledge and the evidence base for recovery in psychosis using a variety of methods. Initially cross sectional studies have allowed exploration of factors that may be associated with recovery whilst longitudinal studies have attempted to measure outcomes and identify potential predictors of recovery. These will be discussed in more detail below.

#### *1.5.3.1 Cross sectional studies of recovery*

Recent research has attempted to investigate factors associated with recovery and improved quality of life. Ho et al (2010) assessed over 200 individuals with a diagnosis of schizophrenia, and highlighted that differences in quality of life ratings could be explained by psychological factors including optimism, internal stigma and personal agency as well as symptoms. In another study, an experience sampling method (ESM) was used with 177 individuals with a diagnosis of schizophrenia. Symptom remission and functioning was assessed alongside psychological factors using the ESM method which records moment to moment ratings. The authors found that negative affect was significantly related to symptom remission and functioning in everyday life (Oorschot et al., 2012). These results suggested that emotion, and particularly negative emotion, may mediate the relationship between psychological and neuropsychiatric variables and recovery. However, further interventional or experimental research would be needed to confirm the direction of any relationship.

In another cross sectional study, Morrison et al (2013b) assessed 122 individuals with experience of psychosis. Results suggested that personal recovery scores were directly influenced by negative emotion and internal locus of control, whilst positive symptoms and internal locus of control appear to have an indirect effect on recovery mediated by negative emotion. This suggests that personal recovery judgments appear to be more directly related to psychosocial than neuropsychiatric factors. Longitudinal research would be required to examine this relationship more thoroughly and allow more causal relationships to be considered.

### 1.5.3.2 *Longitudinal studies*

For over a century, researchers have attempted to study the long term outcomes of schizophrenia, making it the most comprehensively researched of the major psychiatric illnesses (Hegarty, Baldessarini, Tohen, Waternaux, & Oepen, 1994). This is perhaps due to the early diagnostic concept framing schizophrenia as a disorder characterised by progressive deterioration and indeed, Kraepelin's own research suggested clinical improvement was only found in 17% of his patients at follow up (As cited in Hegarty et al., 1994). However, by the 1950's, with the advent of antipsychotic medication, outcome studies appeared less bleak (Odegard, 1967). A complete review of the hundreds of outcome studies of schizophrenia is beyond the scope of this literature review. However, several recent systematic reviews have summarised the key findings and will be discussed here.

For example, Hegarty et al (1994) conducted an extensive review of outcomes studies from 1895 to 1992. Their search revealed 821 studies, of which 320 met the inclusion criteria and were included in the review. In total, 38 cohorts of 51,800 subjects were included. The review indicated that less than half of patients diagnosed with schizophrenia show clinical improvement at follow up. Overall, 40.2% of subjects showed improvement at follow up although this varied between 27.3% if narrow diagnostic criteria were used to 46.5% if broader criteria were used. There was also a significant difference in outcomes depending on the decades of study. For example, studies from the first half of the twentieth century showed improvements of just 35.4% compared to 48.5% in the second half of the twentieth century. If the last decade before the review was considered separately (1986-1996), only 36.4% showed improvements at follow up. This result is not statistically different from the rates found in the first half of the century, which the authors suggest is a result of the return to a narrow set of diagnostic criteria.

The review by Hegarty et al (1994) does note several limitations. Firstly, many of the longitudinal studies of outcomes in schizophrenia use imprecise or potentially unreliable forms of diagnostic and outcome criteria, which can lead to clinically heterogeneous samples and to a large variation in findings. Also, it is possible that the averages taken from large sample sizes may obscure variance between subjects and the

relatively short timescales for follow up (average of 5.6 years) may not give an accurate picture of long term outcomes. The impact of advances in psychosocial care and treatment were not factored into the review and the focus was on changes in diagnostic criteria and medical treatments.

The authors conclude that diagnostic criteria have had a “consistent and predictable impact on outcome before and during the era of modern biomedical therapeutics” indicating that outcome may actually be more dependent on methods of diagnosis than on treatment, although the review concludes that the results indicate a positive and favourable impact of modern treatment.

In a more recent meta analysis by Jobe and Harrow (2005), a similar level of variance in outcome studies was reported. The review by Jobe and Harrow (2005) focuses on ten long term studies, mostly conducted in America, with only 1 being an international study coordinated by WHO. The review demonstrated that schizophrenia, like other major disorders, has heterogeneous outcomes usually classifiable as mild, moderate or severe. Despite the variance in outcomes dependent on the study used, the review indicates a generally poor outcome for individuals diagnosed with schizophrenia, especially in comparison with other major psychiatric disorders. However, the studies do not indicate a progressively worsening illness and subgroups of patients showed periods of recovery even without extensive mental health treatment.

The authors of this review note a lack of standardised diagnostic criteria within the studies and the majority measure recovery in simplistic terms, using symptoms as the main indicator. Most of the studies originate in America and results should therefore not be generalised to patients in the UK. Many of these studies do not take into account the potential mediating of outcome such as age of patients or duration of untreated psychosis. The age of the majority of these outcome studies also limits the generalisations to contemporary groups of patients diagnosed with schizophrenia. Most of the patients in the studies reviewed were based on patients initially diagnosed in the 1950’s and 1960’s, before the advent of many of the treatments available today. The different approaches of mental health services, the attitudes of both professionals and the public, and the advent of recovery oriented services may all have a differing

impact on individuals experiencing psychosis in today's society and are likely to lead to even greater variation in outcomes than have been found previously.

### **1.6. Stage models and frameworks of recovery**

In order to create more clarity around conceptualisations of recovery, a number of researchers have attempted to elicit stages or frameworks of recovery. For example, Andresen, Caputi and Oades (2006) utilised information from five qualitative studies on personal recovery to inform the development of their stage model of recovery. The model consists of five stages of recovery: Moratorium (characterised by loss and hopelessness); Awareness (all is not lost and a fulfilling life is possible); Preparation (identify strengths and weakness and work on recovery skills); Rebuilding (working on individual goals and control); and Growth (self management of illness, resilience and positive sense of self for a full and meaningful life). Andresen et al., (2006) suggest that this model involves sequential stages which could be a measurable indicator of the recovery process. Based on this model, the authors developed the Stages of Recovery Instrument (STORI) to measure movements through the five stages. However, cluster analysis of the STORI revealed only three stages related to recovery, suggesting that either there are only three stages that relate to recovery, or the items in the STORI measure were unable to discriminate between the other two stages. The authors also pointed out that the study is limited by a lack of participants in what the model defines as the early stages of recovery. Further validation of both the model and the measure would be recommended.

An alternative model was developed using a systematic review and narrative synthesis method (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). This approach resulted in thirteen characteristics of recovery, five processes of recovery and recovery stage descriptions which mapped onto the transtheoretical model of change. The five recovery processes were: connectedness, hope, identity, meaning and empowerment (giving the acronym CHIME). This synthesis mapped studies and recovery stages onto the transtheoretical model of change under the stages:

precontemplation, contemplation, preparation, action, maintenance and growth.

A significant limitation of the stages approach appears to be the lack of consensus regarding the number of stages which was apparent in both these studies (Andresen et al., 2006; Leamy et al., 2011). There is also a lack of evidence to support the notion that individuals move through these stages in sequence, or whether it is possible that people fluctuate between the stages. Leamy and colleagues (2011) note that it may be more helpful to begin addressing service level questions and evaluations, rather than pursuing consensus over models of recovery.

### ***1.7. Recovery, psychosis and emotion***

Emotion has been directly linked to formation, maintenance and appraisals of psychosis (Freeman & Garety, 2003). Research indicates increased levels of emotional disorders prior to and accompanying psychosis, suggesting a role for emotion in the development and maintenance of hallucinations and delusions. Delusions appear to be directly related to the emotional state of the individual, and share common maintenance factors with emotional disorders (such as safety behaviours (Freeman & Garety, 2003)). Hallucinations are likely to be triggered by emotion and it is suggested that anxious processes, such as worry, maintain hallucinations. Hallucinatory experiences are often interpreted as threatening, leading to anxiety and worry. As well as maintaining hallucinations, it is also apparent that emotional processes impact on appraisals of anomalous experiences which could have a direct impact on distress (Freeman & Garety, 2003). Despite the literature consistently suggesting links between psychosis and emotion (Bebbington, Fowler, Garety, Freeman, & Kuipers, 2008; Freeman & Garety, 2003; Freeman, Garety, & Kuipers, 2001; Garety et al., 2005; Garety et al., 2001; Smith et al., 2006), little research has directly explored the links between personal recovery in psychosis and emotion.

As discussed earlier, Oorschot and colleagues found that negative affect was significantly related to symptom remission and functioning in everyday life (Oorschot et al., 2012). These results suggested that emotion, and particularly negative emotion, may mediate the relationship

between psychological and neuropsychiatric variables and recovery. However, this study did not measure personal or service user defined recovery per se.

The only study to date which does address service user defined recovery in psychosis in relation to emotion was conducted by Morrison et al., (2013b). In a cross sectional study of 122 individuals with experience of psychosis, personal recovery scores were directly influenced by negative emotion. The authors also investigated the effects of internal locus of control, finding that positive symptoms and internal locus of control appear to have an indirect effect on recovery mediated by negative emotion. These findings suggest that personal recovery judgments are more directly related to psychosocial factors such as self-esteem and emotion than neuropsychiatric factors.

Given the fairly established links between psychosis and emotion, particularly negative emotion, and the early findings from Morrison et al. (2013b) regarding subjective recovery and negative emotion, future research in this area would be beneficial.

### **1.8. Attitudes towards recovery**

Effective recovery orientated practice is dependent on the attitudes and optimism of mental health professionals (Crowe, Deane, Oades, Caputi, & Morland, 2006; Social Care Institute for Excellence, 2007). Health providers can play a huge part in facilitating personal recovery (Crowe et al., 2006) and service users are significantly affected by interpersonal interactions including those with mental health professionals (Tarrier & Barrowclough, 2003). Research has suggested a need for some health professionals to review their knowledge, skills and attitudes (Clement, 1997) and re-examine their roles and core training (Sowers, 2005) in order to fully embrace a recovery approach.

A recent review of studies exploring attitudes towards mental illness found that health professionals had generally positive views about people with mental health problems, although some negative views were also elicited particularly in regard to dangerousness and a need for social distance (Wahl & Aroesty-Cohen, 2010). A national survey of general practitioners found that around thirty percent of their time was spent

consulting patients about mental health difficulties yet they received limited training about mental health (Mental After Care Association, 1999). Research has also suggested that GP's have less positive attitudes and are less optimistic about prognosis than clinical psychologists and psychiatrists (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999).

Only a small number of studies to date have specifically investigated attitudes towards recovery. They suggest that health professionals have generally positive views about adopting a recovery approach, although they place greater emphasis on symptom management and treatment compliance (Cleary & Dowling, 2009). Similarly, health professionals appear to accept the concept of personal recovery and rebuilding the self, but are less aware that recovery is an ongoing process which isn't always reflected by symptoms (Bedregal, O'Connell, & Davidson, 2006).

The attitudes of health professionals may be less optimistic than the general public (Hugo, 2001). This could be because staff are more realistic due to their professional experience or have biased attitudes due to their experiences, i.e. they only come into contact with people experiencing mental health problems when they are most unwell (Jorm, Jacomb, Christensen, & al, 1999). In contrast, other studies indicate that health professionals and the general public have similar attitudes towards people with mental health problems (Lepping, Steinert, Gebhardt, & Rottgers, 2004; Nordt, Rossler, & Lauber, 2006). Less positive attitudes are often related to the belief that people with mental health problems are unpredictable and dangerous (Angermeyer & Matschinger, 2004) leading to an increased desire for social distance (Rusch, Angermeyer, & Corrigan, 2005). Understanding these attitudes and beliefs is important in reducing stigma towards those with mental health problems (Rusch et al., 2005) and many organisations have adopted anti-stigma campaigns. However, health professionals are in a complex role in which they can be recipients of stigma, reducers of stigma and stigmatizers (Schulze, 2007).

Improving attitudes could clearly play a central role in facilitating recovery. Some of the young people in schools and our communities may go on to experience their first episode of psychosis; thus, changing public opinion regarding recovery may benefit service users in terms of



reducing public stigma and discrimination, as well as reducing the likelihood that they will internalise such stereotypes and attitudes.

### *1.8.1 The role of causal beliefs*

Attitudes and stigma towards people with mental health problems are often related to beliefs about the underlying causes of those problems. Health psychology models suggest that responses to physical illnesses are governed by appraisals of causality, perceived outcome, duration and severity of the problem and this model has now been applied to mental health problems (Lobban, Barrowclough, & Jones, 2003, 2004; Watson et al., 2006). Within the field of mental health, biomedical models are based on a framework of mental 'illness', with illnesses having a biological base such as genetics, brain trauma or structure or biochemical imbalances. Psychosocial models on the other hand emphasis the role of stressful life events, trauma and social factors.

In recent years, anti-stigma campaigns have used a medical model approach, identifying schizophrenia as an illness 'like many other medical illnesses such as cancer or diabetes' (National Alliance for Mental Illness, 2008). However, although this has been effective in increasing in biological causal attributions, attitudes have not improved and current research suggests a more psychosocial approach to understanding mental health problems may be most effective (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Walker & Read, 2002).

Biomedical causal beliefs about psychosis are often linked to beliefs that individuals with psychosis are dangerous and unpredictable (Angermeyer & Matschinger, 2004; Rusch, Angermeyer, & Corrigan, 2005) and that psychosis is severe and enduring, with poorer prognosis (Angermeyer & Matschinger, 1994), leading to increased stigma and desire for social distance (Rusch et al., 2005). On the other hand, psychosocial causal attributions are associated with less stigmatising beliefs, more optimistic prognosis and less desire for social distance (Lincoln, Arens, Berger, & Rief, 2008).

It is also apparent that causal attributions in individuals who experience psychosis are important to facilitating recovery. Causal beliefs of patients have been linked to engagement and treatment response. Individuals who report a more psychological view of their difficulties are more likely

to engage in CBT and have better outcomes, even after accounting for severity of their difficulties and insight (Freeman et al., 2013a). Psychological explanations of psychosis may be linked to more positive attitudes towards recovery.

### **1.9. Recovery oriented services**

The academic and service user research discussed above, as well as the new found optimism which is often associated with the recovery approach, has prompted the recent policy and commissioning drives for recovery oriented services. The latest UK policy document to set out a vision for mental health services in the UK is "New Horizons"(Department of Health, 2009), which has a strong emphasis on recovery and embodies the recovery approach to mental health care:

"New Horizons sets out the expectation that services to treat and care for people with mental health problems will be accessible to all who need them, based on the best available evidence and focused on recovery, as defined in discussion with the service user."(Department of Health, 2009).

This document proposes that services should be recovery focussed, that all service users should have access to "quality services" and that "quality includes recovery orientation". Addressing individual needs is viewed as fundamental to the recovery approach, as is tackling stigma and improving employment and volunteer opportunities for people with mental health problems (Department of Health, 2009).

In 2005, the American Psychiatric Association released a position statement which encompassed the viewpoints of service users and states that the organisation "endorses and strongly affirms the application of the concept of recovery". It embraces the individuality and optimism of service user accounts and their conceptualisations of recovery stating that:

"The concept of recovery emphasizes a person's capacity to have hope and lead a meaningful life, and suggests that treatment can be guided by attention to life goals and ambitions. It recognizes that patients often feel powerless or disenfranchised, that these feelings can interfere with

initiation and maintenance of mental health and medical care, and that the best results come when patients feel that treatment decisions are made in ways that suit their cultural, spiritual, and personal ideals. It focuses on wellness and resilience and encourages patients to participate actively in their care, particularly by enabling them to help define the goals of psychopharmacologic and psychosocial treatments.”(American Psychiatric Association, 2005).

The National institute for Mental Health in England (NIMHE (2005) have recommended 12 “Guiding Principles for the Delivery of Recovery-oriented mental health services” which are:

- 1) The user of services decides if and when to begin the recovery process and directs it; therefore, service user direction is essential throughout the process.
- 2) The Mental Health System must be aware of its tendency to promote service user dependency. Users of service need to be aware of the negative impact of co-dependency.
- 3) Users of service are able to recover more quickly when their:
  - Hope is encouraged, enhanced and/or maintained;
  - Life roles with respect to work and meaningful activities are defined;
  - Spirituality is considered;
  - Culture is understood;
  - Educational needs as well as those of families/significant others are identified;
  - Socialisation needs are identified.
  - They are supported to achieve their goals.
- 4) Individual differences are considered and valued across the life span.
- 5) Recovery from mental illness is most effective when a holistic approach is considered; this includes psychological, emotional, spiritual, physical and social needs.
- 6) In order to reflect current "best practices" there is a need for an integrated approach to treatment and care that includes Medical/biological, psychological, Social and Values Based approaches. A Recovery approach embraces all of these.

- 7) Clinicians and practitioners initial emphasis on 'hope' and the ability to develop trusting relationships influences the recovery of users of services.
- 8) Clinicians and practitioners should operate from a strengths/assets model.
- 9) Users of service with the support of clinicians, practitioners and other supporters should develop a recovery management or wellness recovery action plan. This plan focuses on wellness, the treatments and supports that will facilitate recovery and the resources that will support the recovery process.
- 10) Involvement of a person's family, partner and friends may enhance the recovery process. The user of service should define whom they wish to involve.
- 11) Mental Health services are most effective when delivery is within the context of the service user's locality and cultural context.
- 12) Community involvement as defined by the user of service is central to the recovery process.

(Taken from NIMHE, 2005)

As can be seen from the above principles, commissioning and providing recovery oriented services is a complex task and requires effective collaborative working between a variety of health professionals, service users and carers, and the type and level of service offered is likely to be significantly different for each individual. There are obvious difficulties in commissioning, providing and monitoring such services but the fundamental principles of recovery oriented services have been endorsed by many of the most influential UK mental health related organisations including the Department of Health; the National Institute for Mental Health in England; Care Services Improvement Partnership, the Royal College of Psychiatrists & Social Care Institute for Excellence, and the British Psychological Society. Indeed, a recent qualitative study explored 30 international documents describing recovery orientated practice (Le Boutillier et al., 2011). The study highlighted four practice domains for recovery orientated services: promoting citizenship, organisational commitment, supporting personally defined recovery, and working relationship. The authors noted that a key difficulty for services

is the lack of clarity about what constitutes a recovery focussed approach.

### ***1.10. Summary of the literature and rationale for this thesis***

This review of the literature has demonstrated that psychosis is a common experience in a variety of mental disorders and within the general population. With schizophrenia alone affecting twenty four million people world-wide (World Health Organisation, 2010) and estimates for the lifetime prevalence of all psychotic disorders being just over three percent (Perala et al., 2007), furthering our understanding of this phenomenon continues to be a key topic in the field of mental health research.

Traditional biological approaches to understanding and treating psychotic experiences have been criticised in recent years, and the concept of recovery from psychosis has now become an acceptable and achievable goal for many service users. In fact, it is service users themselves who have published their personalised accounts of recovery and increased awareness among the public and health professionals alike, that people can and do recover from psychosis.

However, despite over two decades of service users publishing their accounts of recovery, there is still a lack of a standardised, universally accepted definition of what constitutes recovery. Qualitative research has gathered the central themes of recovery from service users, and clinicians have attempted to develop broader criteria for assessing recovery rather than just focussing on symptom and relapse reduction. The Department of Health have recognised and supported the need for recovery oriented services (Department of Health, 2009), yet the academic, clinical and service user communities are still no closer to bringing together an acceptable definition of the concept of recovery.

This thesis brings together clinical and service user aspects which are central to the recovery theme, to identify more clearly what constitutes recovery for the majority of service users and clinicians. Using data from a range of clinical assessments, self-report scales and service user developed tools, this thesis explores the psychosocial nature of recovery.

This literature review has also established that a range of recovery measures have been developed, yet only one is both service user developed and specific to recovery: the Questionnaire about the Process of Recovery (QPR) (Neil et al., 2009). The authors noted that this measure required further validation on a larger sample size and testing of sensitivity over time. This thesis also re-examines the QPR and discusses its utility within recovery oriented services.

Much of the research examining recovery focuses on either longitudinal quantitative studies investigating relapse prevention and symptom reduction, or qualitative studies concentrating on service user defined recovery. However, another important consideration for recovery oriented services is the perspectives of the health professionals providing these services. The review of the literature noted a small number of studies which have explored the knowledge and attitudes of mental health staff in relation to recovery, but also highlighted that more research into this area is needed. This thesis adopts an innovative approach to investigating the views of health professionals and incorporating these views into the recovery approach.

Finally, in reviewing the literature it became apparent that the service users themselves are key to the recovery approach and its success. They are experts by experience and their views are essential to make truly recovery oriented services a reality. It was therefore essential that this thesis included a study which consulted an expert panel on the topic of recovery, and that these experts would be a panel of service users.

### ***1.11. Broad aims and objectives of this thesis***

The overarching objective of this thesis is to increase our understanding of recovery in psychosis. This would include a contribution to the literature on defining and measuring recovery as well as an exploration of factors which influence subjective recovery judgements and attitudes towards recovery. In order to achieve this objective, five main aims were set:

The first aim is to conduct a service user informed review of self-report style measures of personal recovery.

The second aim is to examine the psychometric properties of one measure of personal recovery: the process of recovery questionnaire (QPR). This will include secondary aims to confirm the factor structure of the measure, to investigate its reliability and validity, and explore predictors of QPR scores.

The third aim of this thesis is to consult a large group of service users about their definitions and conceptualisation of recovery in psychosis. The objective of this consultation will be to reach a consensus about service user defined recovery.

The fourth aim is to examine longitudinal predictors of personal recovery scores.

The fifth aim is to examine attitudes towards recovery in psychosis in a sample of health professionals and the general public.

## **Chapter 2: Methodology employed throughout this thesis**

Chapter one of this thesis provided the reader with an overview of the literature on psychosis and recovery to provide the background and rationale for the aims of this thesis. Chapter two will expand on this by providing an overview of the methodologies used throughout this thesis, along with a rationale for why each approach was selected and the strengths and limitations of each approach. Each of the five individual studies in this thesis is presented in the format of a peer reviewed academic journal article; therefore, the methodology sections are necessarily brief due to the restrictive word counts of academic journals. This chapter is, therefore, essential to provide the reader with a more detailed overview of the methods used to address each of the research aims.

### ***2.1 Summary of research aims and their respective studies***

The detailed aims and objectives of this thesis are presented in chapter one. However, these are summarised again below to identify which study and method are used to address each aim.

Study 1 will address the first aim, which was to conduct a service user informed review of self-report style measures of personal recovery. This study will involve a review of the literature on measures of personal recovery, along with a collaborative review process of the measures identified.

Study 2 will address the second aim, which was to examine the psychometric properties of one measure of personal recovery: the process of recovery questionnaire (QPR). This will include secondary aims to confirm the factor structure of the measure, to investigate its reliability and validity, explore predictors of QPR scores.

Study 3 will address the third aim, which was to consult a large group of service users about their definitions and conceptualisation of recovery in psychosis. The objective of this consultation will be to reach a consensus about service user defined recovery.

Study 4 will address the fourth aim, which was to examine longitudinal predictors of personal recovery scores.



Study 5 will address the fifth aim, which was to examine attitudes towards recovery in psychosis in a sample of health professionals and the general public.

## **2.2 Overview of research designs**

A variety of methods have been employed within this thesis to address the research aims. There is a need for research methods to be both pragmatic and appropriately selected to address the research question. A pragmatic approach puts the research question at the centre of the problem and selects data collection and analysis methods based on which are most likely to give insights into the research question (Creswell, 2003). Therefore, decisions around methodology were empirically/hypothesis driven for the studies within this thesis. The majority of approaches used were quantitative, although some elements within the studies could be considered as quasi-qualitative. These methods are discussed in more detail below. As discussed in chapter 1, there is a wealth of qualitative studies exploring the topic of recovery; therefore, this thesis will not include any further qualitative explorations of recovery in psychosis.

Quantitative research methods are used throughout this thesis to address the aims and objectives for each study. These methods include a variety of research designs which aim to collect data in numerical format to allow statistical analysis and inference. They can include data collection at a single time point (cross sectional) or over a number of time points (longitudinal). The quantitative methods used are described in more detail below for each study. An overview of the five studies in this thesis can be found below in Table 1.

**Table 1: Overview of studies**

<b>Study</b>	<b>Method</b>	<b>N</b>	<b>Strengths and limitations</b>
<b>Study 1</b> User informed review of recovery measures	Literature review, Measures evaluation	n/a	+ User informed - Only considered peer reviewed articles
<b>Study 2</b> Psychometric properties of the QPR	Cross-sectional, Factor analysis	335	+ Large sample size and robust assessments - No examination of sensitivity to change
<b>Study 3</b> Consultation on conceptualising recovery	Delphi method	381	+Large sample and novel approach -Self selecting sample
<b>Study 4</b> Predictors of personal recovery	Longitudinal, Structural equation modelling	110	+ Longitudinal approach - Relatively short follow up
<b>Study 5</b> Attitudes towards recovery	Survey, Implicit association test	146	+ Web based to enable anonymous responses -Self selecting sample

### **2.3 Study 1: Recovery from psychosis- a user informed review of recovery measures**

Study 1 began with a review of the relevant literature on personal recovery measures to identify key papers and their respective self-report recovery measures. Following this, two service users with experience of psychosis were consulted to develop a structured set of criteria with which to evaluate the measures. It was decided that key areas of importance for the service user evaluation included whether the format was simple and the items/scoring were easy to understand; whether the language used was positive and acceptable and whether the items reflected a measure of 'recovery as defined by service users'. Measures were also evaluated based on their psychometric robustness, ease of administration and level of service user involvement during development. Alongside the author of this thesis and a clinical psychologist, the service users evaluated each tool against the criterion and provided qualitative feedback throughout the process. This information was collated into themes and presented in tabular form. It was hoped that publication of

this user informed review of recovery measures would allow health professionals to easily select the most appropriate tools for their requirements.

### *2.3.1 Main strengths and limitations*

Study one provided added value to a standard review by including service user consultants on the review team in accordance with the literature on recovery, which considers service users to be experts by experience. The study adopted a pragmatic approach to reviewing measures of recovery as well as looking at psychometric properties. The main limitations of the study are that it was only possible to review measures which had associated peer reviewed publications, leaving the possibility that other existing and useful recovery measures were not accounted for. Similarly, the review could only be based on the information available in the peer reviewed papers.

## **2.4 Study 2: Psychometric properties of the Questionnaire about the Process of Recovery**

### *2.4.1 Cross sectional design*

Cross sectional studies are a type of descriptive observational study which examine a population or sample of a population at a given time point. They often utilise interviews or questionnaires to examine features of the population or subset at a given time point. Inferences can then be made about relationships between the features of this sample using statistical testing. For example, correlational analyses are often used to examine the degree to which two variables are associated or co-vary with each other. This analysis also demonstrates the direction and magnitude of the relationship. A positive correlation illustrates that as one variable increases so does the other. A perfect positive relationship is indicated by a correlation of 1. A negative correlation indicates that as one variable increases the other decreases, with a perfect negative correlation being -1. If there is no relationship between variables, we find a correlation of 0. From these associations we infer a relationship, but a significant limitation of this approach is that we cannot infer causality or account for the possibility that other unknown or unmeasured variables have

contributed to this relationship. However, the cross sectional approach is useful for initial exploratory analysis which can then be expanded into longitudinal studies. In this thesis, a cross sectional approach will be utilised in study 2 to examine the variables which are associated with recovery scores on the QPR.

#### *2.4.2 Questionnaire development and evaluation*

Questionnaire design and development usually follows a systematic and structured approach, often using qualitative methods to develop items which are then tested and validated using quantitative methods (Oppenheim, 2000). Study 2 of this thesis evaluates a questionnaire measure (the QPR). The QPR had previously been developed by Neil et al., (2009) from series of qualitative interviews (Pitt et al., 2007c). The QPR was developed collaboratively with service users with personal experience of psychosis. Study 2 uses a cross sectional design to further evaluate the psychometric properties of the measure. Data was collected from participants on the QPR as well as a variety of measures associated with recovery, symptoms and functioning. This data from the QPR was subjected to a data reduction technique known as factor analysis. This statistical technique allows examination of the factor structure of a measure and is discussed in more detail in the statistical procedures section. A secondary aim of study 2 was to investigate test retest reliability of the QPR. To facilitate this, a subset of participants were asked to complete the QPR at baseline (timepoint 1) and between one and two weeks later.

#### *2.4.3 Recruitment and sampling*

Data for study 2 was taken from a programme of NIHR funded research (the Recovery Programme) which included one randomised controlled trial, a patient preference study and several cross sectional studies. Participants were invited to take part in the research programme if they were aged between 16 and 65, had a sufficient understanding of English to enable completion of measures and had experience of psychosis or a schizophrenia spectrum diagnosis. All studies in the Recovery Programme were approved by a NHS Research Ethics Committee. A service user reference group were consulted on all aspects of design and procedures within the studies.

Participants were recruited from a range of statutory and non-statutory services via posters, advertisements and referrals from health professionals. Community mental health teams, early intervention teams, inpatient services and voluntary sector agencies across the North West England area were approached for suitable referrals. Potential participants were offered an information sheet for the study and given a minimum of 24 hours to decide whether to take part. A research assistant would meet the participant to take informed consent before administering the measures.

The author of this thesis was the research coordinator and trial manager for the Recovery Research Programme studies and played a central role in developing recruitment strategies and providing management of both the studies and research assistants. This included day to day problem solving for recruitment, assessment and data issues as well as monitoring data quality and study progress.

Sample size for study 2 was based on the intended factor analysis of the 22 item measure. It was anticipated that a minimum of 110 participants were required based on a minimum of 5 participants per item (Field, 2005). However, recommendations for minimum sample sizes and subject to variable ratios for factor analysis vary considerably throughout the literature (MacCallum, Widaman, Zhang & Hong, 1999) so a conservative estimate of 300 participants was used.

#### *2.4.4 Measures*

##### *2.4.4.1 The Process of Recovery Questionnaire (QPR)*

The QPR (Neil et al., 2009) is a 22 item self-report measure developed collaboratively by service user researchers and clinicians. Items are rated on a five point likert scale ranging from "strongly disagree" to "strongly agree". Higher scores on the measure are indicative of recovery. The QPR has two subscales: intrapersonal and interpersonal. Good internal consistency was reported for these subscales (intrapersonal  $\alpha=0.94$ ; interpersonal  $\alpha=0.77$ ) as well as good construct validity and reliability (Neil et al., 2009).

#### 2.4.4.2 *The Positive and Negative Syndrome Scale (PANSS)*

The PANSS (Kay et al., 1987) is a thirty item semi-structured clinical interview including 7 items to assess positive symptoms (such as hallucinations and delusions), 7 items to assess negative symptoms (such as blunted affect and emotional withdrawal) and 16 items to assess global psychopathology (such as anxiety, guilt and depression). All items are rated from 1 (not present) to 7 (severe). The PANSS has been used in a variety of studies and has been shown to have good reliability and validity (Kay et al., 1988).

#### 2.4.4.3 *The Psychotic Symptom Rating Scales (PSYRATS)*

The PSYRATS (Haddock, 1999) is a seventeen item multidimensional measure of auditory hallucinations and delusions which rates symptoms over the past week. Items are rated on a five point scale (0-4). The PSYRATS has been shown to have good reliability and validity (Drake et al., 2007; Haddock, 1999).

#### 2.4.4.4 *The Beck Hopelessness scale (BHS)*

The BHS (Beck et al., 1974) is a 20 item self-report measure designed by clinicians to measure three dimensions of hopelessness: feelings of the future, loss of motivation and expectations. Statements are rated by participants as true or false for their attitudes over the last week. The psychometric properties of the BHS have been examined in various studies and the measure has been shown good reliability and validity (Dyce, 1996; Nunn, 1996; Young et al., 1992)

#### 2.4.4.5 *The Self Esteem Rating Scale-short form (SERS)*

The SERS (Lecomte et al., 2006) is a 20 item self-report measure assessing both positive and negative beliefs about the self. Items are rated on a seven point Likert scale ranging from "never" to "always". The scale demonstrated good internal consistency and reliability and adequate convergent validity (Lecomte et al., 2006).

#### 2.4.4.6 *The Calgary Depression Scale for Schizophrenia (CDSS)*

The CDSS (Addington et al., 1990) is a nine item self-report scale designed to measure aspects of depression in people with a diagnosis of schizophrenia. Items are rated on a three point Likert scale with global

scores range from 0 to 27. The CDSS has been shown to have good reliability and validity (Addington et al., 1992; Addington et al., 1990).

#### 2.4.4.7 *Personal and Social Performance Scale (PSP)*

The PSP is a measure of functioning rated by an observer. The scale is scored across 4 domains assessing socially useful activities, personal and social relationships, self-care and aggression. Total scores range from 1 to 100 with 100 indicating no functional difficulties. The internal consistency of the overall scale has been shown to be adequate ( $\alpha=.76$ ) (Kawata and Revicki, 2008) and reliability and validity of the measure has been demonstrated (Nasrallah et al., 2008).

#### 2.4.5 *Statistical procedures*

Data were analysed using SPSS (version 20) and AMOS (Analysis of Moment Structures-version 22). Sample characteristics were explored using descriptive statistics. Cronbach's alpha coefficients were calculated to examine the internal consistency of the subscales. Test re-test reliability was assessed using Pearson correlation coefficients as the data on QPR was normally distributed.

The empirical basis for a confirmatory factor analysis of the QPR was lacking given that the psychometric properties of the QPR had only been examined previously during its development phase. Therefore an independent exploratory factor analysis (EFA) of the original 22 items was conducted followed by further EFA to test revised solutions after removal of items.

EFA with maximum likelihood estimation and promax rotation was utilised. As recommended by Hu and Bentler (1999), multiple indices were used to evaluate goodness of model fit including the root-mean-square error of approximation (RMSEA)  $<.06$ , the Standardised Root Mean Square Residual (SRMR)  $<0.08$  and the cumulative fit index (CFI)  $>0.95$  whilst also considering the interpretability of the solution and the strength of parameter estimates (e.g., primary factor loadings of  $>.60$  and an absence of salient cross loadings).

#### 2.4.6 *Ethical considerations*

All studies in the Recovery Research Programme were approved by an NHS Research Ethics Committee (REC) (REC numbers: 08/H10008/186; 09/H1012/9; 10/H1011/36; 10/H1015/51; 08/H1012/97). In addition, local NHS Trusts provided Research Governance approvals to allow access to participants within their site.

All participants were briefed fully on the nature of the study and given a minimum of 24 hours to decide whether or not to take part. They were informed that they were free to withdraw from the study at any time without any impact on the care they would receive. Informed consent was taken for each participant who took part in the research programme.

All studies in the Recovery Research Programme had clear Standard Operating Procedures for managing safety and participant distress with the author of this thesis being responsible for implementing, and managing these within the research programme, including training staff on these procedures. A detailed discussion of the programme's Safe Working Policy is beyond the scope of this thesis. However, in summary, research assistants were required to conduct a comprehensive assessment of risk with the participants care team prior to any research visits. This included discussion of any potential factors that may increase risks to the participant or others as a result of taking part in the study (such as self-neglect, environmental hazards, self-harm, harm to others and relapse). A safety call system was also used, which required research assistants to check in with a staff member after their assessment visit was completed. Following an assessment, any concerns arising regarding risk to self or others were passed onto the participants care team.

Additionally, all procedures within the programme were subject to consultation from a service user reference group. As part of this consultation process, the service user reference group suggested a 'distress follow up call' policy. This included researchers asking participants if it would be ok to contact them the day after an assessment to check how things were and ensure no distress had arisen as a result of the assessment. Participants were signposted as appropriate or encouraged to contact their care team.



Although it was not envisaged that any distress would arise from taking part in the Recovery Research Programme, as with any research involving human subjects there was always potential for distress as a result of discussing sensitive or personal topics. The author was responsible for training research assistants to ensure that they were mindful of this possibility. Research assistants were reminded to regularly check with participants that they were ok to continue and were aware they did not have to answer every question.

#### *2.4.7 Main strengths and limitations*

The main strength of this study was the adequate sample size for factor analysis and the variety of psychiatric and psychological measures administered concurrently which allowed assessment of validity and reliability.

The main limitation of this study is that it was not possible to examine the predictive validity and sensitivity to change of the QPR. However, the QPR is currently being used routinely in some clinical services and in several other research trials, including three randomised controlled trials. It is hoped that in the future this data will provide information on the sensitivity of the QPR to change over time.

Another potential limitation of this study is the participant sample which was diagnostically heterogeneous. This could be seen as a limitation; however, this may provide greater generalisability to clinical services which often have considerable diagnostic heterogeneity. The sample also consisted of mainly individuals who had been referred by their care team, which may have led to biases in the recruitment process. Care teams were essentially selecting individuals whom they believed were suitable or appropriate for the research studies. The fact that recruitment was facilitated via two clinical trials could be seen as biasing the sample to individuals who are actively help-seeking and willing to commit to a trial for a considerable number of months. This could lead to a sample of participants with particular unique characteristics (such as motivated or high functioning individuals) and consequently reduce the generalisability of results.

The problem of missing data should also be considered, as this may have limited statistical power, increased the possibility of type II error and resulted in a biased sample. Missing data was not imputed for this study, rather cases were deleted in SPSS where data was missing for 20% or more items on particular scale. In cases where less than 20% of items on a scale were missing, responses were pro-rated. Whilst acknowledging that this is a limitation, it was important that reducing participant burden and ensuring that all participation and responses to each question are voluntary was the main priority.

## **2.5 Study 3: Recovery in psychosis: a Delphi study with experts by experience**

### *2.5.1 The Delphi method and analysis procedure*

The Delphi method is a systematic process of engaging a panel of 'experts' in the chosen field in two or more rounds of questionnaires, with the aim of identifying items which the panel agree are important to the chosen topic. It is primarily a quantitative technique which counts responses to questionnaire items until consensus is reached. However, the Delphi method does often include an initial round of consultation on questionnaire items with qualitative feedback. For this thesis, the Delphi method was selected as the most appropriate technique to reach consensus about key elements of service user defined recovery. Therefore, Study 3 used the Delphi method to address the research aim of achieving consensus with regard to service user conceptualisations of recovery. The Delphi study was carried out in three stages.

In stage 1, elements identified as pertinent to conceptualisation of recovery in psychosis were identified through a literature search and collated into an initial list of statements. A small panel of ten service users were then consulted to further refine this initial statement list.

In stage 2 the finalised list of statements from stage 1 was collated and formatted into a web-based and paper questionnaire. Participants rated the importance of each item on the statement list, on a five point likert scale (1-essential, 2-important, 3-do not know/depends, 4-unimportant

and 5-should not be included). Results were entered into an anonymised database and analysed by obtaining group percentages.

In accordance with the methods used by Langlands et al., (2008) the following criteria were used to determine items for inclusion, exclusion and rerating:

- i. Items rated by 80% or more participants as essential or very important to defining or conceptualising recovery are included as standard.
- ii. Items rated as essential or important to defining or conceptualising recovery by 70%–79% of respondents in stage 2 will be re-rated in stage 3.
- iii. Any statements that did not meet the above 2 conditions were excluded.

In stage 3, participants were asked to re-rate only those items that 70-79% of respondents had rated as essential or important during stage 2.

### *2.5.2 Recruitment and sampling*

Sample size calculations are not necessary for the Delphi methodology because no statistical tests are utilised. Previous Delphi studies have tended to use small numbers (between 10 and 30) of expert clinicians or academics , although some studies have used groups of service users and/or carers (Byrne & Morrison, in press; Langlands, Jorm, Kelly, & Kitchener, 2008). The aim for this study was to consult a large group of service users from across the North West of England with the aim of reaching a consensus on the topic of recovery.

The recruitment strategy for study 3 was inclusive and wide reaching. Participants were recruited via convenience sampling through mental health services (including Community Mental Health Teams and Early Intervention Services), non-NHS groups/voluntary groups and networks (such as MIND, RETHINK and the Hearing Voices Network), and advertising of the study by leaflets, posters, email networks and voluntary organisations websites, social media and local media (including press releases). This was to ensure the study was advertised as widely as possible to facilitate a large and representative sample. Recruitment was

supported by the Mental health Research Network via their Clinical Studies Officers. Recruitment also used a new pilot system being implemented at Greater Manchester West Mental Health NHS Foundation Trust. This system (called FAIR-Free Access to Involvement in Research) allows all service users to opt in to hearing about possible research studies. The FAIR system allows the local R&D department to send letters to service users who have asked to hear about research. The letters do not give details of the research study itself but allow people to contact the research team directly for more information.

Following feedback on the study design from the service user reference group, participants were included in the study if they had (or have had in the past) experience of psychosis, were over the age of 16 and were able to understand English. Feedback from this group also led to a decision to allow people to take part in the study anonymously, with no need for involvement with their care team. It was agreed that specific diagnoses would not be used as an inclusion criteria. This was partly to ensure inclusivity for all service users who wished to contribute to the study but also because it would have been difficult in practical terms to verify diagnosis for each participant whilst maintaining anonymity. However, self-reported demographic details including age, gender, location and mental health diagnosis or description were collected.

Participants who expressed an interest in the study were able to take part either by the study webpage and an online questionnaire or via paper copy of the survey. Submission of questionnaire responses was taken as informed consent for the data to be used (see ethical considerations section below).

### *2.5.3 Ethical considerations*

This study was approved by an NHS Research Ethics Committee (NRES Committee East Midlands-Northampton – 12/EM/0125). The ethics committee advised that, in order to maintain the potential for complete anonymity when taking part in this study, no consent form was used in the study. As noted above, the committee felt that submission of responses either online or by post could be taken as consent. This would

remove the need for participants to sign their name on a form which would then need to be returned with the questionnaire.

#### *2.3.4 Main strengths and limitations*

The main strength of this methodology is the potential to consult a large group of people on a given topic. The innovative use of a large panel of 'experts by experience' as consultants for this study in particular can be seen a strength of the study. This is the first study of its kind to use a large group of service users (n=381) and the first study to aim to reach a consensus about recovery in psychosis.

The main limitations of this study are that recruitment only took place across the North West of England which may mean that results are not representative of other areas of the UK or in other countries. Service users in different areas may have access to different types of services and/or have varying levels of knowledge regarding recovery. Indeed, a number of postal questionnaires for this study were returned with notes about the individual's service and how they had 'never heard about the potential for recovery'. Future research could investigate these varying levels of awareness of recovery and how this could impact on what service users want for their own recovery.

Another limitation is the heterogeneity of diagnoses in the sample. As discussed earlier, this study was not diagnosis specific in terms of inclusion criteria, instead opting to ask only people with experience of psychosis to take part. This resulted in individuals who had received a wide variety of diagnoses taking part in the study and therefore, the results of this study may represent a more trans-diagnostic approach to understanding recovery. The sample was also self-selecting which may have introduced bias. The study topic for example may have attracted service users who had particularly strong views about recovery and a result were keen to be consulted. This could have resulted in a lack of participants who had limited knowledge or less strong views on recovery, which may have reduced generalisability.

Additionally, the study used a convenience sample with some data collected via a web based format. This approach has advantages in terms of practicalities such as efficiency, low burden for participants and

potential for anonymity. However, it also eliminates the possibility of validating diagnosis with care teams, or checking job role and other demographics. Whilst anonymity is often viewed positively by participants and may allow more honest responses, it reduces control and validation of inclusion and exclusion criteria.

## **2.4 Study 4: longitudinal predictors of subjective recovery in psychosis**

### *2.4.4 Longitudinal design*

In contrast with cross sectional research, longitudinal studies are designed to collect data from the same participants at different time points. The main strength of this approach is that it allows examination of predictors of key variables at another time and assessment of change over time. One practical limitation is duration of involvement in research for participants which can lead to increased attrition over time. For this reason, longitudinal research often requires larger sample sizes to account for the possibility of attrition. Study 4 of this thesis utilises a longitudinal approach to explore predictors of personal recovery over time. Data was collected at baseline assessment (time 1) and the six month follow up point (time 2). Data was used to explore which variables predicted change in personal recovery scores (QPR scores) over time. Predictor variables were selected based on initial hypothesis and research questions, existing literature on recovery (Austin et al., 2013; Ho et al., 2010; Morrison et al., 2013a; Oorschot et al., 2012) and initial correlational analysis carried out in study 2.

### *2.4.5 Recruitment and sampling*

As with study 2, data for this study was taken from a programme of NIHR funded research (the Recovery Programme). Details for the recruitment strategy were identical to that described in study 2.

The key study hypotheses related to the additional effects of predictors of recovery at time two, after accounting for the predictive ability of recovery beliefs at time one. Cohen's f-squared statistic is an appropriate effect size statistic for such hierarchical hypotheses. f-squared describes the size of the difference in the variances accounted for by two nested

models, one featuring only a sub-set of the predictors of the other, as a proportion of the variance not explained by the more comprehensive model:

$$f\text{-square} = (R_{ab} - R_a) / (1 - R_{ab})$$

where

$R_{ab}$  = the variance accounted for by the more comprehensive model (i.e. the model with predictor variable sets a and b), and

$R_a$  = the variance accounted for by the nested model (i.e. the model with predictor variable set a)

In this case, the nested model is the core model of recovery at time two predicted by recovery at time one and negative emotion at time one. The more comprehensive models are the ones that add additional predictors to this model. With the sample size of 110 and assuming  $\alpha = 0.05$ , all of the models tested had good statistical power, at least 0.85, to detect 'medium'-sized or larger effects (i.e.  $f\text{-square} \geq 0.15$ ; (Cohen, 1988)). The power of the models to detect 'small' effects (i.e.  $f\text{-square} = 0.02$ ; Cohen, 1988) was weak, ranging from 0.32 to a low of 0.15.

#### *2.4.6 Measures*

Study 4 utilised the Questionnaire about the Process of Recovery (QPR), the Positive and Negative Syndrome Scale, the Personal and Social Performance Scale, the Calgary Depression Scale for Schizophrenia, the Beck Hopelessness Scale and the Self Esteem Rating Scale. These measures have been previously discussed in more detail under the study 2 method section and are discussed in the method of chapter 6.

#### *2.4.7 Statistical procedures*

Regression models were used to investigate factors which predicted recovery scores at time 2. All models were fitted in Mplus version 7 and estimated by Maximum Likelihood. Standard errors were estimated using

the Huber-White Sandwich estimator, robust to non-normality and heteroscedasticity in the outcome variables. Model log-likelihoods and the Likelihood Ratio tests were computed using Satorra-Bentler adjustments for non-normality. Nested models were compared using Satorra-Bentler corrected likelihood ratio chi-square tests.

#### *2.4.7.1 Model variables*

Variables are suffixed 1 to indicate time 1 (baseline) assessments and 2 to indicate time 2 (6 month follow up) assessments.

Core variables were recovery (REC1 and REC2) and negative emotion (Nemo1 and Nemo2). Recovery consisted of the 15 item total QPR score at time 1 or time 2 respectively. Negative emotion was a composite variable constructed by taking the mean of scores from the Calgary depression scale and the Self Esteem Rating Scale, Negative subscale. The SERS-N is scored from 10-70 whereas the Calgary scale is scored from 0-27. To avoid the composite measure being dominated by the higher scores of the SERS-N, the raw SERS-N scores were divided by 7 before taking the composite mean, which gave both contributing scales similar means and standard deviations.

Test variables included symptoms (PANSS1 and PANSS2), hopelessness (Hopeless1 and Hopeless2), Positive self-esteem (SERS-P1 and SERS-P2) and Functioning (FUNC1 and FUNC2). Symptoms consisted of a composite variable representing the overall mean of the 7 Positive, 7 Negative and 16 General PANSS scale items. Hopelessness utilised the total score from Beck hopelessness scale. Positive self-esteem used the total score from the positive subscale of the Self Esteem Rating Scale. Functioning utilised the functioning score of the PSP scale if available (n = 147, 84% of sample), and the functioning subscale of the GAF if not.

Exogenous covariates measured at Time 1 included age; education or employment (emp); marital status (Mar); Religious beliefs (God) and Early intervention (Eint). All covariates except age were binary variables coded as 1 for a positive response (i.e. in education or employment; married or living with a common-law spouse; belief in the existence of a deity and recruited from an early intervention services) and 0 for negative response.



#### *2.4.8 Ethical considerations*

As detailed in study 2, all studies in the Recovery Research Programme were approved by an NHS Research Ethics Committee ((REC numbers: 08/H10008/186; 09/H1012/9; 10/H1011/36; 10/H1015/51; 08/H1012/97)). In addition, local NHS Trusts provided Research Governance approvals to allow access to participants within their site.

Please refer to study 2 'ethical considerations' for details on study procedure for briefing participants, informed consent, safe working and managing participant distress. All procedures and ethical considerations were identical for both study 2 and study 4.

#### *2.4.9 Main strengths and limitations*

The main strength of this study was the longitudinal methodology which allowed examination of factors which predict the outcome variable recovery at time 2. Although this study was fairly unique in assessing both neuropsychiatric and psychosocial factors which may predict recovery over time, the main limitation of this study is that the follow up period was relatively short (6 months). In order to fully understand relationships between recovery and associated factors, as well as factors which may predict recovery, future research should aim to include a longer follow up period.

Although the sample size was adequate for this type of study, as with any longitudinal study attrition led to a reduced sample size. A key ethical consideration for longitudinal studies is the potential for them to be particularly high burden for participants. Whilst the priorities must be with reducing participant burden and ensuring completely voluntary participation for all responses, it is important to note that missing data may have limited statistical power, increased the possibility of type II error and resulted in a biased sample. Missing data was not imputed for this study, rather cases were deleted in SPSS where data was missing for 20% or more items on particular scale.

Also, as with study 2, the sample in this study consisted of mainly individuals referred by their care teams. This could have led biases in the recruitment process, and resulted in a sample of participants who are actively help seeking, able and willing to commit to a research and are

deemed suitable for a research trial by their care team. This is likely to have led a sample of participants with particular unique characteristics (motivated or high functioning individuals) and consequently reduce the generalisability of results.

Finally, participants in this study were recruited to various studies within the recovery research programme which included a randomised controlled trial offering a recovery intervention, and a patient preference study offering self help recovery guide and support. Consequently, the findings may have been influenced by these additional treatment interventions.

## ***2.5 Study 5: The impact of pre-existing causal models of psychosis on implicit and explicit attitudes towards recovery***

This study utilised a cross sectional design to explore beliefs around the causes of psychosis, knowledge and experience of psychosis and recovery, and implicit and explicit attitudes towards recovery. The measures and approach used are described in more details below.

### *2.5.4 What is the implicit association test?*

The implicit association test is a reaction time paradigm (Greenwald, McGhee, & Schwartz, 1998) used to assess attitudes which may be hidden, unidentified or not consciously accepted by the individual due to social norms and expectations.

A common analogy used to explain the IAT methodology is sorting a deck of playing cards. Imagine you are asked to sort a deck of cards into clubs and spades on the right, and hearts and diamonds on the left. These two categories of cards are easily sorted because they share a common attribute: colour. The speed at which the deck is sorted reflects the strength of the association between the categories you are asked to sort. If you are then asked to sort the deck into hearts and clubs on the right and spades and diamonds on the left, the task becomes harder and the speed of sorting deteriorates. There is no longer a shared attribute which allows the categories to be easily associated. Topics which have been explored using the IAT include self esteem (Greenwald & Banaji, 1995),

gender stereotypes (White & White, 2006) and racial discrimination (McConnell & Leibold, 2001). Lincoln et al. (2008) utilised the IAT to investigate stigma and schizophrenia, and highlighted the common association between a diagnosis of schizophrenia and the concept of incurability, despite the current emphasis on recovery in mental health.

#### *2.5.5 Recruitment and sampling*

A power calculation was performed using the programme Gpower (Faul, Erdfelder, Lang, & Buchner, 2007). A minimum of 64 participants would be required for each group based on the sample size calculation for a two tailed test based on a medium anticipated effect size (Cohen's D) of 0.5 with an alpha of 0.05 and power of 0.8. Previous research using the implicit association test has found effect sizes of between 0.3 and 0.7 on a variety of topics. Therefore an effect size of 0.5 was used for this calculation.

Recruitment was a convenience sample of students and staff at the University of Manchester and the general public. Recruitment was via advertising with posters, personal contacts and email circulations. Participants took part in this study via a study web page on the university of Manchester website.

#### *2.5.6 Measures*

##### *2.5.6.1 Demographic information and self-reported knowledge and experience*

Demographic details, including age, gender, location, job title/educational status were requested from participants. Participants then indicated whether they understood the terms psychosis and recovery (on a four point Likert scale ranging from "yes I understand completely" to "no I do not understand") and whether they have professional and/or personal experience of psychosis and/or recovery (response options for personal experience included "I have personal experience" and "a friend or family member has personal experience"). Responses to these questions were used to give a total score for knowledge and experience of psychosis and recovery.

#### *2.5.6.2 Pre-existing causal beliefs*

Pre-existing causal beliefs about psychosis were assessed with a questionnaire used previously by Lincoln et al. (2008). The questionnaire included 9 statements representing 3 potential causes of psychosis which include biogenetic causes (brain disease, brain damage and genetic inheritance), psychosocial causes (stressful events, trauma and problematic childhood) and other causes (coincidence/fate, self-induced and God's will). Participants were asked to what extent they agree each statement could represent a cause of a person's experiences of psychosis and respond using a 5 point Likert scale, ranging from strongly agree to strongly disagree. It should be noted that this is not a validated measure of causal beliefs for psychosis; to date no such measure exists. However, for the purposes of this study, self-report questions sufficed and items covered a range of causal beliefs.

#### *2.5.6.3 Recovery attitudes questionnaire (RAQ)*

The seven item recovery attitudes questionnaire (RAQ-7) (Borkin et al., 2000) was used to measure explicit attitudes towards recovery. The RAQ was developed by service users and mental health professionals to measure respondent's attitudes about the possibility of recovery in mental health. Respondents are asked to rate the degree to which items represent their opinions. Items (e.g. "Recovery can occur even if symptoms of mental illness are present") are rated on a 5 point likert scale ranging from strongly agree to strongly disagree. The RAQ was found to have acceptable reliability and validity (Borkin et al., 2000).

#### *2.5.6.4 Implicit association test for recovery attitudes*

To assess implicit attitudes, the reaction time paradigm known as the implicit association test (IAT) (Greenwald et al., 1998) was utilised. The IAT has been used in several studies to assess attitudes which may be hidden, unidentified or not consciously accepted by the individual due to social norms and expectations. In the IAT participants are timed whilst sorting words into pairs of categories. Reaction times are faster for congruent pairs of categories, enabling us to use reaction times as a proxy for measurement of implicit attitudes. The IAT has been shown to

be more reliable and have greater internal consistency than other implicit measures (Greenwald & Farnham, 2000). See chapter 7 method section for further general explanations of the IAT method.

The IAT was adapted to assess attitudes towards recovery (IAT-R) using a computerised task. Participants were asked to sort a series of target words into three categories ('psychosis', 'recovered' and 'not recovered'). Each target word only matches one of these three categories. This type of IAT with three categories is known as the single-target implicit association test and is useful when a comparator or opposing category is not present (in this case there is no opposing category to psychosis), because it allows the evaluation of a target attitude concept without the need to evaluate a counter category, such as black and white or male and female (Bluemke & Frieze, 2008; Wigboldus, Holland, & van Knippenberg, 2004).

In the first round of the experiment, participants were presented with a series of word stimuli on a computer screen and asked to press the right key when the stimulus matched the category 'psychosis' or 'recovered' and the left key when the stimulus matched the category 'not recovered'. In the second round the categories were switched so that the left key was pressed when the stimulus matched 'psychosis' or 'not recovered' and the right key was pressed when the stimulus matched 'recovered'. Theoretically, sorting should be faster when the two categories which share an implicit attribute are presented on the same response key or side. Stimulus for the psychosis category were adapted from the symptom criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* and for the recovered and not recovered category, synonyms were taken from the recovery literature. This initial list of stimuli were taken to a group of service users and clinicians for discussion and consensus was reached for the stimuli to be used in the final version. The IAT-R was piloted with 10 participants to ensure the instructions were appropriate and there were no outliers in reaction times.

### *2.5.7 Statistical procedures*

IAT scores were calculated as a D-score using the improved scoring algorithm (Greenwald, Nosek, & Banaji, 2003) to measure individual differences between the compatible and incompatible categories corrected by the standard deviation of reaction times. Scores can range from -2 to +2 with 0 representing a neutral score and positive scores representing more positive attitudes.

Associations between attitudes, knowledge and experience and causal beliefs were examined using Pearson's correlation coefficients. Differences between associations in the participants groups were analysed using Fisher's r-to-z transformations. Finally, multiple regression analysis was used to explore predictors of attitudes towards recovery.

### *2.5.8 Ethical considerations*

This study was approved by the University of Manchester (project number 11289).

Although it was not envisaged that there would be any considerable ethical issues from taking part in this study, it was possible that some of the words in the implicit association task may not have been acceptable to some individuals (e.g. Use of the word "sane" or "ill"). However the participant information sheet explained that the study has been designed to tap into a variety of beliefs and attitudes, and consequently participants may or may not agree with the use of all the words included. The design of this study was discussed with a service user reference group to ensure the content was appropriate and the information provided was comprehensive and easily understandable. Participants were free to stop or withdraw from the study at any point.

It was essential that participants could take part in the study anonymously to allow open and honest responses about their personal beliefs. Responses were submitted online without entering any personal identifiable information.

### *2.5.9 Main strengths and limitations*

The main strength of the methods used in this study was their web based format. This enabled participants to take part anonymously, and in their own time from a location of their choice, creating minimal participant burden and increasing accessibility. Whilst this approach has advantages in terms of practicalities such as efficiency, low burden for participants and potential for anonymity, it also eliminates the possibility of validating job role and other demographics.

The participant sample consisted entirely of self-selecting individuals which may have introduced bias. For example, the health professionals and general public who agreed to take part may have had a particular interest in recovery in psychosis, and hence had generally positive attitudes. The study did attempt to account for this possibility by asking about individual's experience and knowledge of recovery and psychosis, but only a small variance in knowledge and experience was observed within the health professional and general public groups. Use of the convenience sampling method was a particular limitation especially for the health professional group within the sample. This group primarily consisted of psychology and nursing professions. A more selective or purposive sampling could have enabled investigation of the attitudes of a range of health professionals, including psychiatrists and general practitioners. This could have increased generalisability of results to other health professionals, as well as enabling comparisons to be made between different health professional groups.

The main limitation of this study was the use of previously un-validated measures (the implicit association test for recovery attitudes and the causal beliefs questions). The novel adaptation of the implicit attitudes test to assess implicit attitudes towards recovery was adapted from previous implicit tasks and steps were taken to pilot the task and ensure stimulus were appropriate. However, the very nature of implicit reaction time paradigms mean it is inherently difficult to assess validity. For example, new measures are usually used alongside other measures assessing similar concepts so that concurrent validity can be examined. However, whilst lack of associations with other measures (such as the explicit attitudes measures) may indicate the test is unreliable or lacks

concurrent validity, it could also mean that there are hidden or implicit attitudes which other measures are not sensitive too.



### **Chapter 3: Recovery from psychosis: a user informed review of self-report instruments for measuring recovery**

This paper has been published in the Journal of Mental Health.

Law, H., Morrison, A.P., Byrne, R., & Hodson, E. (2012). Recovery from psychosis: a user informed review of self-report instruments for measuring recovery. *Journal of Mental Health, 21(2)*, 192-207.

Running head: Measuring personal recovery from psychosis

**Full title: Recovery from psychosis: a review of self report instruments for measuring recovery**

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### **3.1 Abstract**

#### **Background**

Mental health services are being encouraged to adopt a recovery approach, creating a requirement for standardised measures of recovery to be developed and embedded within services. Measurement of this unique concept is inherently difficult, but it is feasible and valid provided that service users and clinicians work collaboratively.

#### **Aims**

To evaluate which measures of recovery have clinical utility and are acceptable to service users.

#### **Method**

Instruments included in this review were: (1) quantitative self-report measures; (2) published in a peer reviewed English language journal; (3) designed to measure personal recovery. The review team included two service-user researchers to allow evaluation of acceptability to service users.

#### **Results**

Twenty-five measures of recovery were identified; six of these met the inclusion criteria. A summary table of the measures is included to enable readers to make an informed choice of measure for their specific needs, along with an overview each measure.

#### **Conclusions**

The Recovery Assessment Scale appears to be the most acceptable and valid measure currently available. No "gold-standard" measure of recovery has been developed to date. Further research is required to examine the longitudinal reliability of existing tools, and their utility within clinical services and as outcome measures.

#### **Declarations of interest**

None.

### **3.2 Introduction**

In everyday life we use the term recovery to imply a cure or healing after illness or injury, and a return to the "normal" condition. Based on this connotation, few people who experience severe mental health problems would ever be fully recovered (Whitwell, 2005). Clinicians advocating the biomedical model define recovery in terms of absence of symptoms, decreases in duration of hospital admissions and reduced rate of rehospitalisation (National Institute for Health & Clinical Excellence, 2010). Bellack (2006) argues that whilst the biomedical approach to defining recovery from physical illness may be acceptable, using the same paradigm to define recovery from mental illness is insufficient. Severe and enduring mental illness may remit and relapse and can result in significant changes in functioning from prior to the onset of illness; however, recent research has indicated that individuals can and have returned to an acceptable level of functioning and quality of life (Bellack, 2006).

The service user movement in conceptualising recovery has moved away from professional classifications towards self-definition. Service users view recovery as something very different to clinicians (Bellack, 2006), not limiting recovery to purely the absence of symptoms, disability or reduction in the use of mental health services (Social Care Institute for Excellence, 2007). There is a strong belief that recovery is different for everyone and that it is a complex process rather than an outcome or end point (Pitt et al., 2007c). Several studies have attempted to extrapolate common themes from service user accounts of recovery; finding that personal factors such as hope, empowerment and determination, as well as social factors such as external support play a key role is what service users define as recovery. It is clear that the meaning of recovery to service users encompasses much more than the majority of professional classifications.

The recovery paradigm appears to have brought a new sense of optimism and enthusiasm to the care and treatment of individuals experiencing severe and enduring mental health problems, particularly for service users themselves (Maddock & Hallam, 2010). This has led to an emphasis by leading national mental health organisations and health commissioners on the need for mental health services which are recovery oriented (Department of Health, 2009; The Future Vision Coalition, 2010). It also poses a new question for clinicians, academics and indeed service users, about how best to evaluate these services

in terms of their effectiveness and performance in supporting people to recover (Essock & Sederer, 2009). When the success of a service is related to levels of treatment compliance to medication regimes or a measurable reduction in symptoms of psychosis, tools designed to measure outcomes are already embedded into routine practice. However, if services are to move to a more individualised approach to care, with the aim of achieving the personal goals of recovery, the task becomes much more complex and it is vital that measures are developed, validated and implemented to ensure evidence based practice and the use of measurement based interventions (Essock & Sederer, 2009).

If we are to accept that recovery is a profoundly personal experience and that it describes a process rather than an endpoint (Pitt et al., 2007), it would be inherently difficult, if not impossible, to measure in an objective and standardised way. Measuring recovery as an outcome, when it is defined as a process, has been questioned by Resnick, Fontana, Lehman, & Rosenheck (2005) although the authors do suggest that measurement of recovery is not only feasible, but valid if service users and clinicians work collaboratively to set recovery targets and measure the outcomes achieved.

The purpose of this review is to systematically examine existing measures of recovery from psychosis to establish those that could inform evidence based practice within recovery oriented services, whilst also determining which measures have been developed to be acceptable to service users. A secondary aim of this review is to raise awareness of the growing literature on recovery from psychosis and to encourage discussion about integrating the principles of recovery into everyday clinical practice.

### **3.3 Method**

#### *3.3.1 Selection of measures and inclusion criteria*

Firstly, a literature search using the Medline and Psych-INFO databases was carried out to identify candidate measures for inclusion in this review. The terms psychosis, recovery and measure, and their common synonyms, were each searched for as keywords using unlimited truncation to retrieve all possible variations of the key search terms. These searches were then combined using Boolean logic and the search was limited to manuscripts published in English between 1990 to the present. These criteria generated 21

articles from Medline and 75 articles from Psych-INFO, with some duplication of results. Informal internet searches were also conducted to identify other possible measures and additional articles were selected from the reference lists of the manuscripts and subjected to the same criteria for inclusion.

From these articles, a total of twenty five measures were identified. Measures were selected for inclusion in this review if they met three specific criteria for inclusion. First, the instrument must have been scientifically scrutinised via publication in a peer reviewed journal; this excluded fourteen measures. Secondly, the instrument must be in a self-report questionnaire format which yields quantitative results in order to maximise potential for use within routine clinical practice; this criteria excluded the Recovery Interview. This criteria was included to ensure that the measures reviewed are suited to use in a range of clinical settings. Finally the instruments must aim to measure factors relating to personal recovery. This excluded the recovery attitudes questionnaire, which was primarily designed to assess general attitudes towards the concept of recovery, rather than personal recovery.

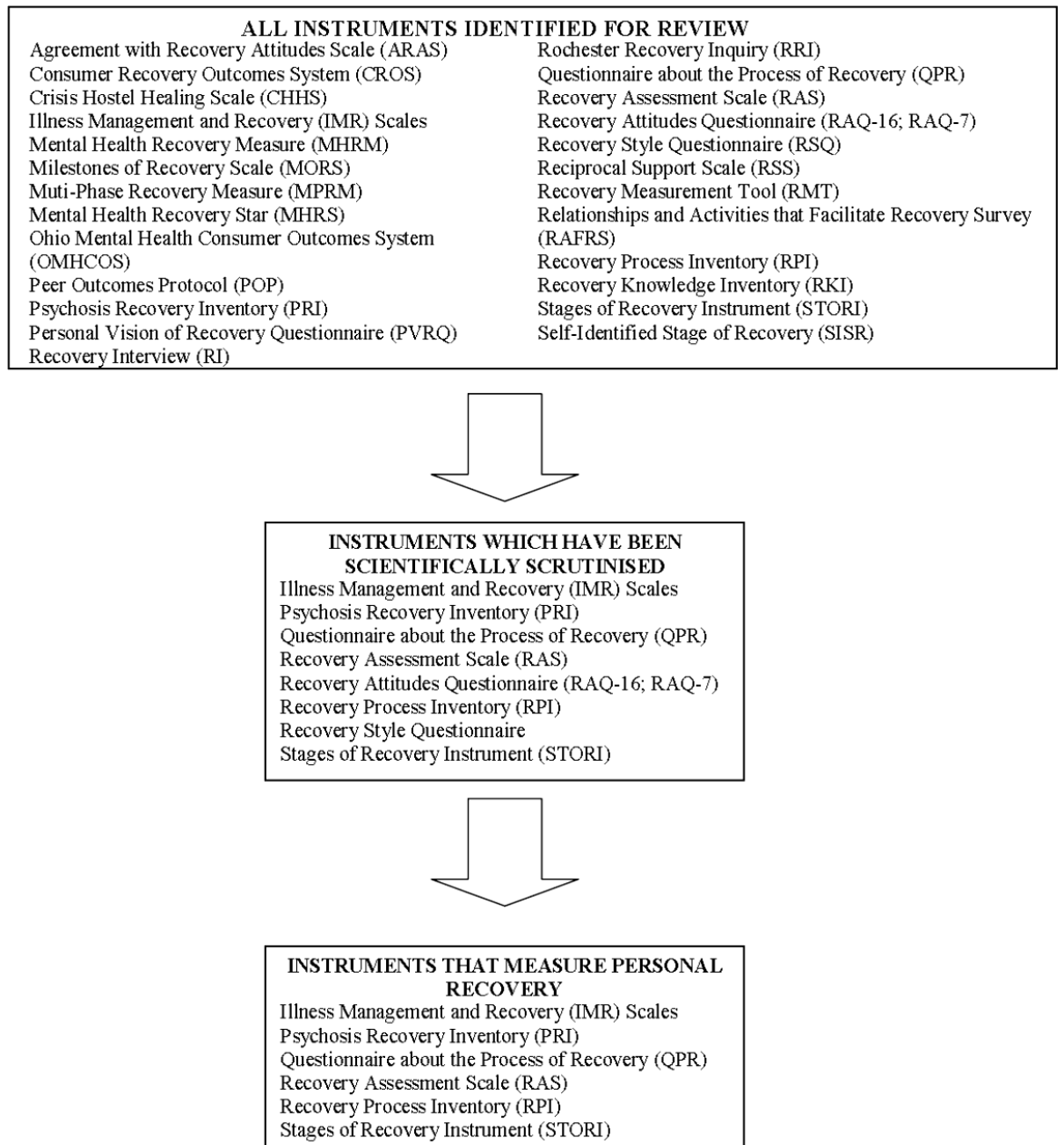
Overall, this search criterion yielded six measures of recovery for review. See Figure 1 for summary of measures included based on these criteria.

### *3.3.2 Criteria for evaluating measures of recovery*

Measures were evaluated based on their psychometric robustness, ease of administration, level of service user involvement during development and service user acceptability. Each of these domains is described in more detail below.

A table summarising the main features of each measure, as well as the evaluation domains listed below, was also compiled to allow readers to easily determine which measure is the most appropriate for their needs.

**Figure 1: Flowchart of measures subjected to initial inclusion criteria**



#### *3.3.2.1 Psychometric robustness*

This domain includes an evaluation of whether the measure demonstrates sound psychometric properties including internal consistency, validity and reliability. Sensitivity to change was not evaluated for the purposes of this review, due to the majority of the measures being in the early stages of their development.

Measures are evaluated as having good internal consistency when factor analysis has been used to establish if the items form a single scale or multiple subscales and the Chronbach's alpha is above the acceptable level of 0.6. An instrument is seen to have good convergent validity if it correlates highly with other instruments which aim to measure the same or similar concepts. Manuscripts which report re-administering the measure after a set period of time and report high correlation coefficients were deemed to have good test retest reliability.

Content validity (the extent to which the items comprehensively measure personal recovery) is considered in detail under the domains below, by assessing the level of service user input during the development of the measure and service user opinions of the content and relevance of the items (see evaluation domains below).

#### *3.3.2.2 Ease of administration*

The length of time needed to administer a measure is often of central importance to health professionals when adopting a new tool as part of routine practice. It is essential that any tool which is to be used regularly by health professionals is brief but effective, both for the benefit of the service user and to make good use of staff time and other resources. It is also important that measure is easily scored and interpreted by health professionals. This review considers the number of items in each measure, the length of time to complete the measure and ease of scoring.

#### *3.3.2.3 Level of service user input during development of the measure*

With the movement towards service user defined recovery it is considered essential that service users are actively involved in the development of any tools designed to measure recovery. Therefore this domain evaluated the level



of service user collaboration during the development phase of each instrument. For this process to be considered truly collaborative, the research team should include service user researchers working with other academics or clinicians. Other types of service user involvement considered include focus groups, feedback from service users at various stages during development and at the very least the use of qualitative studies/interviews to inform item development.

#### *3.3.2.4 Service user evaluation*

The review team included two service user consultants to provide a comprehensive overview of the measures from a range of perspectives. Service users on the review team were consulted about what criteria would be important to them when completing a measure of recovery. It was decided that key areas of importance for the service user evaluation included whether the format was simple and the items/scoring were easy to understand; whether the language used was positive and acceptable and whether the items reflected a measure of 'recovery as defined by service users'. Service users identified these criteria, completed each of the measures individually and then provided feedback which is discussed in more detail below.

**Table 2: Overview of instruments**

Measure	Development method	Service user input in design	No. of items	Factors/ dimensions	Samples in validation studies	Psychometric robustness	Administration	Service user evaluation
RAS	Analysis of four personal narratives of recovery	Service user focus group was consulted	41	Five factors: personal confidence & hope, willingness to ask for help, goal & success orientation, reliance on others no domination by symptoms	35 US service users with serious mental illness 168 Australian service users with severe and persistent psychiatric disability 209 Japanese service users with chronic mental illness	Good internal consistency Good test re-test reliability Good concurrent validity	6-10 minutes Easy to scorer	Easy to complete and understand Items are very relevant to recovery as defined by service users Positive framing of questions Overall an effective measure
PRI	Interviews with 20 service users used by clinicians to generate items	Feedback from service users to ensure items were appropriate	25	Three factors: Attitude to illness Attitude to treatment Perceptions of recovery and relapse	Initial validation in Hong Kong, N=35 (N=20 for test retest) Participants needed to have had a diagnosis of schizophrenia, with an illness duration of between 6 months and two years	Good internal consistency Good test re-test reliability Moderate to Good concurrent validity	10-15 minutes Easy to score	More difficult to complete Not relevant to recovery as defined by service users Seems to focus on medication adherence and relapse Negative language used Overall does not seem to measure recovery as defined by service users

Measure	Development method	Service user input in design	No. of items	Factors/ dimensions	Samples in validation studies	Psychometric robustness	Administration	Service user evaluation
RPI	Four focus groups with service users which staff initially used to generate 10 dimensions.	Service user focus group Informal pretesting with service users Service users were "interviewers" during validation	22	Six factors: Anguish Connected to others Confidence and purpose Others' help and care Living situation Hopeful/cares for self	US sample of 459 service users diagnosed with schizophrenia or mood disorder	Good internal consistency Moderate test re-test reliability Moderate convergent validity	6-10 minutes Easy to score	Simple format, easy to complete Measures personal recovery attitudes/mood Some focus on negative thoughts/beliefs Has some potential as a measure of personal attitudes/"illness" perceptions
STORI	Review of five qualitative studies informed the development of a five stage model of recovery. This model was used to generate themes and items.	Pilot with 10 service user researchers	50	Five stage model but only three factors clustered: Moratorium Awareness Preparation Rebuilding Growth	Validation in Australia with 94 service users with a diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, other psychotic disorder or self-reported schizophrenia.	Good internal consistency Test retest reliability not established Moderate to good convergent validity for first and fifth subscales but no significant correlations for the middle subscales.	10-30 minutes More complex to score	Difficult to complete, complex format Addresses some important aspects of recovery effectively Does not measure quality of life or social aspects of recovery Potentially a good measure of attitudes/perceptions of recovery and hope and resilience.

Measure	Development method	Service user input in design	No. of items	Factors/ dimensions	Samples in validation studies	Psychometric robustness	Administration	Service user evaluation
QPR	Items were generated based on themes from 7 previous interviews with service users	Service user researchers on study team Service user steering committee consulted at each stage	22	Two factors: Interpersonal Intrapersonal	UK validation with 111 service users with experience of psychosis.	Good internal consistency Good test retest reliability Good convergent validity	4 to 10 minutes Easy to score	Easy to complete, very user friendly Items are very relevant to recovery as defined by service users Positive language and framing of items Measures quality of life and wider perception of recovery Overall an effective measure of personal recovery
IMRS	Measure was developed by service users and clinicians to assess content of IMR programme	Service users clearly involved generally with the IMR programme and provided feedback on item selection and wording along with clinicians.	15 (plus 15 item clinician version)	Designed to measure 10 dimensions but factor analysis suggests three factors: Coping with Illness Outcome, Knowledge and Goals, Effective Medication Use/Reduced Alcohol and Drug Abuse	Pilot with 11 item version in US and Australia (N=24) Validation with US sample of 59 service users with severe mental illness. 210 service users with serious mental illness in Israel .	Good internal consistency Good test retest reliability Moderate convergent validity	15-30 minutes May be more complex to score if not in the context of the illness management and recovery programme	Difficult to complete, not service user friendly Items are relevant to symptom management and functioning but less focussed on broader aspects of recovery Language is less positive than other measures and items are formal, direct questions Overall not user friendly

Note: RAS, Recovery assessment scale; PRI, psychosis recovery inventory; RPI, recovery process inventory; STORI, Stages of Recovery Instrument; RSQ, Recovery styles questionnaire; QPR, Questionnaire about the process of recovery; IMRS, illness management and recovery scale; RI, Recovery Interview.

## 4. Results

Table 2 provides a summary of the main elements of each of the measures included in this review.

**Table 3: Common themes within the six measures of recovery**

	Confidence/ empowerment	Hope	Awareness/ understanding	Help seeking	Goals/ purpose	Support from others
RAS	✓	✓		✓	✓	✓
PRI			✓			
RPI	✓	✓			✓	✓
STORI		✓	✓			
QPR	✓	✓		✓	✓	✓
IMRS			✓		✓	✓

Note: RAS, Recovery assessment scale; PRI, psychosis recovery inventory; RPI, recovery process inventor; STORI, Stages of Recovery Instrument; RSQ, Recovery styles questionnaire; QPR, Questionnaire about the process of recovery; IMRS, illness management and recovery scale.

Table 3 provides an overview of the communalities in factors or themes within the measures. As indicated in Table 3, hope was the most common theme, being present in five of the six measures. Goal orientation or purpose was also common in four of the six measures, as was support from others. Confidence or empowerment, awareness or understanding and help seeking were also common to three of the six measures. These themes are discussed in more detail following the evaluation of each individual measure.

### 4.1 Recovery Assessment Scale

The recovery assessment scale is a 41 item measure rated on a five point likert scale. It was developed in the US by Giffort, Schmook, Woody, Vollendorf and Gervain (1995) by analysing personal narratives of recovery from four service users to identify the key concepts. These key concepts led to the development of 39 items which were reviewed by a service user group whose feedback resulted in the final 41 item scale.

The scale was tested on 35 consumers in the initial validation and has since been validated in two studies (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999; Corrigan, Salzer, Ralph, Sangster, & Keck, 2004) as well as being tested with an Australian sample (McNaught, Caputi, Oades, & Deane, 2007) and developed for use with a Japanese sample (Chiba, Miyamoto, & Kawakami, 2009). These studies indicated that the scale had good internal consistency ( $\alpha=0.93$ ), and test re-test reliability over a period of 14 days (Corrigan et al., 2004; McNaught et al., 2007). Concurrent validity of the RAS was also found to be good, demonstrating significant correlations with the Herth Hope Index, the Empowerment Scale, Subjective Quality of Life, Meaning of Life and the Hopkins Symptom checklist (Corrigan et al., 2004).

The exploratory factor analysis showed that recovery was positively associated with self-esteem, empowerment, social support and quality of life. In a further validation study in 2004, Corrigan et al. conducted a confirmatory factor analysis on a sample of 1824 which yielded five factors: personal confidence and hope, willingness to ask for help, goal and success orientation, reliance on others and no domination by symptoms. Although the scale was deemed to be psychometrically and conceptually valid (Corrigan et al., 2004), it should be noted that the instrument was developed and validated on samples with serious mental illness rather than specifically for people experiencing psychosis.

The service user consultants in this review team felt the measure was easy to complete, user friendly and that the items were relevant to measuring service user defined recovery. It was also felt that the items were positively framed and that the language was generally appropriate and acceptable. A few of the items did raise some concerns that responses would be very specific to each individual and may or may not be important towards a total recovery score. For example it was noted that responses to the item "things happen for a reason" may reflect a person's religious beliefs and not necessarily their beliefs about illness or recovery. Similarly, "being able to work is important to me" may not always be reflective of an individual's recovery if they are happy with engaging in other meaningful activities. These questions may still be a useful discussion point for each service user and clinician, but care may need to be taken if particular items impact on a total recovery score. Overall this measure has been shown to be psychometrically valid and service user friendly. It has the potential to be a highly effective and useful tool in recovery orientated clinical services.

#### 4.2 *Psychosis Recovery Inventory*

This inventory was developed in Hong Kong by Chen, Tam, Wong, Law & Chiu (2005) to look specifically at the issues around recovery from first episode psychosis. Interviews were conducted with twenty patients using open ended questions to explore what they felt the important aspects of their illness were in relation to recovery. These interviews were then analysed and from this, experienced clinicians generated items to make up the 25 item questionnaire, with each item being scored on a six point scale. Although interviews with service users informed the development of items and feedback from service users was collated to ensure their appropriateness, ultimately the items were generated by clinicians, which could mean that the items reflect the domains which clinicians feel are important in recovery.

The authors found the inventory to be reliable and valid; there was good test re-test reliability over four weeks and good internal consistency ( $\alpha=0.79$ ), although it should be noted that the sample size was small ( $n=20$  for test re-test reliability and  $n=48$  for the validation study) (Chen et al., 2005). Concurrent validity was examined by comparing the relevant PRI subscales to scores on the Scale to Assess Unawareness of Mental Disorder and the Drug Attitude Inventory. Modest to good correlations were identified with these measures.

The study does have several other limitations to be considered. Firstly, the inventory seems to focus on issues such as attitudes towards medication and treatment compliance, rather than on many of the aspects of recovery that the literature seems to suggest is important to recovery. This may be a result of cultural differences in service user views of the concept of recovery, or it may be due to the nature of the questions asked during the interviews guiding the respondents to answer in a particular way. As stated earlier, another possibility is that the items reflect the domains which the clinicians feel are important in recovery, as there was no direct service user involvement in generating the items. However, the authors set out to create a measure which would assess complex illness and treatment related issues, and further research may indicate that this measure is a useful tool in assessing attitudes and appraisals of recovery in psychosis.

The service user evaluators also felt that the measure doesn't cover many of the important aspects of recovery as defined by service users. It seemed there

was a focus on medication adherence and no items about general quality of life or social recovery. They found the measure difficult to complete because of this focus and the negative language and phrasing of the items (for example, "If I relapse it would be disastrous for me"). It was also felt that responses to certain items could be interpreted in different ways; for example "I think a lot about what has caused my unusual experiences" and "my condition has been absolutely normal" are two items which could be difficult to answer and difficult to interpret. It may be helpful for one service users to think about the causes of unusual experiences but not for another and similarly unusual experiences are fairly common place and clinicians often "normalise" such experiences but this could also be interpreted as the individual not accepting that they have unusual experiences. Overall, it was felt this measure wasn't user friendly and did not reflect a measure of recovery in the broader sense.

#### *4.3 Recovery Process Inventory*

Developed in the USA by Jerrell, Cousins and Roberts (2006), this inventory is a 22 item measure designed to cover psychosocial factors that are important in recovery. Initially four focus groups with consumers were conducted to generate key aspects of recovery. These were then summarised by the staff work group into ten main dimensions which the group felt were essential to capture within the instrument. These dimensions were hope, empowerment/self-control, self-esteem, self-management, social relations, family relations, housing, employment, stigma and spirituality. As with the psychosis recovery inventory, the main disadvantage of this measure seems to be that the items were essentially generated by the research team from focus groups with service users.

In the validation study for the Recovery Process Inventory, a convenience sample of 459 service users diagnosed with either schizophrenia or mood disorders was utilised. The study concluded that the inventory had good internal consistency ( $\alpha=0.71-0.81$ ) and moderate test-retest reliability over a two to four week period (co-efficients ranged from 0.36-0.63). The six RPI subscales demonstrated good convergent validity with the two main subscales of the MHSIP adult consumer survey (service quality/appropriateness and perceived outcomes), although overall convergent validity for the total RPI could only be considered to be moderate.



The authors conducted a principal axis analysis which revealed a six factor structure consisting of: anguish, connect to others, confidence and purpose, others' care and help, good living situation and hopeful/cares for self. However, as the authors note, the initial ten hypothesised dimensions, which the work group felt should be included in an instrument to measure recovery, were not supported. The analysis revealed only six factors, suggesting that either recovery has only six factors, or that the instrument is not sensitive enough to measure the other four factors. Further research to confirm the six factor structure and to provide additional information on the validity and reliability of measure would be beneficial.

The service user review of this measure concluded that the measure was easy to complete and quite user friendly. It was felt that the items reflected the concept of personal attitudes towards illness/recovery and would be an effective measure of the individual's current attitude/mood in relation to their recovery. However it was also apparent that some of the items were framed quite negatively, using language such as "lost", "hopeless", "isolated", "discriminated against" and "excluded". Although some of the items were positively framed, it was felt that the negative items may impact on the person completing the questionnaire. Two of the items were also focussed on religion and prayer which may not be applicable to everyone and therefore should be used with caution in the total score or interpretation of scores.

#### *4.4 Stages of Recovery Instrument*

Andresen, Caputi and Oades (2006) reviewed five qualitative studies to inform the development of their stage model of recovery. The model consists of five stages of recovery:

Moratorium - characterised by loss and hopelessness;

Awareness - all is not lost and a fulfilling life is possible;

Preparation - identify strengths and weakness and work on recovery skills;

Rebuilding - working on individual goals and control;

Growth -self management of illness, resilience and positive sense of self for a full and meaningful life.

Andresen et al. (2006) posit that this model involves sequential stages which could be a measurable indicator of the recovery process. Using this model as a basis, they developed themes and concepts found in the literature and generated 50 items for the measure. They piloted this measure with ten service user researchers, six with a diagnosis of schizophrenia and four with a diagnosis of bipolar disorder, anxiety or depression. Despite reviewing the literature, which included service user accounts of recovery, items were generated by the research team before being piloted with the help of a group of service user researchers.

Following the pilot, a larger validation study using 94 participants, the majority having been diagnosed with schizophrenia, was then conducted. This study indicated that the measure had good internal consistency ( $\alpha=0.88-0.94$ ) and that its subscales were reliable, although test re-test reliability was not established. The STORI has been shown to have moderate to good concurrent validity for the first and fifth subscales (moratorium and growth), which had significant correlations with other recovery related measures including the Recovery Assessment Scale, the Psychological Well Being Scale, the Adult State Hope Scale, the Mental Health Inventory and the Connor Davidson Resilience Scale. However, the middle subscales (awareness, preparation and rebuilding) were not significantly correlated with the concurrent measures, suggesting those subscales are measuring something distinct about those stages which differ from the concepts in the recovery related measures.

Cluster analysis of the STORI revealed only three stages related to recovery, not the five the authors outlined in their model. This suggests that either there are only three stages that relate to recovery, or the items in this measure were unable to discriminate between the other two stages. The authors also point out that the study is limited by a lack of participants in what the model defines as the early stages of recovery. Further validation of both the model and the measure would be recommended, along with test re-test reliability and sensitivity to change analysis. The authors of the measure also suggest further work to consider the language used in the items and the possibility of a shorter measure.

In agreement with some of the above suggestions from the authors of the measure, the service user evaluation also concluded that the measure was

quite complex and was difficult to complete. As well as having a relatively large number of items, it was difficult to understand the items and the response. Despite this it was felt that the measure did contain items which reflect some of the areas that are important to service users, for example independence, hope and resilience, and that the STORI would be a valuable measure of these. However, as with some of the other measures, it was felt there was a lack of items addressing more general aspects of quality of life and social contacts. Overall, it was agreed the measure was quite complex, lacked user friendliness and despite being a comprehensive measure of current attitudes/beliefs about hope, independence and resilience, it was felt it did not cover the equally important more pragmatic 'quality of life' aspects of recovery.

#### *4.5 Questionnaire about the Process of Recovery*

The Questionnaire about the Process of Recovery is one of the only tools developed in collaboration with service users that specifically addresses the measurement of recovery from psychosis (Neil et al., 2009). Interviews with service users were used to generate themes and subsequently the core items of the scale. Development of the tool was in collaboration with service users, including two service user researchers as members of the research team and a steering committee of ten service users who were consulted at each stage of the research.

The initial version of the tool was a 25 item measure which was piloted with 111 participants completing the QPR and comparator measures. The final version of the tool consisted of 22 items which showed good internal consistency ( $\alpha=0.77-0.94$ ) and test re-test reliability over a period of two weeks ( $r=0.77-0.87$ ). Concurrent validity of the QPR was also shown to be good, with scores on the subscales correlating significantly with recovery related measures including the General Health Questionnaire, the Making Decisions and Empowerment Scale and the Schizophrenia Quality of Life Scale.

Factor analysis revealed two subscales: "intrapersonal" involving tasks the individual is responsible for carrying out to rebuild their lives and "interpersonal" which relates to the individual's ability to reflect on the external world, processes and relationships. The authors acknowledge that further validation via a confirmatory factor analysis on a larger sample size is necessary. The main disadvantage of this measure is the lack of real world outcome studies and further psychometric testing.

The service user review of this measure was generally positive. It was felt that the measure was very easy and quick to complete and that the language and items were positive. The QPR seemed to be an effective measure of recovery as defined by service users and also included items reflecting the wider aims of recovery including quality of life and social relationships. Overall it was felt that the measure was user friendly and that individuals would feel positive after completing the QPR.

#### *4.6 Illness Management and Recovery Scale*

The Illness Management and Recovery Scale (2006a) is fairly unique in that it was developed in the context of the illness management and recovery (IMR) programme. The aims of the programme are to help service users manage their illness and pursue personal goals. As such, this measure was designed to assess the domains which have been targeted by the programme and enable the clinician and service user to assess recovery in two different versions of the scale (client version and clinician version). Both scales consist of fifteen items each measured on a five point Likert scale. The measure was developed by practitioners and service users to assess outcomes in IMR programme content: personal goals, knowledge of mental illness, involvement with significant others, impaired functioning, symptoms, stress, coping, relapse prevention, hospitalization, medication, use of drugs and alcohol. Service user involvement also appears to be high, although the authors do not provide details on the process of designing the scales in the peer reviewed.

In a recent paper investigating the psychometric properties of the scale, the internal consistency of the client version was found to be adequate ( $\alpha=0.68-0.72$ ) (Salyers, Godfrey, Mueser, & Labriola, 2007). This study also indicated good test-retest reliability over a two week period ( $r= 0.81$ ) and the client version of the scale has also shown good concurrent validity with recovery related measures, including the Recovery Assessment Scale and the Colorado Symptom Inventory. The IMRS is also the only measure reviewed here which, to date, had been used in a randomised controlled trial. The authors of the trial did not however report the scales sensitivity to change but the trial did note significant improvements in the treatment group compared to the control group, indicating that the scale is likely to be sensitive to change. Despite the obvious strengths of this instrument, the main disadvantage of this scale is that

it was designed to measure outcomes which are targeted in the illness management and recovery programme. It may be that the scale is still useful in measuring recovery in other contexts, however further research would be needed to confirm this.

The service user review of the IMRS found the measure was quite difficult to complete and used a complex response format. It was felt that the measure provided a thorough assessment of wellbeing in terms of symptoms and functioning but didn't have a clear focus on recovery as defined by service users. It was also apparent that language was very formal and the questions were quite direct. As stated above, the service user consultants also noted that some items seemed to reflect the specific goals of the illness management and recovery programme and therefore may not be suitable for use in a more general recovery measure. Overall the measure was seen as difficult to complete and not user friendly, although this may not be the case for service users who are involved in the IMR programme and aware of the goals and targets they have set.

## **5. Discussion**

The purpose of this review was to examine published measures of recovery from psychosis. If 'the recovery approach' is to be adopted within mental health services, it is important to consider how to ensure that services are effective in achieving the goals of recovery by developing and standardising the measurement of recovery.

Firstly, it is interesting to note that this review initially identified twenty-five measures of recovery from psychosis. This indicates that the concept of recovery is becoming more widely accepted in both the academic literature and within health services. However it was also clear that to date, there is no "gold standard" measure of recovery, nor has any one measure been used routinely within research or clinical service for a significant period.

During the review process it also became apparent that there were several communalities in recovery themes revealed from the factor analysis of the various measures. As indicated in table 3, hope was the most common theme, followed by goal orientation or purpose. Confidence/empowerment, awareness/understanding and help seeking were also common themes. These themes have a strong presence within the wider recovery literature and a

review of these themes may be a useful basis for researchers aiming to develop existing measures or design new measures. Indeed it is positive that despite the individual nature of recovery, there are several common themes emerging from a variety of sources. The main differences in recovery themes may be due to varying methods of questionnaire development; for example those with more academic input may have conceptualised recovery differently to those with more clinical or service user input. Using different types of clinical samples and different methodologies to generate the questionnaire items may have also influenced the final themes. Alternatively, variations in recovery themes could be accounted for by cultural differences between the authors and samples used. Further research to explore cultural similarities and differences in conceptualising and measuring recovery would be advantageous.

Overall, this review has shown that the recovery assessment scale (RAS) has received the most attention in the academic literature and it was the preferred measure in this review based on the service user feedback. The questionnaire about the process of recovery (QPR) has received less attention in the academic literature, however the service user consultants felt this measure was very user friendly. In comparison, the service user consultants felt the items on the QPR were less focussed than the recovery assessment scale. As discussed earlier, the other measures in this review have various strengths and may be more suited to particular contexts. For example the illness management and recovery scale may well be effective in the context of the illness management and recovery programme. It was noted by the review team that several of the measures lacked items relating to more general quality of life aspects of recovery, such as social relationships and social activity. Items relating to religion or work were also seen as problematic because they may not be applicable to all service users. The service user review also highlights the importance of positive framing of items and a simple item/response format. Finally, of central importance to service users, clinicians and academics is that the measures address a broad range of recovery themes in order to be most useful.

Further research could explore alternative approaches to measuring recovery. For example, it may be that questionnaires relating to the common themes in the recovery literature, such as hope, empowerment, goal orientation and social support, may be as effective as a more global recovery measure. Conversely, it may be appropriate to develop alternative approaches to the

measurement of recovery, which do not use a questionnaire based approach. For example, a more idiosyncratic generation and rating of themes or concepts important to the individual's recovery could be effective, utilising methodologies such as Q-sort or consideration of self-discrepancies (Higgins, 1987; Stephenson, 1953). Such an approach could also incorporate recovery specific goal attainment scaling which maybe a useful tool for clinical services.

This review of measures of personal recovery does have several limitations. Firstly, although the initial search identified twenty-five measures, only six were included in this review. Future reviews could consider including measures which have not yet been scientifically scrutinised or published or are not in the traditional self-report questionnaire format, as well as including measures designed to assess the recovery orientation of services, all of which were beyond the scope of this review.

This review and future reviews of measures of recovery could have a number of significant clinical implications. Measures which are reviewed as acceptable to service users, clinically useful and psychometrically valid may be considered for adoption into routine clinical practice. Further work is needed to determine clinical utility, and also to inform decisions around when and how frequently recovery measures should be used, as well as planning for how benchmarking and service evaluation could be informed by these individual assessments of recovery. At present, the biggest clinical implication seems to be encouraging clinicians and service user to talk about recovery and working collaboratively to determine recovery goals.

To conclude, it is clear that a variety of useful, valid and reliable instruments to measure recovery have been developed over the last decade or so, although none could be considered as the gold standard measure for recovery at present. All of the studies discussed use cross sectional data and there is a lack of real world outcome studies which utilise measures of recovery. Research on the topic of measuring recovery is adding to the growing literature on conceptualising recovery and could be the first step towards mental health services which are truly recovery oriented. A Secondary aim of conducting this review was to raise awareness of the possibilities of measuring recovery in the hope that more of these instruments and approaches will be adopted by clinical services and research teams. However, it is also hoped that this review will raise the question about the practicality and utility of measuring recovery, and

whether we should be attempting to measure something so personal and varied in such a standardised way. It may be that individual collaborative goal setting in the context of recovery, along with regular collaborative review is the best approach.



## **Chapter 4: Psychometric properties of the Questionnaire about the process of recovery (QPR)**

This paper is in press at Schizophrenia Research.

## **Psychometric properties of the Questionnaire about the process of recovery (QPR)**

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#### **4.1 Abstract**

The latent structure, reliability and validity of the Questionnaire about the Process of Recovery (QPR) (Neil et al., 2009) was examined in a sample of participants with experience of psychosis (N=335). The original two factor model proposed by Neil et al (2009) was examined using exploratory factor analysis followed by a further independent exploratory factor analysis to test revised solutions. Model fit statistics indicated that the most interpretable solution was a one factor model using 15 items from the original measure. Internal consistency, test re-test reliability and convergent validity of this new 15 item version were found to be high. Recommendations for the utility of the QPR in routine clinical practice along with suggestions for future research are discussed.

#### **4.2 Introduction**

There is a significant body of research on recovery in mental health and the emphasis has recently moved away from traditional biomedical definitions of recovery and towards service user defined recovery (Bellack, 2006). The biomedical paradigm focuses on absence of symptoms, decreased hospital admissions, reduced rates of rehospitalisation (National Institute for Health & Clinical Excellence, 2010) and return to functioning within the normal range (Torgalsboen, 1999). Based on biomedical connotations of recovery, few people who experience psychosis would ever be fully recovered (Whitwell, 2005); yet research has indicated that people can return to an acceptable level of functioning and quality of life, and many consider themselves to be recovered or 'in recovery' (Bellack, 2006).

Service users define recovery differently to clinicians, describing recovery as a process rather than an end point (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007). Pitt et al., (2007) also found that recovery had three main themes: rebuilding life; rebuilding self; and hope for a better future. Several studies have attempted to identify the common themes of recovery, particularly from service user accounts. Personal factors such as hope, empowerment and determination appear to be a key part of the recovery process, as well as social factors such as external support (Deegan, 1988; Leete, 1989; Mead & Copeland, 2000; Pitt et al., 2007; Ralph, 2000; Ridgeway, 2001). A recent systematic review and synthesis led to the development of a conceptual

framework of recovery with five core process: connectedness, hope, identity, meaning and empowerment (giving the acronym CHIME) (Leamy et al., 2011).

Leading mental health organisations have also started to focus on providing recovery oriented services (Department of Health, 2009; The Future Vision Coalition, 2010). This poses a question about how best to evaluate the effectiveness of services in supporting people to recover (Donnelly et al., 2011; Essock & Sederer, 2009). Instruments designed to measure outcomes such as symptom reduction or treatment compliance are already embedded into routine practice, however attempting to measure the personal goals of recovery is much more complex and as yet, no gold standard tool has been developed and widely accepted. As suggested by Resnick et al.(2005), if we define recovery as a complex personal process then it is inherently difficult to measure recovery. However, the authors also posit that measurement of recovery is feasible and valid if it is conducted in collaboration with service users.

A review of published recovery measures concluded that the Recovery Assessment Scale (RAS) appeared to be the most validated measure of recovery currently available, although only two scales were designed specifically for people with experience of psychosis: the Psychosis Recovery Inventory (PRI) and the Questionnaire about the Process of Recovery (QPR) (Law, Morrison, Byrne, & Hodson, 2012). Although the RAS, QPR and the PRI all aim to measure recovery in similar clinical populations, a recent systematic review of personal recovery measures concluded that QPR was the only measure to map to all five areas of the CHIME framework for recovery (Shanks et al., 2013). Similarly, the QPR was one of three tools identified to measure recovery outcomes, although the authors suggested further psychometric validation was needed (Donnelly et al., 2011). These studies provide a growing evidence base for selection of the QPR as a measurement tool for service user defined recovery in psychosis provided further psychometric evaluations are conducted.

The purpose of the current study is to revisit the psychometric properties of the Questionnaire about the Process of Recovery (QPR) (Neil et al., 2009). The QPR was designed collaboratively by clinicians and service users. Items were generated using themes identified from a previous study (Pitt et al., 2007). Exploratory factor analysis indicated a two factor structure, comprising of interpersonal and intrapersonal subscales. Since publication, the QPR has been

used in several research trials (Morrison et al., in press; Slade et al., 2011; Tarrier; et al., in submission), and has been translated into Chinese (Chien & Chan, 2013). Work is currently underway to translate and validate the measure in German, Norwegian and Swedish, and mental health services across England are endorsing the QPR as a routine measure of recovery (Neil, 2013).

Given the increasing body of knowledge on recovery and the current drive for recovery oriented services, it is important to revisit the utility of the QPR. The aim of this study was to re-evaluate the QPR in terms of its psychometric properties and to conduct a further factor analysis with a larger sample.

### **4.3 Method**

#### *4.3.1 Participants*

Data for the present study are taken from a programme of NIHR funded research (the Recovery Programme). Participants were invited to take part in the research programme if they met the inclusion criteria: aged between 16 and 65; sufficient understanding of English to enable completion of measures; and either had a formal schizophrenia spectrum diagnosis or met criteria for an ICD-10 schizophrenia spectrum diagnosis. Exclusion criteria were being unable to give informed consent or presently at high risk to themselves or others (as defined by care coordinator).

Recruitment took place across a variety of mental health and voluntary sector services to ensure the sample was heterogeneous with respect to severity of symptoms, social functioning, duration of illness, and subjective appraisal of recovery status.

#### *4.3.2 Measures*

##### *4.3.2.1 The Process of Recovery Questionnaire (QPR)*

The QPR (Neil et al., 2009) is a 22 item self report measure developed collaboratively by service user researchers and clinicians. Items are rated on a five point likert scale ranging from "strongly disagree" to "strongly agree". Higher scores on the measure are indicative of recovery. The QPR has two subscales: intrapersonal and interpersonal. Good internal consistency was

reported for these subscales (intrapersonal  $\alpha=0.94$ ; interpersonal  $\alpha=0.77$ ) as well as good construct validity and reliability (Neil et al., 2009).

#### 4.3.2.2 *The Positive and Negative Syndrome Scale (PANSS)*

The PANSS (Kay, Fiszbein, & Opler, 1987) is a thirty item semi-structured clinical interview including 7 items to assess positive symptoms (such as hallucinations and delusions), 7 items to assess negative symptoms (such as blunted affect and emotional withdrawal) and 16 items to assess global psychopathology (such as anxiety, guilt and depression). All items are rated from 1 (not present) to 7 (severe). The PANSS has been used in a variety of studies and has been shown to have good reliability and validity (Kay, Opler, & Lindenmayer, 1988).

#### 4.3.2.3 *The Psychotic Symptom Rating Scales (PSYRATS)*

The PSYRATS (Haddock, 1999) is a seventeen item multidimensional measure of auditory hallucinations and delusions which rates symptoms over the past week. Items are rated on a five point scale (0-4). The PSYRATS has been shown to have good reliability and validity (Drake, Haddock, Tarrier, Bentall, & Lewis, 2007; Haddock, 1999).

#### 4.3.2.4 *The Beck Hopelessness scale (BHS)*

The BHS (Beck, Weissman, Lester, & Trexler, 1974) is a 20 item self-report measure designed by clinicians to measure three dimensions of hopelessness: feelings of the future, loss of motivation and expectations. Statements are rated by participants as true or false for their attitudes over the last week. The psychometric properties of the BHS have been examined in various studies and the measure has been shown good reliability and validity (Dyce, 1996; Nunn, 1996; Young, Halper, Clark, Scheftner, & Fawcett, 1992)

#### 4.3.2.5 *The Self Esteem Rating Scale-short form (SERS)*

The SERS (Lecomte, Corbiere, & Laisne, 2006) is a 20 item self-report measure assessing both positive and negative beliefs about the self. Items are rated on a seven point Likert scale ranging from "never" to "always". The scale demonstrated good internal consistency and reliability and adequate convergent validity (Lecomte et al., 2006).

#### 4.3.2.6 *The Calgary Depression Scale for Schizophrenia (CDSS)*

The CDSS (Addington, Addington, & Schissel, 1990) is a nine item self-report scale designed to measure aspects of depression in people with a diagnosis of

schizophrenia. Items are rated on a three point Likert scale with global scores range from 0 to 27. The CDSS has been shown to have good reliability and validity (Addington, Addington, Maticka-Tyndale, & Joyce, 1992; Addington et al., 1990).

#### 4.3.2.7 *Personal and Social Performance Scale (PSP)*

The PSP (Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000) is a measure of functioning rated by an observer. The scale is scored across 4 domains assessing socially useful activities, personal and social relationships, self-care and aggression. Total scores range from 1 to 100 with 100 indicating no functional difficulties. The internal consistency of the overall scale has been shown to be adequate ( $\alpha=.76$ ) (Kawata & Revicki, 2008) and reliability and validity of the measure has been demonstrated (Nasrallah, Morosini, & Gagnon, 2008).

#### 4.3.3 *Procedure*

All studies in the Recovery Programme were approved by an NHS Research Ethics Committee. A service user reference group were consulted on all aspects of design and procedures within the studies. Participants were recruited via posters, advertisements and referrals from health professionals. Community mental health teams, early intervention teams, inpatient services and voluntary sector agencies across the North West were approached for suitable referrals. Potential participants were offered an information sheet and given a minimum of 24 hours to decide whether to take part. A research assistant would meet the participant to take informed consent before administering the measures. A subset of 30 participants were approached one to two weeks later to complete the QPR again for test re-test reliability. To reduce participant burden, participants were given the option to complete some or all of the measures. Core measures included the QPR and PANSS positive and negative subscales, whilst the other measures were optional.

#### 4.3.4 *Statistical analyses*

Data were analysed using SPSS (Statistical Package for the Social Sciences - version 20) and AMOS (version 22). Sample characteristics were explored using descriptive statistics. Cronbach's alpha coefficients were calculated to examine

the internal consistency of the subscales. Test re-test reliability was assessed using Intra Class Correlations (ICC) as the data on QPR was normally distributed and on a linear scale.

The empirical basis for a confirmatory factor analysis of the QPR was lacking given that the psychometric properties of the QPR had only been examined previously during its development phase. Therefore an independent exploratory factor analysis (EFA) of the original 22 items was conducted followed by further EFA to test revised solutions after removal of items.

EFA with maximum likelihood estimation and promax rotation was utilised. As recommended by Hu and Bentler (1999), multiple indices were used to evaluate goodness of model fit including the root-mean-square error of approximation (RMSEA)  $<.06$ , the Standardised Root Mean Square Residual (SRMR)  $<0.08$  and the cumulative fit index (CFI)  $>0.95$  whilst also considering the interpretability of the solution and the strength of parameter estimates (e.g., primary factor loadings of  $>.60$  and an absence of salient cross loadings).

#### **4.4 Results**

##### *4.4.1 Sample characteristics*

Characteristics of the 335 participants can be seen in Table 4. The majority of participants were male (66.3%), White (82.7%) and in contact with mental health services (82%). The average age of participants was 36 (SD = 11.62). ICD-10 diagnoses of participants were as follows: schizophrenia (n=166), schizoaffective disorder (n=30), persistent delusional disorder (n=16), unspecified non-organic psychosis (n=15), acute and transient psychotic disorder (n=12), mental and behavioural disorder due to alcohol (n=1), mental and behavioural disorder due to opioids (n=1). The remaining participants described themselves as having experience of psychosis but had not been formally given a diagnosis (n=94), although 66% of these participants were accessing mental health services and all met the inclusion criteria for this study. Descriptive statistics for sample measures can be seen in Table 5.



**Table 4: Sample characteristics**

		N	%
Gender	Male	222	66.3
	Female	113	33.7
Service type	CMHT	162	48.4
	EI	89	26.6
	Assertive Outreach	9	2.7
	Inpatient	9	2.7
	Review and Recovery	7	2.1
	Other	6	1.8
	Unknown	53	15.8
Ethnicity	White	277	82.7
	Black	19	5.7
	Asian	16	4.8
	Mixed	13	3.9
	Other	10	3.0
Marital status	Single	255	76.1
	Divorced	28	8.4
	Married	22	6.6
	Common law	21	6.3
	Separated	5	1.5
	Widowed	4	1.2
Employment status	Employed	28	8.3
	Unemployed	158	47.2
	Disabled/DLA	97	29
	Retired	8	2.4
	Voluntary	26	7.8
	Student	18	5.4
	Religious beliefs	Christianity	117
Atheism		71	21.2
Islam		26	7.8
Other		66	19.7
None		53	15.8
	Not stated	2	0.6

**Table 5: Sample scores on study measures**

	<i>N</i>	<i>Range</i>	<i>Mean</i>	<i>Std. Deviation</i>
QPR (15 item)	335	15-75	50.13	11.56
PANSS				
Positive	334	7-26	14.041	4.66
Negative	334	7-28	13.23	4.17
General	213	16-47	28.31	6.85
PSYRATS				
Hallucinations	300	0-22	10.19	6.61
Delusions	314	0-38	11.72	13.85
Calgary	208	0-20	6.14	4.62
BHS	313	0-20	9.17	5.02
SERS				
Positive	324	10-70	40.73	12.77
Negative	323	10-70	35.06	13.93
PSP	247	0-100	58.88	20.89

#### 4.4.2 Factor analysis

The original 22 items of the QPR were submitted to an EFA (n=335). The first five eigenvalues from an initial principal component analysis were the following: 9.142, 1.609, 1.118, .814 and .792. The proposed two factor model was found to be a poor one with several primary factor loadings below 0.60 and a significant Chi-square ( $X^2(208) = 511.143, p < 0.001$ ). The model fit statistics however were approaching acceptability: RMSEA= .066; SRMR = .0551; CFI= .906.

Items which did not have salient loadings were removed before a further exploratory factor analysis was conducted (see Table 6). The removed items also appeared to have less face validity in terms of their utility in assessing the recovery process or potential ambiguity in item wording, therefore these items were excluded from the final version. EFA suggested a uni-dimensional solution provided an improved fit to the data (RMSEA= .066; SRMR=.0389; CFI=.949) although the  $X^2(90)=219.054, p < 0.001$  remained significant.

#### 4.4.3 Reliability

Examination of the 22 item-total correlations and Cronbach's Alpha also revealed items which may be redundant, supporting the above analysis following removal of redundant items. Items which improved the overall scale

Cronbach's Alpha or had item-total correlations below 0.6 were removed (see Table 6).

Cronbach's alpha coefficients were computed for internal consistency of items on the original 22 item solution for this sample at  $\alpha=0.930$ . For the uni-dimensional solution the alpha coefficient was improved ( $\alpha =0.933$ ) indicating high internal consistency of the remaining 15 items.

Test re-test reliability was calculated by comparing 30 participant's scores on the QPR at time one and time two (between one and two weeks later). The data was normally distributed so an Intra Class Correlation (ICC 2,1) was used. Results indicated adequate test re-test reliability with a 95% confidence interval (ICC= .681, CI .430-.834).

#### 4.4.4 *Validity*

Pearson's correlations between the QPR and all other measures can be seen in Table 7. The QPR demonstrated significant relationships with all measures. Largest correlations were observed between the QPR and self-esteem (SERS), depression (CDSS), PANSS general and hopelessness (BHS). Increased scores on recovery (QPR) were associated with increased positive self-esteem (SERS) and increased functioning (PSP), as well as decreased scores for general psychopathology (PANSS general), hopelessness (BHS) and depression (CDSS).

Table 6: Internal consistency of original 22 item measure

<i>Item</i>	<i>Corrected Item-Total Correlation</i>	<i>Cronbach's Alpha if Item Deleted</i>
QPR 1 I feel better about myself	.658	.926
QPR 2 I feel able to take chances in life	.639	.926
QPR 3 I am able to develop positive relationships with other people	.647	.926
QPR 4 I feel part of society rather than isolated	.629	.926
QPR 5 I am able to assert myself	.631	.926
QPR 6 I feel that my life has a purpose	.654	.926
QPR 7 My experiences have changed me for the better	.655	.926
QPR 8 I have been able to come to terms with things that have happened to me in the past and move on with my life.	.657	.926
QPR 9 I am basically strongly motivated to get better	.663	.926
QPR 10 I can recognise the positive things I have done	.712	.925
QPR 11 I am able to understand myself better	.656	.926
QPR 12 I can take charge of my life	.729	.924
QPR 13 I am able to access independent support*	.478	.929
QPR 14 I can weigh up the pros and cons of psychiatric treatment*	.516	.928
QPR 15 I feel my experiences have made me more sensitive towards others*	.245	.932
QPR 16 Meeting people who have had similar experiences makes me feel better*	.282	.932
QPR 17 My recovery has helped challenge other people's views about getting better*	.522	.928
QPR 18 I am able to make sense of my distressing experiences*	.541	.928
QPR 19 I can actively engage with life	.719	.924
QPR 20 I realise that the views of some mental health professionals is not the only way of looking at things*	.442	.929
QPR 21 I can take control of aspects of my life	.662	.926
QPR 22 I can find the time to do the things I enjoy	.603	.927

**Table 7: Relationship between QPR and measures of symptoms, functioning, self esteem and hopelessness.**

		<i>QPR</i>	<i>PANSS positive</i>	<i>PANSS negative</i>	<i>PANSS general</i>	<i>PSYRATS del.</i>	<i>PSYRATS hall.</i>	<i>Calgary</i>	<i>BHS</i>	<i>SERS positive</i>	<i>SERS negative</i>	<i>PSP</i>
QPR	Pearson Correlation (N)	1 (335)										
PANSS positive	Pearson Correlation (N)	-.333** (334)	1 (334)									
PANSS negative	Pearson Correlation (N)	-.250** (334)	.382** (334)	1 (334)								
PANSS general	Pearson Correlation (N)	-.549** (213)	.691** (213)	.513** (213)	1 (213)							
PSYRATS del.	Pearson Correlation (N)	-.400** (300)	.683** (299)	.383** (299)	.642** (210)	1 (300)						
PSYRATS hall.	Pearson Correlation (N)	-.355** (314)	.480** (313)	.092 (313)	.467** (211)	.406** (287)	1 (314)					
Calgary	Pearson Correlation (N)	-.560** (208)	.458** (207)	.257** (207)	.656** (139)	.416** (185)	.492** (187)	1 (208)				
BHS	Pearson Correlation (N)	-.458** (313)	.322** (313)	.327** (313)	.522** (206)	.445** (282)	.312** (294)	.515** (194)	1 (313)			
SERS positive	Pearson Correlation (N)	.617** (324)	-.241** (324)	-.259** (324)	-.460** (209)	-.311** (291)	-.278** (304)	-.491** (204)	-.413** (312)	1 (324)		
SERS negative	Pearson Correlation (N)	-.632** (323)	.353** (323)	.255** (323)	.610** (209)	.449** (290)	.347** (303)	.658** (203)	.535** (312)	-.627** (323)	1 (323)	
PSP	Pearson Correlation (N)	.412** (247)	-.336** (246)	-.322** (246)	-.409** (129)	-.223** (213)	-.128 (227)	-.234** (127)	-.246** (230)	.192** (240)	-.232** (239)	1 (247)

\*\* .correlation is significant at the 0.01 level (2-tailed)

#### 4.4.5 Predictors of recovery score (QPR)

Significant correlations between QPR and other measures suggested further exploratory analysis of predictors of QPR recovery score may be useful. Variables were entered in three stages: firstly hope (as measured by BHS) and self-esteem (as measured by SERS) were entered (these variables were indicated by the existing literature); secondly measures of general functioning (PSP), psychopathology (PANSS general) and depression (CDSS) were added; and finally symptom measures (which are seen as traditional indicators of recovery) were entered. Variables were entered simultaneously at each stage.

**Table 8: Multiple regression analysis: predictors of subjective recovery (QPR scores)**

		b	SEb	$\beta$
1	Constant	42.79	8.216	
	Positive self esteem	.351	.127	0.37**
	Negative self esteem	-.142	.131	-0.17
	BHS	-.544	.293	-0.27
2	Constant	31.008	7.747	
	Positive self esteem	.419	.099	0.44***
	Negative self esteem	.103	.118	0.12
	BHS	-.710	.234	-0.35***
	PSP	.238	.042	0.47***
	PANSS General	-.128	.216	-0.07
	CDSS	-.570	.351	-0.23
3	Constant	40.644	8.927	
	Positive self esteem	.331	.105	0.35***
	Negative self esteem	.086	.124	0.10
	BHS	-.707	.256	-0.35**
	PSP	.215	.044	0.42***
	PANSS General	-.162	.352	-0.09
	CDSS	-.479	.393	-0.19
	PANSS Positive	.323	.397	0.13
	PANSS negative	-.726	.310	-0.24*
	PSYRATS delusions	-.020	.237	-0.01
PSYRATS hallucinations	.019	.109	0.02	

Regression models are shown in Table 8. The first stage model was significant ( $F[3,49]=14.948$ ,  $p<.001$ ; adjusted  $R^2= .446$ ). Adding measures of functioning, general psychopathology and depression significantly improved the model ( $F[6,46]=19.720$ ,  $p<.001$ ;  $R^2$  change= .242  $P<.001$ ). Addition of measures of symptoms in the final stage did not significantly improve the model although it remained significant overall ( $F[10,42]=12.986$ ,  $p<.001$ ;  $R^2$  change= .036).

#### **4.5 Discussion**

Three recent reviews highlighted that the QPR was potentially a valid measure of recovery from psychosis, but lacked psychometric validation (Donnelly et al., 2011; Law et al., 2012; Shanks et al., 2013). The present study is the first to further examine the psychometric properties of this measure in a clinical sample. EFA suggests that the original 22 item measure with two subscales as proposed by Neil et al (2009) provided a poor fit to the data. Furthermore, examination of primary factor loadings indicated that internal consistency could be improved following the removal of seven items. Although these items were identified as relevant to recovery in the initial study (Neil et al., 2009), it may be that these items are not generalisable to a larger sample. As noted earlier, the items which were identified for removal also appear to lack face validity or be ambiguously worded (for example the word sensitive in 'I feel my experiences have made me more sensitive towards others' could be interpreted as positive or negative). It is also possible that the items which were removed relate to levels of recovery knowledge, although it is likely that a range of levels of knowledge were present in the current sample.

The present study provided additional support for the reliability and validity of the QPR. Test re-test reliability was adequate and the QPR demonstrated significant correlations with symptom measures (PANSS and PSYRATS) and other measures associated with recovery (SERS and BHS). The significant inverse relationships between the QPR and symptoms of psychosis support the assumption that symptom reduction is associated with increased recovery (National Institute for Health & Clinical Excellence, 2010). Items on the QPR were consistent with key themes identified in the recovery literature, such as hope, meaning, empowerment, connectedness, identity and external support (Deegan, 1988; Leamy et al., 2011; Leete, 1989; Mead & Copeland, 2000; Pitt et al., 2007; Ralph, 2000; Ridgeway, 2001), which supports the face validity of the measure. Similarly, regression analyses highlight the important role of hope, self-esteem and negative emotion in recovery, which is consistent with the literature on negative emotion and psychosis (Freeman & Garety, 2003; Garety et al., 2001; Smith et al., 2006). This also suggests that recovery orientated services could utilise interventions which target negative emotion (Birchwood & Trower, 2006; Hepworth, Startup, & Freeman, 2011) and self-esteem (Hall & Tarrrier, 2003) in order to improve service user's recovery satisfaction as measured by the QPR.

It should be noted that there are limitations to this study. Firstly, it was not possible within the constraints of this study to examine the predictive validity and sensitivity to change of the QPR. However, it is noted that the QPR is currently being used routinely in some clinical services and also in a large scale research programme which includes three randomised clinical trials. It is hoped that this data will provide information on the sensitivity of the QPR. The sample used in the present study was diagnostically heterogeneous which could be seen as a limitation, however this may provide greater generalisability to clinical services which often have considerable diagnostic heterogeneity. Also, the original three factor structure of the PANSS was utilised in this analysis, rather than the proposed five or seven factor solutions (Emsley, Rabinowitz, & Torreman, 2003; Lindenmayer, Bernstein-Hyman, & Grochowski, 1994) due to the high proportion of missing data on the PANSS general subscales. This may limit the generalisability of the statistical analyses presented, particularly in relation to the role of factors such as depression and anxiety.

The QPR appears to have clinical utility as a tool to measure the recovery process and to collaboratively set goals and monitor change. The exploratory factor analysis suggested an overall recovery score, rather than distinct subscales, provided the most interpretable solution. As suggested by Neil et al. (2009) the most apparent advantage of using the QPR in clinical services is to promote engagement and demonstrate a collaborative recovery focussed approach. However, previous studies have also utilised scores on the QPR to detect change in recovery (Slade et al., 2011). The present study would suggest that a medium effect size of 0.4 would be equivalent to a change of 4.63 on the overall 15 item QPR score. A recent randomised controlled trial found a difference of +3.32 in total QPR scores post treatment (Morrison et al., in press). The present study suggests the QPR may have utility as a Patient Reported Outcome Measure (PROM) with the possibility of standardised change scores. Utilisation of PROM's in mental health services could have positive impacts on patient care processes (Marshall, Haywood, & Fitzpatrick, 2006) and to date, no recovery related mental health PROM's have been widely used and validated. Further exploration of a recovery related PROM such as the QPR would be beneficial.

It is envisaged that the QPR and the research processes used to develop it could promote the concept of recovery and collaborative research with service users. This message is perhaps most important to service commissioners and



policy leads who have recently placed recovery high on the agenda. If the aim is to be “recovery oriented”, it is vital that that we work with service users to determine what is meant by recovery and how we can most effectively monitor the success of services in achieving the personal goals of recovery.

## **Chapter 5: Recovery in psychosis: A Delphi study with experts by experience**

This paper is in press at Schizophrenia Bulletin.

Running title: Recovery in psychosis: a Delphi Study

**Recovery in psychosis: A Delphi study with experts by experience.**

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## **5.1 Abstract**

This study aimed to establish consensus about the meaning of recovery amongst individuals with experience of psychosis. A Delphi approach was utilised to allow a large sample of service users to be anonymously consulted about their views on recovery. Service users were invited to take part in a three stage consultation process. A total of 381 participants gave their views on recovery in the main stage of this study, with 100 of these taking part in the final review stage. The final list of statements about recovery included 94 items, which were rated as essential or important by >80% of respondents. These statements covered items which define recovery, factors which help recovery, factors which hinder recovery and factors which show that someone is recovering. As far as we are aware, it is the first study to identify areas of consensus in relation to definitions of recovery from a service user perspective, which are typically reported to be an idiosyncratic process. Implications and recommendations for clinical practice and future research are discussed.

## **5.2 Introduction**

Mental health services typically define recovery from psychosis in terms of absence of symptoms, decreases in duration of hospital admissions and reduced rate of rehospitalisation (National Institute for Health & Clinical Excellence, 2010). Clinical research trials often attempt to quantify recovery by demonstrating significant improvements in symptoms and other so called 'deficits' to the degree that they could be considered within the 'normal' range (Schrank & Slade, 2007). In stark contrast, service users conceptualise recovery differently (Bellack, 2006), believing that recovery is a unique process rather an end point with key recovery themes including hope, rebuilding self and rebuilding life (Pitt et al., 2007c). Many qualitative studies of service user accounts demonstrate these themes of recovery and indicate that there is potential for all individuals to recover to some extent (Davidson, 2003).

This optimism about the potential for recovery has been adopted in various health policies (American Psychiatric Association, 2005; Department of Health, 2009; Mental Health Network NHS Confederation, 2012; National Institute for Mental Health in England, 2005; The Future Vision Coalition, 2010), which have a focus upon collaborative working between clinicians and service users,

rebuilding lives with or without ongoing symptoms and recognising the importance of hope and empowerment. Despite this recognition of what may be required for recovery-orientated mental health services, it is not always clear how health professionals can provide effective recovery-orientated services that can be evaluated for performance in supporting people to recover (Essock & Sederer, 2009).

Various measures of service user defined recovery have been developed with items covering a variety of themes including hope, empowerment, awareness/understanding, help-seeking, social support and goals/purpose (Law, Morrison, Byrne, & Hodson, 2012). Only two measures have been developed to measure service user defined recovery from psychosis: the Psychosis Recovery Inventory (Chen et al., 2005) and the Questionnaire about the Process of Recovery (Neil et al., 2009). Such user defined recovery measures have yet to be adopted as routine outcome measures in mental health services, although in the US, New York State has mandated recovery-orientated treatment planning and measurement for state funded psychiatric programs. Despite this, there is continued debate about whether recovery can be measured as an outcome when it is defined as an idiosyncratic process. It has been suggested that if measurement of recovery is a collaborative process involving service users and clinicians, it could be a feasible and valid method for evaluation of effective recovery-orientated services (Resnick, Fontana, Lehman, & Rosenheck, 2005).

Although there has been a reasonable level of agreement that mental health services should aim to be recovery-orientated, the problem of reaching consensus about what is meant by recovery and producing a definition that is acceptable to service users, whilst being practical and achievable for clinicians and services, has yet to be resolved. Service user accounts (Deegan, 1988; Leete, 1989; Mead & Copeland, 2000; Ridgeway, 2001) and qualitative studies exploring recovery (Pitt et al., 2007c; Smith, 2000; Spaniol et al., 2002), identify common themes with most, if not all, concluding that recovery is a unique and individual process. This makes it extremely difficult for clinicians and services to provide recovery-orientated services. The extent to which service users agree about what constitutes recovery and what helps their recovery has yet to be explored.

Various techniques can be employed to reach consensus about a given debated topic (Jones & Hunter, 1995). One such technique is the Delphi method, which is a systematic process of engaging a panel of 'experts' in the chosen field in two or more rounds of questionnaires, with the aim of identifying items which the expert panel agree are important to the chosen topic. The Delphi method has been utilised to identify essential elements in schizophrenia care (Fiander & Burns, 1998), indicators of relapse (Burns, Fiander, & Audini, 2000), essential elements of early intervention services (Marshall, Lockwood, Lewis, & Fiander, 2004), first aid guidelines for psychosis (Langlands et al., 2008), and components of CBT for psychosis (Morrison & Barratt, 2010).

Expert panels usually consist of clinicians and academics, although some studies have utilised small groups of service users (Byrne & Morrison, in press; Langlands et al., 2008). On the topic of recovery from psychosis, it could be argued that service users are the experts. Indeed, many of the documents which endorse a recovery approach accept that recovery should be defined by service users. Many current National Health Service (NHS) initiatives in the UK aim to view the patient as the expert (Department of Health, 2001) and mental health services are increasingly taking this approach of valuing service users as 'experts by experience' (British Psychological Society, 2000).

This study utilises the Delphi methodology to consult a large group of service users with the aim of determining levels of consensus for service user conceptualisations of recovery. As such, it will provide unique information to establish shared agreement regarding the definition of a process which is often viewed as an idiosyncratic journey.

### **5.3 Method**

#### *5.3.1 Participants*

Participants were included in the study if they have (or have had) experience of psychosis, were over the age of 16 and able to understand English. Participants were recruited via convenience sampling through mental health services (including Community Mental Health Teams and Early Intervention Services), non-NHS/voluntary groups and networks, and advertising of the study by leaflets, posters, email networks, websites, social media and local media (including press releases). This study was supported by the Mental Health

Research Network who provided clinical studies officers to advertise and recruit participants using the methods described above. Recruitment took place across seven NHS mental health trusts in the North West of England.

### *5.3.2 Procedure and analysis*

This study was approved by the National Research Ethics Service (NRES) Committee East Midlands. The Delphi process consisted of three stages based around those identified by Langlands et al (Langlands et al., 2008).

#### *5.3.2.1 Stage 1:*

Elements identified as pertinent to conceptualisation of recovery in psychosis were identified through a literature search of journals, policy documents, recovery measures and websites. This was reviewed by the authors and collated into an initial list of statements (n=141). Due to the complexities of including a large panel of service users as the experts to be consulted, the authors decided to use a smaller panel of service users (a local service user reference group with ten members, all of whom have personal experience of psychosis and using mental health services) during stage one to further refine this initial statement list. Five members of this group suggested changes which resulted in the addition of a further three items, rewording of several items to increase acceptability to service users (for example including the word "experiences" alongside "symptoms" and removing the word "illness" where possible) and deletion of seven items which were felt by the service users to be duplications. For ease of administration, the statement list was divided into 4 sections depending on the nature of the statement: defining recovery, factors that help recovery, factors that hinder recovery and factors that show someone is recovering. The service user group approved the four subsections within the statement list.

#### *5.3.2.2 Stage 2:*

The finalised list of 137 statements from stage 1 was collated and formatted into an web-based and paper questionnaire. A demographics sheet was added to collect data on age, gender, mental health trust, diagnosis and length of diagnosis. Participants were also asked if they would like to provide a postal or

email address so they could be invited to take part in the final stage of the study, although this was optional to allow complete anonymity if preferred.

Participants rated the importance of each item on the statement list, on a five point Likert scale (1-essential, 2-important, 3-do not know/depends, 4-unimportant and 5-should not be included). A total of 426 participants completed the stage 2 questionnaire, although 45 were not included in the final sample (26 were deemed to be ineligible due to reporting no experience of psychosis, 14 people did not complete the questionnaire, 1 person added a note to say they had already completed the study before and 4 people posted the questionnaire after the deadline). Results from the remaining 381 eligible participants were entered into an anonymised database and analysed by obtaining group percentages.

In accordance with the methods used by Langlands et al (2008) the following criteria were used to determine items for inclusion, exclusion and rerating.

1. Items rated by 80% or more participants as essential or important to defining or conceptualising recovery are included as standard.
2. Items rated as essential or important to defining or conceptualising recovery by 70%–79% of respondents in stage 2 will be re-rated in stage 3.
3. Any statements that did not meet the above 2 conditions were excluded.

This resulted in the inclusion of 71 items, the exclusion of 30 items and 36 items to be rerated in stage 3.

#### *5.3.2.3 Stage 3:*

In stage 3, participants were asked to re-rate only those items that 70-79% of respondents had rated as essential or important during stage 2 (N=36 items). 206 participants provided contact details to be invited to take part in stage 3. The majority of participants opted to be sent a postal paper version rather than complete the questionnaire online. A total of 154 postal questionnaires were distributed in stage 3 and 52 participants were sent the online questionnaire link. Participants were also given a leaflet summarising the findings from the previous stages. 100 participants completed the final stage resulting in a further 23 statements being included and 13 statements being excluded. As in stage 2, items were included if they were rated by 80% or more participants as



essential or important to defining or conceptualising recovery. Items which did not reach this level of consensus were excluded in line with recommendations by Langlands et al (2008). The Delphi methodology utilises this process of multiple rounds and feedback of results to facilitate the establishment of expert consensus.

#### **5.4 Results**

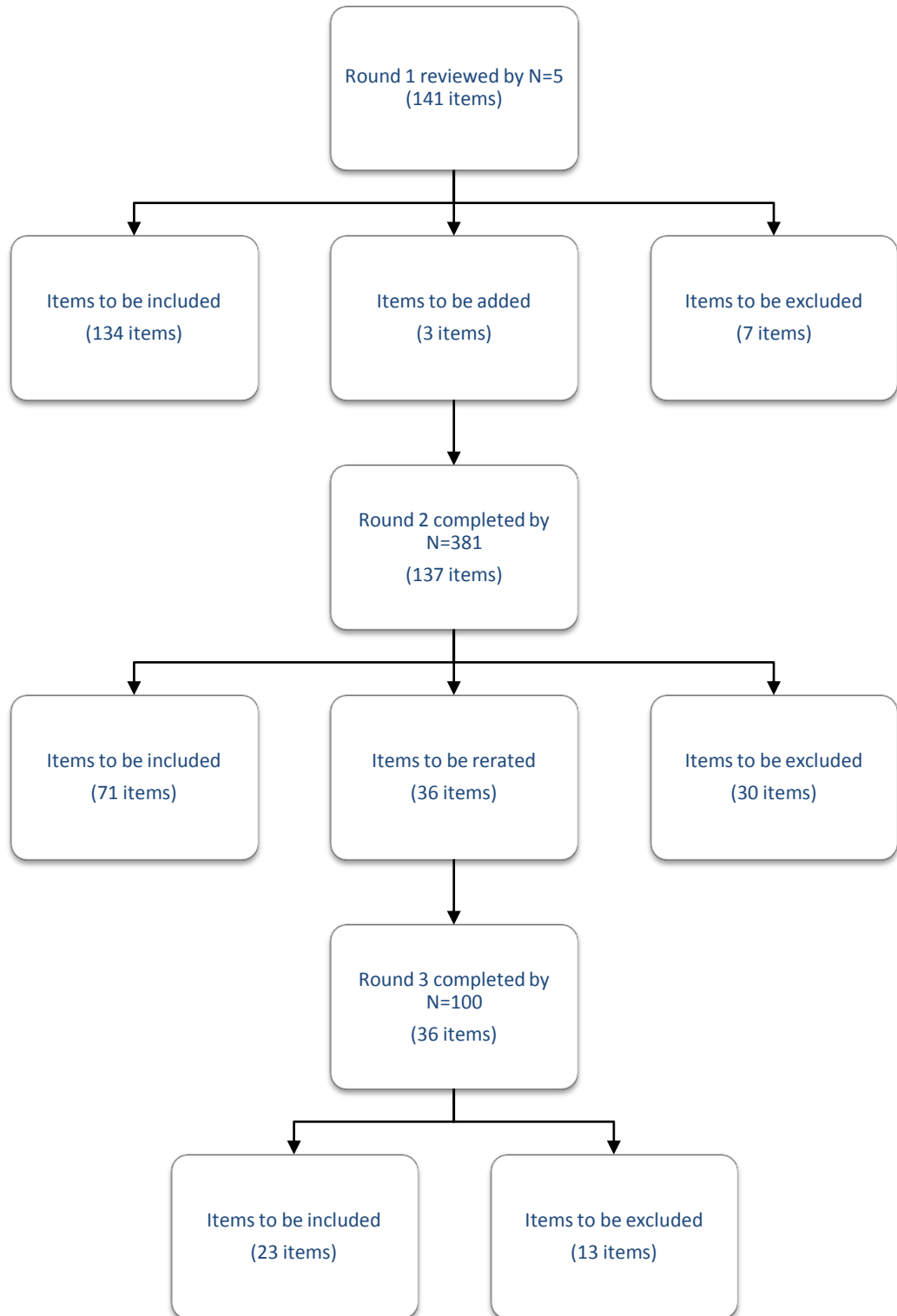
Table 9 provides an overview of the demographic information. The majority of participants were male in stage 2 (59.6%) and female in stage 3 (56%). The most common age range was 40-49 years in both stages and Schizophrenia was the most commonly reported diagnosis. Around half of participants in both stages had an established diagnosis (diagnosis given more than ten years ago).

**Table 9: Participant characteristics**

		Stage 2 (N=381)	Stage 3 (N=100)
Gender	Male	223 (59.6%)	43(43%)
	Female	151 (39.6%)	56(56%)
	Not stated	7 (1.8%)	1 (1%)
Age	17-20	7 (1.8%)	1 (1%)
	21-29	53 (13.9%)	9 (9%)
	30-39	94 (24.7%)	16 (16%)
	40-49	108 (28.3%)	29 (29%)
	50-59	72 (18.9%)	27 (27%)
	60 or older	40(10.5%)	17 (17%)
	Not stated	7 (1.8%)	1 (1%)
Diagnosis	Schizophrenia	152 (39.9%)	32 (32%)
	Bipolar disorder	66 (17.3%)	28 (28%)
	Prefer not say	62 (16.3%)	11 (11%)
	Other	26 (6.8%)	8 (8%)
	Psychosis	24 (6.3%)	8 (8%)
	Depression	20 (5.2%)	1 (1%)
	Schizoaffective disorder	16 (4.2%)	5 (5%)
	No diagnosis	15 (3.9%)	7 (7%)
Length of diagnosis	Within the last year	36 (9.4%)	5 (5%)
	1-4 years ago	64 (16.8%)	15 (15%)
	5-10 years ago	78 (20.5%)	25 (25%)
	More than 10 years ago	177 (46.5%)	50 (50%)
	Not stated/no diagnosis	26 (6.8%)	5 (5%)

A total of 94 items were retained in the final statement list after being rated as important or essential by >80% of participants. No items reached consensus for not being included (rated as should not be included by >80% of participants). Figure 2 illustrates the number of items which were included, rerated and excluded at each round of the study.

**Figure 2 Number of items included, rerated and excluded at each round of the study**



The final 94 items are shown in the respective four categories: defining recovery (n=19 items), factors that help recovery (N=43 items), factors that hinder recovery (n= 11 items) and factors that show someone is recovering (N= 21 items). Table 10, Table 11 and Table 12 show the final statements in their respective category, with percentage of participants who rated the item as essential or important. Items with extremely high consensus obtained in stage 2 (>90%) are highlighted in grey. The percentage in brackets represents the responses of participants who reported a diagnosis of schizophrenia, schizoaffective disorder or psychosis. Only one of the differences in percentage agreements between the sample as a whole and this subgroup was significant (Item "Believing that something good will happen eventually"  $\chi^2(2, N=100) = 4.822$   $P=.028$ ; indicating that this item was less important to those in this subgroup than the sample as whole). Supplementary tables show the items that were excluded.

**Table 10: Essential items for defining recovery**

<b>Item</b>	<b>Stage included</b>	<b>Percentage agreement</b>
Recovery is the achievement of a personally acceptable quality of life	2	91 (89)
Recovery is feeling better about yourself	2	91 (90)
Recovery is a return to a state of wellness	2	89 (87)
Recovery is the process of regaining active control over one's life	2	88 (86)
Recovery is being happy with who you are as a person	2	87 (86)
Recovery is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by symptoms/experiences of psychosis	2	87 (85)
Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems	2	86 (84)
Recovery is knowing that you can help yourself	2	86 (82)

become better		
Recovery is the unique journey of an individual living with mental health problems to build a life for themselves beyond illness	2	85 (82)
Recovery is learning how to live well in the context of continued mental health problems	2	84 (82)
Recovery is understanding how to control the symptoms of psychosis	2	83 (83)
Recovery is when there is meaning and purpose to life	2	83 (82)
Recovery is a process of changing one's orientation and behaviour from a negative focus on a troubling event, condition or circumstance to the positive restoration, rebuilding, reclaiming or taking control of one's life	2	83 (82)
Recovery is believing that you can meet your current personal goals	2	82 (81)
Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental health problems	3	89 (89)
Recovery is a process or period of recovering	3	88 (89)
Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles	3	88 (84)
Recovery is accepting that mental health problems/symptoms/experiences are a part of the whole person	3	86 (84)
Recovery is regaining optimum quality of life and having satisfaction with life in disconnected circumstances	3	81 (86)

**Table 11: Factors that help and hinder recovery**

<b>Items that help recovery</b>	<b>Stage included</b>	<b>Percentage agreement</b>
Having a good, safe place to live	2	96 (95)
Having the support of others	2	94 (93)
Having a good understanding of your mental health problems	2	94 (89)
Living in the kind of place you like	2	91 (92)
Knowing what helps you get better	2	91(89)
Knowing how to take care of yourself	2	91 (90)
Recognising the positive things you have done	2	90(87)
Knowing that there are mental health services that do help	2	90 (89)
Working on things that are personally important	2	89 (89)
Being strongly motivated to get better	2	89 (88)
Being able to identify the early warning signs of becoming unwell	2	89 (88)
Having a positive outlook on life	2	88 (87)
Having a plan for how to stay or become well	2	88 (87)
Having goals/purpose in life	2	87 (86)
Accomplishing worthwhile and satisfying things in life	2	87 (86)
Being able to develop positive relationships with other people	2	87 (83)
Knowing that there are things that you can do that help you deal with unwanted symptoms/experiences	2	86 (82)
Being able to handle stress	2	85 (85)
Feeling part of society rather than isolated	2	85 (83)

Being hopeful about the future	2	85 (83)
Learning from mistakes	2	85 (85)
Accepting that you may have set backs	2	85 (82)
Being able to come to terms with things that have happened in the past and move on with life	2	84 (83)
Receiving treatment for distressing/unusual thoughts and feelings	2	84 (81)
Taking medication as prescribed	2	84 (83)
Having healthy habits	2	83 (84)
Having a desire to succeed	2	82 (82)
Health professionals and service users working collaboratively as equals	2	82 (84)
Knowing that even when you don't care about yourself, other people do	2	82 (81)
Spending time with people to feel connected and better about yourself	2	82 (80)
Being able to fully understand mental health problems/experiences	2	80 (79)
Having courage	2	80 (80)
Allowing personalisation or choice within health services	2	80 (77)
Knowing that even when you don't believe in yourself, other people do	2	80 (78)
Knowing that you can handle what happens next in your life	3	90 (89)
Knowing that all people with experience of psychosis can strive for recovery	3	88 (86)
Being able to make sense of distressing experiences	3	85 (82)
Making a valuable contribution to life	3	84 (86)



Knowing that recovery from mental health problems is possible no matter what you think may cause them	3	83 (82)
When services understand/consider the culture and beliefs of the individual	3	83 (82)
Continuing to have new interests	3	81 (75)
Knowing that you are the person most responsible for your own improvement	3	80 (84)
Being able to assert yourself	3	80 (82)
<b>Items that hinder recovery</b>	<b>Stage included</b>	<b>Percentage agreement</b>
When health services do not provide help and support to recover	2	84 (83)
When a person feels lost or hopeless for much of the time	2	82 (79)
When a person feels isolated or alone even when with family or friends	2	81 (77)
When a person feels discriminated against or excluded from the community because of mental health problems	3	91 (93)
Health professionals who do not accept that their views are not the only way of looking at things	3	89 (93)
The impact of a loved one's mental health problems on their family	3	88 (82)
When a person can't find the kind of place you want to live in	3	87 (84)
When a person deliberately stopping taking medication although the doctor recommends taking it regularly	3	83 (80)
Medication that can affect concentration and memory	3	83 (87)

When no one will employ the person due to past mental health problems	3	81 (84)
When other people are always making decisions about the person's life	3	80 (80)

**Table 12 Factors that show recovery**

<b>Item</b>	<b>Stage included</b>	<b>Percentage agreement</b>
When the person is able to find time to do the things they enjoy	2	93 (93)
When the person is able to ask for help when they need it	2	92 (90)
When the person can trust themselves to make good decisions and positive changes in life	2	92 (88)
When the person knows when to ask for help	2	91 (89)
When the person is able to take control of aspects of their life	2	90 (87)
When the person feels reasonably confident that they can manage their mental health problems	2	90 (87)
When the person is able to actively engage with life	2	90(88)
When the person feels like they are coping well with mental or emotional problems on a day to day basis	2	89(88)
When symptoms/experiences of psychosis interfere less and less with daily life	2	88(87)
When the person is able to define and work towards achieving a personal goal	2	88(87)
When fear doesn't stop the person from living the life they want to	2	85(80)
When the person knows a great deal about coping	2	85(84)

strategies		
When symptoms/experiences of psychosis don't get in the way of doing things they want or need to do	2	84(83)
When the person finds places and situations where they can make friends	2	83(82)
When the person feels in touch with their own emotions again	2	83(79)
When the person knows a great deal about their own symptoms/experiences	2	82(80)
When the person knows a great deal about their treatment options	2	82(79)
When the person is able to access independent support	2	81(75)
When coping with mental health problems is no longer the main focus of a person's life	2	81(76)
When the people who are important to someone are actively supporting their mental health treatment	2	81(83)
When symptoms/experiences of psychosis are a problem for shorter periods of time each time they occur	3	85 84)

Table 13 includes a summary of the key themes arising from the consultation. Reviewing the themes from this consultation as a whole has highlighted key areas which are important to service users. The two most frequently occurring themes were knowledge and support. The knowledge theme included an understanding of mental health problems as well as coping and help seeking skills such as 'knowing what helps you get better'. The support theme included items on social support and relationships, as well as support from mental health services. Another important recovery theme was choice and control, including having control of life and symptoms, as well as control and choice surrounding treatment options. A sense of meaning and purpose also appeared to be an

important theme with items about having goals, meaning and purpose in life often being rated as important. Similarly, participants felt that quality of life, even in the context of continued symptoms and mental health problems was important. Having hope for the future and feeling positive about yourself and your future was an important theme, as well as self-esteem. Finally, having a good, safe place to live was important.

**Table 13: Summary of themes**

<b>Knowledge</b>	<b>Support</b>	<b>Control and choice</b>	<b>Meaning and Purpose</b>	<b>Quality of life</b>	<b>Hope and positivity</b>	<b>Self esteem</b>	<b>Environment</b>
<p>Good understanding of mental health problems</p> <p>Knowing what helps you get better</p> <p>Knowing how to take care of yourself</p>	<p>Support of others</p> <p>Mental health services that provide help and support</p> <p>Receiving treatment for distressing/unusual thoughts and feelings</p>	<p>Regaining active control over one's life</p> <p>Personalisation or choice within health services</p> <p>Understanding how to control the symptoms of psychosis</p>	<p>Building a meaningful and satisfying life</p> <p>Having goals/purpose in life</p> <p>Development of new meaning and purpose</p>	<p>Personally acceptable quality of life</p> <p>Regaining optimum quality of life and having satisfaction with life</p> <p>Finding time to do the things you enjoy</p>	<p>Living a satisfying, hopeful and contributing life</p> <p>Knowing that recovery is possible</p> <p>Having a positive outlook on life</p>	<p>Feeling better about yourself</p> <p>Being happy with who you are as a person</p> <p>Feeling confident</p>	<p>A good, safe place to live</p> <p>Living in the kind of place you like</p> <p>Living in a place you want to live in</p>

## **5.5 Discussion**

This is the first study to reach a consensus about understanding recovery from psychosis. It is also one of a small number of studies which consults services users as experts on their own experiences (Byrne & Morrison, in press; Langlands et al., 2008). A high level of consensus was reached for a range of items which were deemed important in defining recovery, understanding what helps and hinders recovery and what would show that someone is recovering. The findings of this study have identified areas of communality among service user definitions, which is a significant addition to the current literature since service user views have traditionally emphasised the idiosyncratic nature of recovery, and provides a pragmatic basis for service planning and provision. In line with other studies involving service user defined recovery, this study found that the concepts of rebuilding life, self and hope are essential in defining recovery (Pitt et al., 2007c). In contrast with previous studies exploring service user defined recovery, the Delphi methodology allowed collation of views from a large sample of individuals with psychosis. Although it was agreed that recovery is a unique process which is different for each individual, the Delphi method allows us to identify areas of recovery which appear to be the same for the majority of people.

Regarding definitions of recovery, the highest level of consensus was reached for "recovery is the achievement of a personally acceptable quality of life" and "recovery is feeling better about yourself". This indicates the importance of routine measures of quality of life and self-esteem when evaluating recovery orientated services, as well as a focus on working with service users to improve quality of life and esteem rather than a focus solely on symptoms and relapse prevention. Service users endorsed a number of factors which may facilitate their recovery, with the highest levels of agreement reached for environmental factors (such as a safe place to live), social support and items focussing on personal understanding of mental health problems and recovery. The role of services was also deemed to be important, although it was an awareness that there are services which can help with mental health problems which was rated the highest, rather than the impact of the services or treatments on offer per se. Personal factors such as having goals and purpose, hope for the future and motivation to succeed were also felt to be important, in agreement with previous research (Pitt et al., 2007c; Smith, 2000; Spaniol et al., 2002). There was less agreement about what factors may hinder recovery. Participants

agreed that lack of services providing help and support would hinder recovery as well as feeling lost, hopeless or isolated. Participants also highlighted stigma as a potential barrier to recovery, including discrimination such as not being able to gain employment. Interestingly, although a high proportion of people felt that not taking medication as prescribed could hinder recovery, the same proportion of people also felt that side effects of medication, such as concentration problems and memory loss, could also hinder recovery. As highlighted in previous research (Byrne, Davies, & Morrison, 2010), a choice of treatment options, as well as the cost-benefit ratio of specific interventions are important factors for services to consider. The final section of the study considered which items would demonstrate that someone is recovering. Service users felt that engaging in and enjoying activities was essential, as well as feeling able to make 'good' decisions in life. Items around effective help seeking behaviours (such as knowing when and how to ask for help) and having personal skills to manage or cope with day to day life were also important to recovery. Reduced impact of symptoms on daily life was seen as evidence of the recovery process, although this was ninth in the ranked list of factors that show someone is recovering; as such, it may be important for services to rethink their approach to viewing reduction in symptoms as a primary outcome for mental health. Participants did not feel that factors such as reduced hospitalisation or relapses were essential for demonstrating recovery.

There are several limitations to this study. Firstly, recruitment only took place across the North West of England which may mean that results are not representative of other geographical areas or cultures. Service users in different areas may have access to different types of services and have varying levels of knowledge regarding recovery (indeed, a number of postal questionnaires for this study were returned with notes about the individual's local service and mentioning that they had never heard about the potential for recovery). Future research could investigate the relationship between general awareness of recovery and personal expectations of recovery. Another limitation is the heterogeneity of diagnoses in the sample. The study was primarily aimed at individuals with experience of psychosis and as a result of initial feedback on the design of the study from a group of service users, a decision was made not to exclude participants based on diagnosis. Instead of using diagnosis as an exclusion criteria, the study asked a screening question about whether the individual defined themselves as having experience of psychosis. As can be

seen in the participant characteristics table, this resulted in individuals who had received a wide variety of diagnoses taking part in the study. Although each question reiterated that the study was asking about relevance to recovery from psychosis, it may be that participants prioritised their own experiences when thinking about the concept of recovery. However, comparisons between consensus ratings observed for the entire sample and those for participants reporting a diagnosis of schizophrenia, schizoaffective disorder or psychosis, were generally very similar and only one of the differences was statistically significant; this significant difference was found for "believing something good will eventually happen", although neither group felt that this item should be included overall. Future studies could explore differences in recovery conceptualisations and goals throughout the recovery process. The majority of participants in this study, particularly in the final stage, had established diagnoses (more than 5 years) so further investigation of the impact of length of time since diagnosis or first experience of psychosis would not have been appropriate. However, it would be useful to understand recovery for those with recent onset of symptoms and experiences compared to those with more established diagnoses and experiences. This would ensure that services are effectively geared towards their client groups. For example, early intervention services may require a different approach to mental health teams for people with more long-term difficulties.

Finally, it is possible given the nature of psychosis that cognitive impairments could have impaired the ability of participants to understand the statements presented in the questionnaire and the implications of their responses. Whilst it is possible this could threaten the validity of the study, previous research has suggested that even individuals experiencing acute psychosis retain decision making capacity (Hamann, Leucht, & Kissling, 2003).

Although research has indicated that it is essential for recovery to be defined by service users themselves, it is also important to consider the views of clinicians working in mental health services. Without agreement shared understanding between clinicians and services users, mental health services will struggle to engage and meet the needs of people with psychosis. Therefore, it would be interesting to ask clinicians to rate similar statements about recovery and examine agreement between the two groups.



There are many implications from the results of this study. Service users agreed that an awareness and understanding of recovery was essential. Collaborative approaches to training by clinicians and service users may provide a good vehicle to promote the recovery approach to a mixed audience of clinicians, service users and carers who want to understand more about recovery from psychosis. This study identifies service user priorities regarding recovery. It is apparent that less focus on reduction of symptoms, relapse and hospital admissions, in combination with a greater emphasis on improving quality of life and self-esteem, inspiring hope and facilitation of achievement of personal goals is required for truly recovery orientated services. Finally, further consideration of the measurement of recovery should be undertaken. This study is the first of its kind to approach a large group of individuals with personal experience of psychosis and ask them what they believe demonstrates that someone is recovering. This may be a useful technique to develop user informed audit tools for evaluating the effectiveness of recovery-orientated services. Identification of treatment and support priorities for recovery followed by routine measurement and audit of these priorities may indicate the effectiveness of services and enable a comparison of services to ensure that there is equality of access to high quality recovery-orientated services. There is potentially scope to utilise the items rated as essential or important within an audit tool for the benchmarking of clinical services.

Similarly, the items rated as essential or important to 'show that someone is recovering' may provide a useful tool for measuring individual recovery. Whilst there are several measures already developed for this purpose, none have undergone such an extensive process of consulting service users about relevance and importance. Such items could be used as a stand-alone tool for an individualised assessment of the recovery process or developed into a Patient Reported Outcome Measure (PROM).

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## **Chapter 6: Longitudinal predictors of subjective recovery in psychosis**

This paper has been submitted to the British Journal of Psychiatry.

## **Longitudinal predictors of subjective recovery in psychosis**

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## **6.1 Abstract**

**Background:** Research has highlighted the importance of service user defined recovery and suggests a link to negative emotion, although little is known about the role of negative emotion in predicting subjective recovery.

**Aims:** To investigate longitudinal predictors of recovery with a focus on the role of negative emotion.

**Method:** 110 participants with experience of psychosis completed measures of psychiatric symptoms, social functioning, recovery, depression, hopelessness and self-esteem at baseline and 6 months later. Structural equation modeling was utilised to examine predictive factors for recovery and negative emotion.

**Results:** Subjective recovery was predicted by negative emotion, positive self-esteem, hopelessness, and to a lesser extent by symptoms and functioning. Current recovery score was not predicted by past recovery score after accounting for past symptoms, current hopelessness and current positive self-esteem.

**Conclusions:** Psychosocial factors and negative emotion appear to be the strongest longitudinal predictors of subjective recovery, rather than psychiatric symptoms.

**Declaration of interest:** None.

## **6.2 Introduction**

Recovery in psychosis has traditionally been defined within a biomedical framework based on symptom remission, decreased hospital admissions or relapse (National Institute for Health & Clinical Excellence, 2010) or operationally defined as a return to functioning in the normal range (Torgalsboen, 1999). These approaches to understanding and defining recovery have received criticism in recent years for not taking into account the consumer perspective (Bellack, 2006). Consumers and service users define recovery as a personal journey or process (Deegan, 1988; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007a) often characterised by themes including hope, empowerment and social support (Deegan, 1988; Leete, 1989; Mead and Copeland, 2000; Pitt et al., 2007; Ralph, 2000; Ridgeway, 2001). Recent cross-sectional research has investigated factors associated with recovery and improved quality of life, demonstrating a significant role for psychosocial factors including negative

emotion (Morrison et al., 2013). However, little is known about the role of such factors in predicting subjective recovery over time. The present longitudinal study aims to investigate predictors of recovery with a particular focus on the role of negative emotion; based on an a-priori theoretical model, we hypothesised that recovery at 6 months would be predicted by recovery and negative emotion at baseline.

### **6.3 Method**

#### *6.3.1 Participants*

Participants were recruited from Early Intervention Teams, Community Mental Health Teams, inpatient settings and voluntary services across the North West of England to take part in the Recovery Research Programme. This programme of research included a randomised controlled trial of a recovery focussed intervention, a patient preference trial of recovery support and several cross sectional studies. Data from across this research programme was used in the present study. Participants were included in the dataset if they were aged 16-65; had a diagnosis of schizophrenia spectrum disorder; sufficient understanding of the English language to allow them to complete the measures and the capacity to provide informed consent. A total of 110 participants were assessed at baseline and 6 months. Average age of participants was 37.3 (SD= 11.62) and the majority of participants were White British (83.6%). Diagnoses at referral were: schizophrenia (n=50), schizoaffective disorder (n=13), persistent delusional disorder (n=7), unspecified non organic psychosis (n=4), acute and transient psychotic disorder (n=2). The remaining 30 participants had not been given a diagnosis but were experiencing psychosis. Participants were recruited from early intervention services (n=27), other community based mental health teams (n=45), and an inpatient service (n=1). Data on service type at referral was missing for 37 participants.

#### *6.3.2 Measures*

##### *6.3.2.1 The Process of Recovery Questionnaire (QPR).*

The original version of the QPR (Neil et al., 2009) is a 22 item self-report measure with two subscales which was developed collaboratively by a team of service user researchers and clinicians. Items are rated on a five point likert

scale ranging from “strongly disagree” to “strongly agree” (4) and measure key service user defined elements of recovery including hope, self-esteem, social integration and empowerment. Higher scores on the measure are indicative of recovery. A factor analysis of the psychometric properties of the QPR suggested an amended 15 item one-dimensional version of the measure provided the most interpretable and reliable solution. The 15 item total is used in this study; Chronbach’s alpha for the 15 item version in the sample used in this study is 0.947.

#### *6.3.2.2 The Positive and Negative Syndrome Scale (PANSS).*

The PANSS (Kay, Opler, & Fiszbein, 1986) is a thirty item semi structured clinical interview including 7 items to assess positive symptoms (such as hallucinations and delusions), 7 items to assess negative symptoms (such as blunted affect and emotional withdrawal) and 16 items to assess global psychopathology (such as anxiety, guilt and depression). All items are rated from 1 (not present) to 7 (severe). The PANSS has been used in a variety of studies and has been shown to have good reliability and validity (Kay, Opler, & Fiszbein, 1988).

#### *6.3.2.3 The Personal and social performance scale (PSP).*

The PSP (Morosini et al., 2000) is a measure of functioning rated by an observer across 4 domains: socially useful activities, personal and social relationships, self-care and aggression. The scale has been shown to have adequate internal consistency ( $\alpha=.76$ ) (Kawata & Revicki, 2008). Total scores range from 1 to 100 with 100 indicating no functional difficulties. The majority of participants were rated for functioning using PSP. For a small number of participants (n=27) the functioning subscale of the Global Assessment of Functioning scale (GAF) (Hall, 1995) was used instead. The GAF is also a measure of functioning which is used by an observer to rate symptoms, social, psychological and occupational functioning. Scores range from 1-100 with a score of 100 representing no functional difficulties.

#### *6.3.2.4 The Calgary Depression Scale for Schizophrenia (CDSS)*

The CDSS (Addington et al., 1990) is a nine item scale with items rated on a three point likert scale. Global scores range from 0 to 27. The scale measures items on depression, hopelessness, self-depreciation, guilty ideas of reference, pathological guilt, morning depression, early wakening, suicide, observed depression.

#### *6.3.2.5 The Beck Hopelessness scale (BHS).*

The BHS (Beck et al., 1974) is a 20 item self-report measure designed by clinicians to measure three dimensions of hopelessness: feelings of the future, loss of motivation and expectations. Statements are rated by participants as true or false for their attitudes over the last week. The psychometric properties of the BHS have been examined in various studies and the measure has been shown good reliability and validity (Dyce, 1996; Nunn, 1996; Young, Halper, Clark, Scheftner, & Fawcett, 1992)

#### *6.3.2.6 The Self Esteem Rating Scale-short form (SERS).*

The SERS (Lecomte et al., 2006) is a 20 item self-report measure assessing both positive and negative beliefs about the self. Items are rated on a 7 point likert scale ranging from "never" to "always". The scale demonstrated good internal consistency and reliability and adequate convergent validity (Lecomte et al., 2006).

#### *6.3.3 Procedure*

Data for the current study was collected as part of an NIHR funded programme of research. Recruitment took place across early intervention teams, community mental health teams, inpatient settings and voluntary services across the Greater Manchester area to ensure heterogeneity of service provision and experience of psychosis. Potential participants were approached by the care team and offered information about the study. Interested participants were given a minimum of 24 hours to read the participant information sheet and decide whether to take part. Those who agreed to take part met with a researcher to complete a consent form and the baseline study measures. The researcher then attempted to contact all participants again six months later to repeat the set of measures in a follow up assessment. Participants were recompensed for their time.

#### *6.3.4 Statistical analysis*

All models were fitted in Mplus version 7 and estimated by Maximum Likelihood. Standard errors were estimated using the Huber-White Sandwich estimator, robust to non-normality and heteroscedasticity in the outcome variables. Model log-likelihoods and the Likelihood Ratio tests were computed using Satorra-Bentler adjustments for non-normality. Nested models were compared using Satorra-Bentler corrected likelihood ratio chi-square tests.



#### *6.3.4.1 Model variables*

Variables are suffixed 1 to indicate time 1 (baseline) assessments and 2 to indicate time 2 (6 month follow up) assessments.

Core variables were recovery (REC1 and REC2) and negative emotion (Nemo1 and Nemo2). Recovery consisted of the 15 item total QPR score at time 1 or time 2 respectively. Negative emotion was a composite variable constructed by taking the mean of scores from the Calgary depression scale and the Self Esteem Rating Scale, Negative subscale. The SERS-N is scored from 10-70 whereas the Calgary scale is scored from 0-27. To avoid the composite measure being dominated by the higher scores of the SERS-N, the raw SERS-N scores were divided by 7 before taking the composite mean, which gave both contributing scales similar means and standard deviations.

Test variables included symptoms (PANSS1 and PANSS2), hopelessness (Hopeless1 and Hopeless2), Positive self-esteem (SERS-P1 and SERS-P2) and Functioning (FUNC1 and FUNC2). Symptoms consisted of a composite variable representing the overall mean of the 7 Positive, 7 Negative and 16 General PANSS scale items. Hopelessness utilised the total score from Beck hopelessness scale. Positive self-esteem used the total score from the positive subscale of the Self Esteem Rating Scale. Functioning utilised the functioning score of the PSP scale if available and the functioning subscale of the GAF if not.

Exogenous covariates measured at Time 1 included age; education or employment (emp); marital status (Mar); Religious beliefs (God) and Early intervention (Eint). All covariates except age were binary variables coded as 1 for a positive response (i.e. in education or employment; married or living with a common-law spouse; belief in the existence of a deity and recruited from an early intervention services) and 0 for negative response.

## **6.4 Results**

### *6.4.1 Sample characteristics*

Demographic characteristics of the sample are shown in Table 14. Table 15 shows scores from baseline and 6 month follow up for the sample.

**Table 14: Participant characteristics**

<b>Variable</b>	<b>%</b>	<b>N</b>
<b>Gender:</b>		
<b>Male</b>	69.1	76
<b>Female</b>	30.9	34
<b>Ethnicity:</b>		
<b>White</b>	83.6	92
<b>Asian</b>	8.2	9
<b>Black</b>	4.5	5
<b>Mixed</b>	3.6	4
<b>Marital status:</b>		
<b>Single</b>	78.2	86
<b>Married</b>	11	12
<b>Separated</b>	10.9	12
<b>Employment status:</b>		
<b>Employed</b>	7.3	8
<b>Unemployed</b>	76.4	84
<b>Student</b>	2.7	3
<b>Volunteer</b>	11	10
<b>Retired</b>	3.6	4
<b>Religious belief:</b>		
<b>None</b>	35.5	39
<b>Christian</b>	31.8	35
<b>Muslim</b>	10.9	12
<b>Other</b>	21.8	24

**Table 15: Participant scores for key measures at baseline and 6 month follow up**

	Baseline (time 1)			6 month follow up (time 2)		
	N	Mean	Std. Deviation	N	Mean	Std. Deviation
<b>GAF functioning</b>	61	44.72	10.73	57	46.98	12.98
<b>PSP</b>	147	63.63	16.71	148	85.43	121.62
<b>PANSS positive</b>	174	13.64	4.63	171	12.37	4.32
<b>PANSS negative</b>	174	12.42	3.65	171	11.84	3.78
<b>PANSS general</b>	110	27.78	6.91	108	25.10	7.09
<b>PSYRATS delusions</b>	152	9.72	6.93	169	6.91	7.21
<b>PSYRATS hallucinations</b>	152	12.75	14.33	169	9.44	13.26
<b>Calgary depression</b>	125	6.09	4.67	125	4.48	4.26
<b>QPR 15 item total</b>	173	47.46	12.39	170	56.65	11.55
<b>BHS total</b>	166	8.49	5.96	122	8.22	5.31
<b>SERS positive</b>	173	39.70	13.46	121	40.35	13.42
<b>SERS negative</b>	173	36.11	14.64	121	34.35	14.34

#### 6.4.2 Model of recovery and negative emotion

Recovery (Rec) and negative emotion (Nemo) were highly correlated at each time point ( $r = -0.66$  in both). These core constructs were entered into a cross-lagged autoregressive model, as shown in Figure 3, which for simplicity does not show these within time-point correlations. Residual variance (i.e. variance which is not explained by the model presented) for each of the endogenous variables are represented by dotted arrows. Significant predictors are depicted using solid arrows and the theoretical (but non-significant relationships) are illustrated using dashed arrows (e.g. the hypothesised predictive relationship between recovery at time 1 and negative emotion at time 2 was not supported by the statistical model and is therefore illustrated by a dashed arrow in Figure 3).

**Figure 3: Core model: recovery and negative emotion at time 2 predicted by recovery and negative emotions at time 1.**

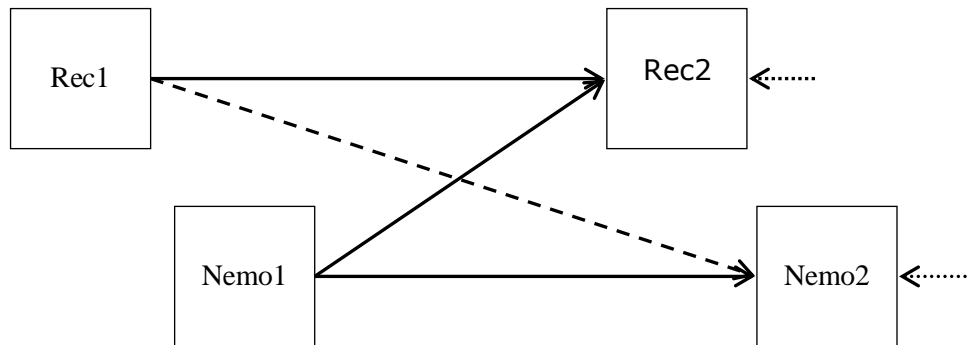


Table 16 shows the parameter estimates for this model. Both recovery and negative emotion at time 1 were significant predictors of recovery at time 2, but only negative emotion at time 1 was a significant predictor of negative emotion at time 2. The R-square for recovery at time 2 was 31.8% and for negative emotion at time 2 was 58.3%. The large R-square for negative emotion at time 2 was mainly accounted for by its relationship with negative emotion in the previous timepoint.

**Table 16: Parameter Estimates for Core Model of recovery and negative emotion**

Predictor of Rec2	B	SE	P	Beta
rec1	0.26	0.08	0.001	0.35
nemo1	-0.85	0.31	0.006	-0.27

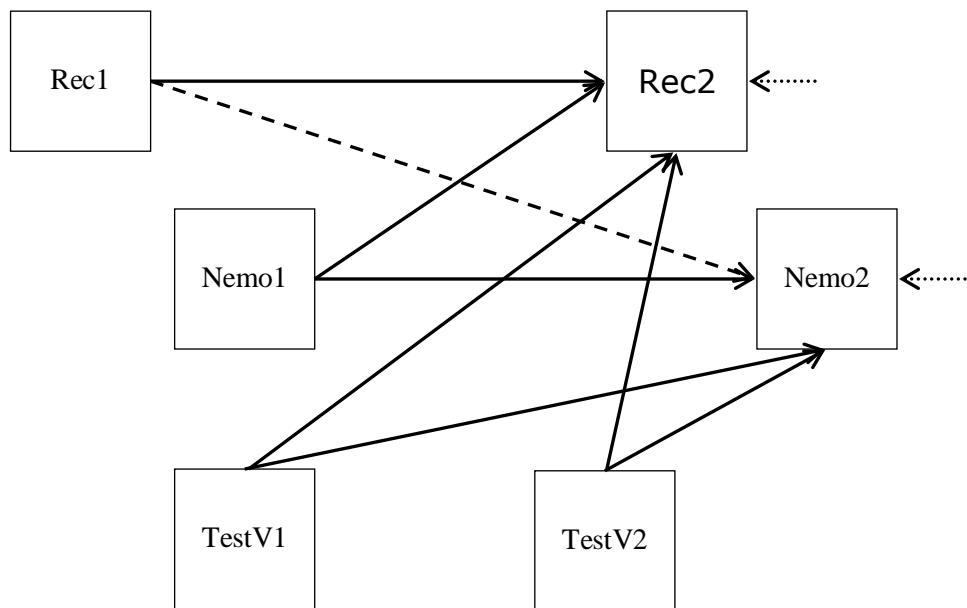
Predictor of Nemo2	B	SE	p	Beta
rec1	-0.02	0.02	0.213	-0.09
nemo1	0.64	0.07	<0.001	0.70

Note: N = 110

### 6.4.3 Further development and testing of the model

The influence of the test variables (symptoms scores, hopelessness, positive self esteem and functioning) on negative emotion and recovery was evaluated by comparing the core model of recovery and negative emotion above with each of the test models (models 2.1-2.4) described below. The fit of these nested models were formally compared using Satorra-Bentler corrected likelihood ratio chi-square tests.

**Figure 4: Models 2.1-2.5: core model with recovery and negative emotion at time 2 controlled for the effects of the test variables (M2.1 PANSS symptoms scores, M2.2 hopelessness, M2.3 positive self esteem, M2.4 functioning, M2.5 all test variables combined).**



In each test model, the core model was added to by including extra predictors of the outcome variables (recovery and negative emotion at time2). In the first test model (M2.1) overall PANSS symptom scores at times 1 and 2 were added as additional predictors. In Model M2.3 the extra predictors were the Hopelessness scores at time 1 and time 2. Positive Self-Esteem was the extra predictor in Model 2.3 and Functioning was included in Model 2.4.

Table 17 shows the results of the Likelihood-Ratio tests comparing each of Models 2.1-2.4 with the core model. All models improved significantly upon the fit of the core model, with the largest improvements seen in the prediction of recovery scores at time 2 due to Hopelessness and Positive Self-Esteem.

**Table 17: Omnibus tests comparing the fit of Core Model (M1) with the Test Models M2.1-M2.4 using Corrected Likelihood Ratio Chi-Square Tests**

	Para-meters	Model Log-Likelihood	Likelihood Ratio Chi-Square vs. M1	p for LR Chi-Square	R-square improvement
M1 compared with	9	-592.30	-	-	
M2.1 - Symptoms	13	-579.76	24.21	<0.001	Rec2 7.1% Nemo2 5.8%
M2.2 – Hopelessness	13	-576.61	32.93	<0.001	Rec2 14.3% Nemo2 4.7%
M2.3 – Positive SE	13	-578.56	22.75	<0.001	Rec2 14.1% Nemo2 3.7%
M2.4 - Functioning	13	-584.71	16.08	0.003	Rec2 7.6% Nemo2 2.6%

**Note:** All models N = 110.

A further model was then fitted, which combined the predictors that were tested separately in Models M2.1-2.4 into a single model, M2.5. The parameter estimates for M2.5 are shown in Table 18. Recovery at Time 2 was predicted by symptoms at time 1 and Hopelessness and Positive Self-Esteem at Time 2. After accounting for these influences, Recovery at Time 1 was no longer a significant predictor of Recovery at Time 2.

Negative Emotion at Time 1 was a significant predictor of Negative Emotion at Time 2, along with Symptoms, Hopelessness and Positive Self-Esteem at Time 2.

**Table 18: Parameter Estimates for Full model M2.5.**

Predictor of Rec2	B	SE	p	Beta
REC1	0.01	0.08	0.94	0.01
NEMO1	-0.09	0.38	0.81	-0.03
PANSS1	-3.49	1.56	<b>0.03</b>	-0.17
HOPE1	-0.18	0.13	0.17	-0.11
SEP1	0.00	0.07	0.98	0.00
FUNC1	-0.09	0.06	0.12	-0.15
PANSS2	-0.32	2.38	0.89	-0.01
HOPE2	-0.50	0.14	<b>0.00</b>	-0.26
SEP2	0.24	0.06	<b>0.00</b>	0.33
FUNC2	0.14	0.07	0.05	0.23

Predictor of Nemo2	B	SE	P	Beta
REC1	0.00	0.02	0.93	-0.01
NEMO1	0.57	0.07	<b>0.00</b>	0.63
PANSS1	-0.57	0.47	0.22	-0.09
HOPE1	-0.03	0.04	0.40	-0.07
SEP1	0.02	0.02	0.26	0.09
FUNC1	-0.01	0.01	0.68	-0.03
PANSS2	1.46	0.62	<b>0.02</b>	0.21
HOPE2	0.11	0.04	<b>0.01</b>	0.20
SEP2	-0.04	0.02	<b>0.02</b>	-0.19
FUNC2	0.00	0.02	0.99	0.00

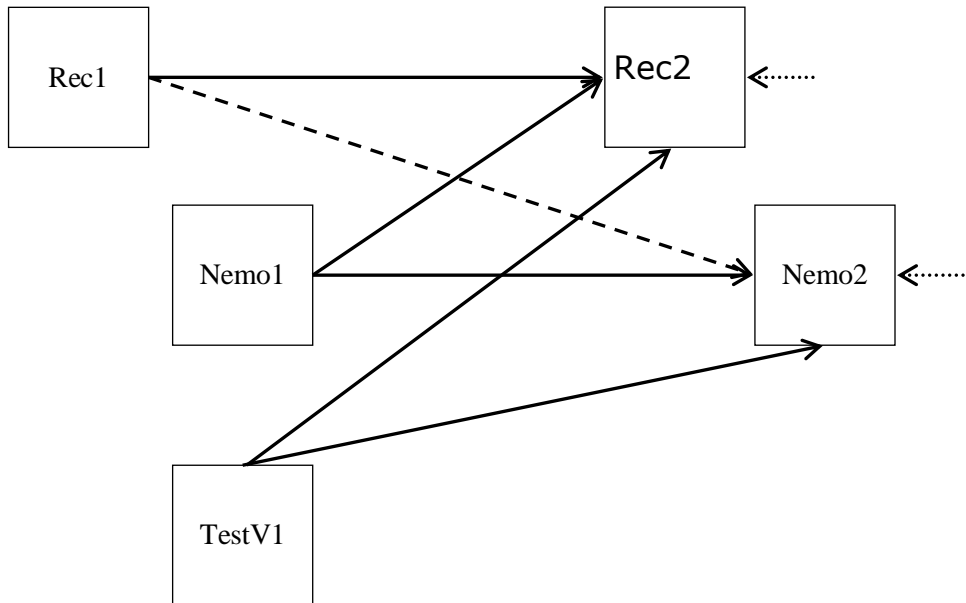
Note: N = 110.

#### 6.4.4 Checking for Endogeneity

There was a possibility that regressing closely related constructs upon one another within each data collection time point would be stretching assumptions of exogeneity with regard to these constructs. To test for this we ran a model, M2.6 Figure 5, which regressed Recovery and Negative Emotion at Time 2 on the other Variables from Time 1 only, not including the other Time 2 variables as predictors. From Table 19, we see that symptoms and positive self-esteem at Time 1 are significant predictors of Recovery beliefs at Time 2, each with broadly equal magnitude. These predictors accounted for 44% of the variance in Recovery at Time 2. By far the strongest predictor of negative emotion at time 2 is the time 1 score on this variable. No other time 1 variables were significant predictors of negative emotion at time 2. The R-square for this model was 61%.

The fact that Recovery and Negative Emotion have different sets of predictors is evidence in support of the fact that these are distinct constructs.

**Figure 5: Model 2.6: Core model with recovery and negative emotion 2 controlled for the effects of the test variables (PANSS symptoms scores, hopelessness, positive self esteem and functioning) at time 1 only.**



**Table 19: Parameter Estimates for Full model M2.6**

Predictor of Rec2	B	SE	p	Beta
REC1	0.07	0.08	0.35	0.10
NEMO1	0.08	0.41	0.86	0.02
PANSS1	-6.65	1.67	<b>0.00</b>	-0.32
HOPE1	-0.28	0.17	0.10	-0.17
SEP1	0.18	0.08	<b>0.03</b>	0.25
FUNC1	0.03	0.04	0.43	0.06

Predictor of Nemo2	B	SE	P	Beta
REC1	0.00	0.02	0.92	-0.01
NEMO1	0.58	0.09	<b>0.00</b>	0.65
PANSS1	0.61	0.44	0.17	0.10
HOPE1	-0.02	0.04	0.59	-0.05
SEP1	-0.02	0.02	0.21	-0.09
FUNC1	-0.02	0.01	0.11	-0.10

Note: N = 110

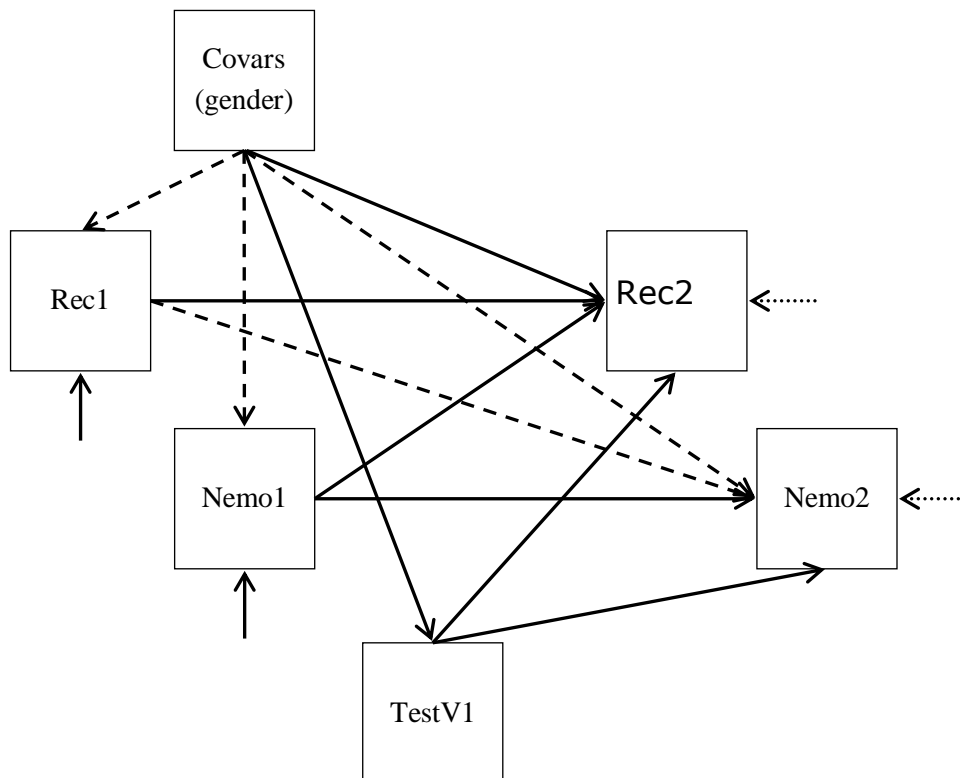


#### 6.4.5 Checking for Confounding

In the previous analyses, no attempt was made to control for the effects of potential demographic and other confounding factors. Such variables available in this study were age, gender, marital status, employment status, religious beliefs and whether the participant was drawn from an early intervention or other service. We therefore fitted the same series of models above but this time regressed the outcome variables (i.e. Rec2 and Nemo2) on these covariates. The pattern of model improvement was identical to that seen in Table 17, and the only significant potential confounder variable was gender.

We decided to fit a final model (M3 Figure 6) exploiting the fact that we could plausibly assume that gender was a truly exogenous variable and so include it as a predictor of both the time1 and time2 outcomes. The results for this model, Model M3, are shown in Table 20 below.

**Figure 6: Model 3- As Model 2.x but with Recovery and Negative Emotion at Times 1 & 2 predicted by Covariates (gender).**



**Table 20: Parameter Estimates for path Model M3.**

Predictor of Rec2	B	SE	p	Beta
REC1	0.07	0.07	0.36	0.11
NEMO1	-0.19	0.39	0.63	-0.07

PANSS1	-5.73	1.66	<b>0.00</b>	-0.32
HOPE1	-0.23	0.16	0.15	-0.17
SEP1	0.20	0.08	<b>0.01</b>	0.33
FUNC1	-0.01	0.04	0.91	-0.01
MALE	-4.33	1.37	<b>0.00</b>	-0.24

Predictor of Nemo2	B	SE	p	Beta
REC1	0.00	0.02	0.89	-0.01
NEMO1	0.55	0.09	<b>0.00</b>	0.67
PANSS1	0.74	0.43	0.09	0.13
HOPE1	-0.02	0.04	0.69	-0.04
SEP1	-0.02	0.02	0.31	-0.08
FUNC1	-0.02	0.01	0.06	-0.15
MALE	-0.58	0.43	0.17	-0.11

Outcome variables, predicted BY	B	SE	p	Beta
<b>Male</b>				
REC1	0.74	2.66	0.78	0.03
NEMO1	-1.03	0.67	0.12	-0.15
PANSS1	0.14	0.09	0.14	0.14
HOPE1	-0.69	1.31	0.60	-0.05
SEP1	4.08	2.80	0.15	0.14
FUNC1	-7.27	3.34	<b>0.03</b>	-0.22

Note: N = 110

The pattern of significant results in Model M3 is identical to that in model M2.6 with the notable addition that gender is a significant and substantial predictor of recovery score at Time 2, with men having an average recovery score four points less than women. This is despite the fact that gender was a significant predictor neither of recovery at Time 1 nor negative emotion at either time point. It was not simply the case that one of these gender effects had reached significance and the other not – a test of the difference between the effects of gender on recovery between Time 1 and Time 2 was also significant ( $p < 0.01$ ).

## **6.5 Discussion**

### *6.5.1 Main findings*

This study found that subjective recovery scores at time 2 were predicted by negative emotion, positive self-esteem, hopelessness, and to a lesser extent by symptoms and functioning at time 1. Additionally, current recovery score was predicted by current hopelessness and positive self-esteem. Current recovery score was not predicted by past recovery scores after accounting for past symptoms and current hopelessness and positive self-esteem.

The strongest predictor of negative emotion was past negative emotion, suggesting a trait-like interpretation. Other predictors of negative emotion included current scores for symptoms, hopelessness and positive self-esteem. The analysis supports the notion that recovery and negative emotion are distinct but related constructs, each with a distinct set of predictors. Additionally, the present study found that gender was a significant predictor of recovery score over time, with men having lower recovery scores than women. Gender did not predict recovery scores at baseline, or negative emotion at either time point.

#### *6.5.2 Comparison of findings with previous research*

Previous research has highlighted the importance of user defined recovery which is often characterised by themes including hope, empowerment and social support (Deegan, 1988; Leete, 1989; Mead and Copeland, 2000; Pitt et al., 2007; Ralph, 2000; Ridgeway, 2001). Several qualitative research studies have been conducted including a user-led study which revealed themes of rebuilding self, rebuilding life and hope for a better future as central to the recovery process (Pitt et al., 2007). A recent systematic review of recovery resulted in the "CHIME" conceptual framework of recovery with five core process: connectedness, hope, identity, meaning and empowerment (Leamy et al., 2011). The present study is consistent with previous studies which suggest a role for hope and self-esteem in personal recovery.

The findings from our longitudinal study replicate and extend those from cross-sectional studies. For example, Morrison et al (2013b) assessed 122 individuals with experience of psychosis and found that personal recovery ratings were directly influenced by negative emotion and internal locus of control, whilst positive symptoms and internal locus of control appeared to have an indirect effect of recovery mediated by negative emotion, which suggested that psychosocial factors were more directly related to personal recovery judgments than neuropsychiatric factors.

Similarly, these findings are consistent with those that have examined the relationship between symptom remission, functioning and psychological factors over shorter moment-to-moment timeframes. For example, a study that used an experience sampling method with 177 individuals with a diagnosis of schizophrenia (Oorschot et al., 2012) found that negative affect was significantly related to symptom remission and functioning in everyday life.

These results suggested that emotion, and particularly negative emotion, may mediate the relationship between psychological and neuropsychiatric variables and recovery. Our study suggests a key role for negative emotion in predicting subjective recovery scores over more extended time periods.

Moreover, the present study supports previous research which suggests a key role for emotion in psychosis (Freeman & Garety, 2003; Garety et al., 2001; Smith et al., 2006), and extends these findings in terms of their relevance for subjective recovery. The cognitive model of psychosis suggests that emotional changes occur within the context of psychosis like experiences (Garety et al., 2001). These emotional changes can feed into the way psychosis-like experiences are processed and appraised, maintaining their occurrence (Garety et al., 2001). Further research has supported this claim that low mood, low self-esteem and anxiety contribute to the development and maintenance of psychosis (Barrowclough et al., 2003; Hartley, Barrowclough, & Haddock, 2013; Krabbendam et al., 2005; Smith et al., 2006). The findings of the present study suggest that emotion may mediate the relationship between experiences of psychosis and subjective recovery judgments. Negative emotion could contribute to the maintenance of psychosis which will in turn impact upon the individual's quality of life, social functioning, hope and self-esteem, resulting in lower subjective recovery beliefs. Lower subjective recovery scores and recovery beliefs could be an additional perpetuating factor in psychosis.

Previous research has also investigated the role of gender in outcomes for people with a diagnosis of schizophrenia, finding that men generally have lower recovery expectations than women (Goldstein, Tsuang, & Faraone, 1989). The present study found this to be the case at Time 2 but not Time 1. This finding is intriguing because it suggests that different processes may be at work shaping the development of recovery beliefs of men and women over time. Gender was not a predictor of negative emotion at either time point, suggesting that the relationship between recovery and gender was not mediated by negative emotion. It is possible that other processes may explain these differences; for example sample selection may have played a part if males and females find their ways into services at different rates and at different stages of recovery. In addition, this research only explored demographic categories of male and female. Further research using a more sociocultural approach to examine gender roles and identity (for a review see (Nassar, Walders, & Jankins, 2002)

in relation to recovery from psychosis may improve our understanding of the role of gender in both negative emotion and recovery.

### *6.5.3 Strengths and weakness of the study*

The main strength of the present study is the longitudinal design, allowing exploration of factors which may predict recovery. However, there are a number of methodological limitations to the study. Firstly, the study used a relatively modest sample size. Further research could examine a larger group which would allow for more extensive testing with a larger number of potential predictors and parameters. Secondly, the sample was mostly male and diagnostically heterogeneous, which may mean that conceptualisations of recovery were very different within the sample. However the sample was recruited across a variety of services and settings to ensure it was representative of the target clinical population. As part of this research programme, a number of participants were also involved in randomised controlled trials of recovery focussed interventions, which may impact on the generalisability of results. Finally, although this study was fairly unique in assessing both neuropsychiatric and psychosocial factors which may predict recovery over time, the follow up period was relatively short (6 months). Further research could aim to examine the course of recovery and associated predictors over a longer timeframe.

Future research could also aim to examine the impact of insight on recovery judgements and on negative emotion. Previous research has suggested mixed results with regards to insight and recovery. For example, in one study improved insight was associated with improved outcomes (Rosen & Garety, 2005), whilst other studies have suggested that increased insight can be associated with increased negative outcomes including greater suicidality (Kim, Jayathilake, & Meltzer, 2003). Developing an understanding of the role of insight in relation to recovery and negative emotion would be beneficial.

### *6.5.4 Implications for clinical practice*

There are several potential implications from this research. Interventions which aim to reduce negative emotion whilst promoting self-esteem and hope may be beneficial to promoting recovery. Strategies such as improvement of self-esteem (Hall & Tarrier, 2003) and reduction of internalised stigma (Lucksted et al., 2011) for example may lead to improved recovery outcomes. Cognitive behaviour therapy (CBT) has been recommended in recent NICE guidelines

(National Institute for Health & Clinical Excellence, 2010) for the treatment and management of psychosis. A recent editorial on the future of CBT highlighted the need for the approach to evolve in light of our advancing understanding of the role of emotion in psychosis (Birchwood & Trower, 2006) . The present study supports this viewpoint, suggesting a key role for negative emotion in recovery outcomes which should be address in future therapeutic intervention trials.

Similarly, interventions which aim to reduce distress associated with experiences of psychosis and improve emotional processing may be of benefit. A recent study piloted a brief intervention to reduce distress associated with persecutory delusions (Foster, Startup, Potts, & Freeman, 2010; Hepworth et al., 2011). The intervention, Emotional Processing and Metacognitive Awareness (EPMA), was effective in reducing distress associated with delusions (Hepworth et al., 2011) by enhancing the emotional processing of experiences . It was suggested that worry may lead to distress by preventing emotional processing of upsetting experiences such as delusions. Consideration of other factors which may reduce distress surrounding experiences of psychosis should also be considered. For example, a current trial is investigating the impact of sleep on psychosis using a cognitive behavioural intervention for insomnia (CBT-I) (Freeman et al., 2013b). Early pilot studies of this approach have indicated improvements in sleep, as well as reduction in delusions, anomalies of experience, anxiety and depression (Myers, Startup, & Freeman, 2011). Emphasis in services should move away from purely symptom and functioning based approaches and towards a more psychosocial approach, which takes into account the key role of negative emotion on personal recovery outcomes.

## **Chapter 7: The impact of pre-existing causal models of psychosis on implicit and explicit attitudes towards recovery**

This paper has been submitted to *Psychology and Psychotherapy: Theory, Research and Practice*.

**Full title: The impact of pre-existing causal models of psychosis on implicit and explicit attitudes towards recovery**

Short title: Attitudes towards recovery in psychosis

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## **7.1 Abstract**

**Objectives:** Research indicates that optimistic attitudes towards recovery are important components of effective recovery services. There is currently a lack of research examining attitudes towards recovery in psychosis.. This study explores implicit and explicit attitudes towards recovery in a sample of health professionals and the general public. It aims to investigate these attitudes in the context of pre-existing causal attributions of psychosis and knowledge and experience of psychosis and recovery.

**Design:** This study was an anonymous online survey and computer task.

**Method:** A total of 146 participants in the United Kingdom completed a web based study including self-report measures and an implicit association test on the topic of recovery from psychosis.

**Results:** Overall, explicit attitudes towards recovery were positive, with health professionals having significantly more positive attitudes than the general public group. Greater knowledge of recovery and preference for psychosocial causal models of psychosis were found to be significant predictors of positive attitudes towards recovery.

**Conclusions** Results suggest that recovery training should focus on psychosocial causal explanations and increasing knowledge and awareness of recovery in the general public.

Declaration of interest: None

**Practitioner Points:**

- Training of health professionals should include psychosocial causal explanations of psychosis
- Promotion and awareness of service user defined recovery and psychosocial causal explanations of psychosis is essential to providing recovery orientated services.

**7.2 Introduction**

Traditionally, the medical profession was dominated by the view that schizophrenia is a disease characterised by inevitable deterioration (Frese, Knight, & Saks, 2009). During the second half of the twentieth century however, with the development of new antipsychotic medication and the advent of care in the community, a new optimism for the possibility of recovery for people with a diagnosis of schizophrenia evolved (Whitwell, 2005). Service users, some of them health professionals in their own right, became an active voice, publishing personal accounts of recovery (Frese et al., 2009). In recent decades this has become known as the 'recovery movement'; led by service users this approach moves away from a purely medical "illness model" and towards a holistic model that recognises recovery as being more than the absence of symptoms.

Health service commissioners have also recognised the need to embrace a recovery approach (Department of Health, 2009; The Future Vision Coalition, 2010). In practice, providing recovery orientated services which support people in achieving their personalised goals is complex and presents a new challenge for clinicians and commissioners alike. Effective recovery orientated practice is dependent on the attitudes and optimism of mental health professionals (Crowe, Deane, Oades, Caputi, & Morland, 2006; Social Care Institute for Excellence, 2007), with research suggesting a need to review knowledge, skills and attitudes (Clement, 1997) and re-examine roles and core training (Sowers, 2005) in order to fully embrace a recovery approach. Service users are significantly affected by interpersonal interactions including those with mental

health professionals (Tarrier & Barrowclough, 2003) and personal recovery can be facilitated or hindered by mental health providers (Crowe et al., 2006).

Previous research into the attitudes of health professionals and the general public has focussed on attitudes towards mental health problems rather than recovery. In a recent review of nineteen studies exploring attitudes towards mental illness, health professionals were found to have generally positive views about people with mental health problems, although some negative views were also elicited (Wahl & Aroesty-Cohen, 2010). A national survey found that general practitioners spend around thirty percent of their time consulting patients about mental health difficulties yet they received limited training about mental health (Mental After Care Association, 1999). Research has also suggested that GPs have less positive attitudes and are less optimistic about prognosis than clinical psychologists and psychiatrists (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999).

Some studies have suggested that attitudes of health professionals are less optimistic than the general public (Hugo, 2001). This may be because staff are more realistic due to their professional experience or have biased attitudes due to their experiences, i.e. they only come into contact with people experiencing mental health problems when they are most unwell (Jorm, Jacomb, Christensen, & al, 1999). In contrast, other studies indicate that health professionals and the general public have similar attitudes towards people with mental health problems (Lepping, Steinert, Gebhardt, & Rottgers, 2004; Nordt, Rossler, & Lauber, 2006) These attitudes are often related to the belief that people with mental health problems are unpredictable and dangerous (Angermeyer & Matschinger, 2004) leading to an increased desire for social distance (Rusch et al., 2005). Understanding these attitudes and beliefs is important in reducing stigma towards those with mental health problems (Rusch et al., 2005). Whilst many health organisations have adopted anti-stigma campaigns, health professionals are seen to be in a complex role in which they can be recipients of stigma, reducers of stigma and stigmatizers (Schulze, 2007).

Attitudes and stigma towards people with mental health problems are often related to beliefs about the underlying causes of those problems. In recent years, attempts to improve knowledge and attitudes towards mental health problems have used a medical model approach identifying schizophrenia as an

illness 'like many other medical illnesses such as cancer or diabetes' (National Alliance for Mental Illness, 2008). However, despite an increase in biological causal attributions, attitudes have not improved and current research suggests a more psychosocial approach to understanding mental health problems may be most effective (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Walker & Read, 2002).

More recently, researchers have specifically investigated attitudes towards recovery, revealing that health professionals have generally positive views about adopting a recovery approach although with an emphasis on symptom management and treatment compliance (Cleary & Dowling, 2009). A similar study found that health professionals accept the concept of personal recovery and rebuilding the self, but were less aware that recovery is an ongoing process which isn't always reflected by symptoms (Bedregal et al. 2006).

Investigating the recovery attitudes and knowledge of health professionals has led the development of new measures including the recovery attitudes questionnaire (RAQ) which has been used in several studies (Borkin et al., 2000; Crowe et al., 2006; Salgado, Deane, Crowe, & Oades, 2010), the Staff Attitudes to Recovery Scale (STARS) (Crowe et al., 2006; Oades, Crowe, Lambert, Kavanagh, & Lloyd, 2005; Salgado et al., 2010) and more recently the Recovery Knowledge Inventory (Bedregal et al., 2006; Cleary & Dowling, 2009). A weakness of all of these measures could be the use of self-reported attitudes which may be subject to response biases such as social desirability. This is especially important when considering the attitudes of mental health professionals for whom negative or stereotypical views of mental illness and recovery may be highly taboo (Lincoln et al., 2008). Implicit association tests (IAT), which use reaction times to indirectly measure attitudes and stereotypes, may be a more accurate measure in these circumstances. A common analogy used to explain the IAT methodology is sorting a deck of playing cards. Imagine you are asked to sort a deck of cards into clubs and spades on the right and hearts and diamonds on the left. These two categories of cards are easily sorted because they share a common attribute: colour. The speed at which the deck is sorted reflects the strength of the association between the categories you are asked to sort. If you are then asked to sort the deck into hearts and clubs on the right and spades and diamonds on the left, the task becomes harder and the speed of sorting deteriorates. There is no longer a shared attribute which allows the categories to be easily associated. Topics which have

been explored using the IAT include self-esteem (Greenwald & Banaji, 1995), gender stereotypes (White & White, 2006) and racial discrimination (McConnell & Leibold, 2001). Lincoln et al(2008), utilised the IAT to investigate stigma and schizophrenia and highlighted the common association between a diagnosis of schizophrenia and the concept of incurability, despite the current emphasis on recovery in mental health.

The present study explores implicit and explicit attitudes towards recovery in mental health professionals and the general public. It investigates pre-existing causal attributions of psychosis and knowledge and experience of psychosis and recovery, allowing further examination of the links between causal attributions, knowledge, experience and attitudes. The authors hypothesised that explicit recovery attitudes would be associated with greater knowledge and awareness of psychosis and recovery and a preference for psychosocial causal beliefs about psychosis.

### **7.3 Method**

#### *7.3.1 Participants*

Posters, leaflets and adverts were used over a six month period to recruit an opportunistic sample of 146 participants, predominantly from the north west of England (82%). The sample included health professionals ( $n=54$ ), students from health related disciplines ( $n= 21$ ), students from non-health related disciplines ( $n=24$ ) and the general public ( $n=47$ ). This sample was collapsed into two categories to increase statistical power and allow appropriate sample sizes for statistical analysis: general public  $n=71$  (general public and non-health students) and health  $n= 75$  (health professionals and health students). The breakdown of health professional roles can be seen in Table 21. The average age of participants was 34 in the lay sample and 29 in the health professional sample and the majority of respondents were female (75%).

**Table 21 : Breakdown of health roles**

Profession	N	%
Psychology	34	45.33
Psychiatry	1	1.33
Nursing	14	18.67
Other therapist/ Counsellor	6	8
Social work	1	1.33
Health researcher/student	15	20
Other/not stated	4	5.33

### 7.3.2 Procedure

This study was approved by the University of Manchester Research Ethics Committee. A service user reference group including 8 individuals with experience of psychosis was consulted about the design and conduct of the study. This group collectively preferred the term 'service users' and 'experience of psychosis' rather than consumers or patients and diagnostic labels so these terms of reference were used throughout the present study and this paper. A pilot study with 10 volunteers was conducted to ensure clarity of instructions and functioning of the web based method.

Participation in this study was completed via the study webpage. Participants were provided with an information sheet explaining the study. Upon the advice of the ethics committee and to allow complete anonymity, submission of responses upon completion of the study was taken as informed consent for the data to be used. Participants were free to exit the study webpage at any time without submitting their responses.

### 7.3.3 Self-report measures

Participants provided demographic information, and indicated whether they understood the terms psychosis and recovery (on a four point scale ranging from "yes I understand completely" to "no I do not understand") and whether they have professional and/or personal experience of psychosis and/or recovery (response options for personal experience included "I have personal experience" and "a friend or family member has personal experience"). Responses to these questions were used to give a composite score for knowledge and experience of psychosis and recovery.

Pre-existing causal attributions of psychosis were assessed with a questionnaire used previously by Lincoln et al. (Lincoln et al., 2008). The questionnaire included 9 statements representing 3 potential causes of psychosis which include biogenetic causes (brain disease, brain damage and genetic inheritance), psychosocial causes (stressful events, trauma and problematic childhood) and other causes (coincidence/fate, self-induced and God's will). Participants are asked to what extent they agree each statement could represent a cause of a person's experiences of psychosis and respond using a 5 point Likert scale, ranging from strongly agree to strongly disagree.

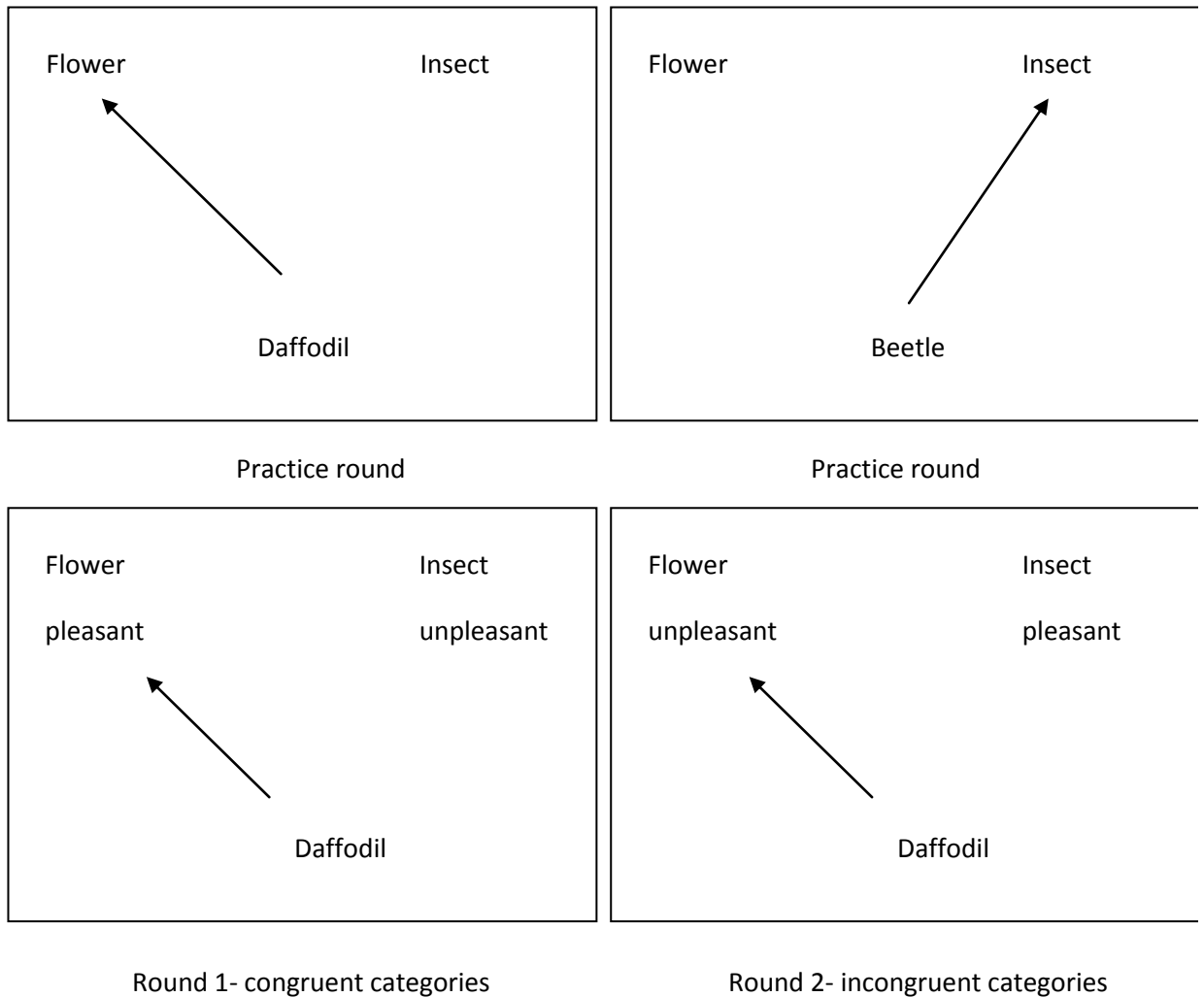
The seven item recovery attitudes questionnaire (RAQ-7) (Borkin et al., 2000) was used to measure explicit attitudes towards recovery. The RAQ was developed by service users and mental health professionals to measure respondent's attitudes about the possibility of recovery in mental health. Respondents are asked to rate the degree to which items represent their opinions. Items (e.g. "Recovery can occur even if symptoms of mental illness are present") are rated on a 5 point Likert scale ranging from strongly agree to strongly disagree. The RAQ was found to have acceptable reliability and validity (Borkin et al., 2000).

#### *7.3.4 Implicit Association Test for recovery attitudes (IAT-R)*

To assess implicit attitudes, the reaction time paradigm known as the implicit association test (IAT) (Greenwald et al., 1998) was utilised. The IAT has been used in several studies to assess attitudes which may be hidden, unidentified or not consciously accepted by the individual due to social norms and expectations. In the IAT participants are timed whilst sorting words into pairs of categories. For example, participants could be asked to sort words into four categories: flower, insect, pleasant and unpleasant. Each target word (e.g. flower, beetle, happy, rotten) matches only one category (see Figure 7 for example). Initially participants complete a practice round where only two categories are presented along with the target word to be sorted (e.g., daffodil). Following this practice round, all four categories are presented in pairs with the target words for sorting. The categories are presented in random blocks of plausibly congruent pairs (e.g. flower and pleasant) or incongruent pairs (e.g. flower and unpleasant). Reaction times are faster for congruent pairs of categories, enabling us to use reaction times as a proxy for measurement of implicit attitudes. The IAT has been shown to be more reliable and have

greater internal consistency than other implicit measures (Greenwald & Farnham, 2000).

**Figure 7: Example implicit association demonstrating 4 stages of sorting.**



The IAT was adapted to assess attitudes towards recovery (IAT-R) using a computerised task. Participants were asked to sort a series of target words into three categories ('psychosis', 'recovered' and 'not recovered'). Each target word only matches one of these three categories. This type of IAT with three categories is known as the single-target implicit association test and is useful when a comparator or opposing category is not present (in this case there is no opposing category to psychosis), because it allows the evaluation of a target attitude concept without the need to evaluate a counter category, such as black



and white or male and female (Bluemke & Friese, 2008; Wigboldus et al., 2004).

In the first round of the experiment, participants were presented with a series of word stimuli on a computer screen and asked to press the right key when the stimulus matched the category 'psychosis' or 'recovered' and the left key when the stimulus matched the category 'not recovered'. In the second round the categories were switched so that the left key was pressed when the stimulus matched 'psychosis' or 'not recovered' and the right key was pressed when the stimulus matched 'recovered'. Theoretically, sorting should be faster when the two categories which share an implicit attribute are presented on the same response key or side. Stimulus for the psychosis category were adapted from the symptom criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* and for the recovered and not recovered category, synonyms were taken from the recovery literature. This initial list of stimuli were taken to a group of service users and clinicians for discussion and consensus was reached for the stimuli to be used in the final version. The IAT-R was piloted with 10 participants to ensure the instructions were appropriate and there were no outliers in reaction times. Categories and stimuli are presented in Table 22.

Table 22: IAT stimuli

RECOVERED	NOT RECOVERED	PSYCHOSIS
Well	Unwell	Seeing things
Healthy	Unhealthy	Hearing things
Hopeful	Hopeless	Unusual thoughts
Fit	Unfit	Unusual beliefs
Better	Poorly	Bizarre behaviour
Normal	Abnormal	Paranoia
Sane	Insane	Delusions
Cured	Sick	Bizarre speech

Each block of the IAT began with instructions and a practice round. If the incorrect response was given, an error message was displayed to prompt the correct response. Stimuli were presented in random order.

#### *7.3.5 Statistical analysis*

IAT scores were calculated as a D-score using the improved scoring algorithm (Greenwald, Nosek, & Banaji, 2003) to measure individual differences between the compatible and incompatible categories corrected by the standard deviation of reaction times. Scores can range from -2 to +2 with 0 representing a neutral score and positive scores representing more positive attitudes.

Associations between attitudes, knowledge and experience and causal beliefs were examined using Pearson's correlation coefficients. Differences between associations in the participants groups were analysed using Fishers r-to-z transformations. Finally, multiple regression analysis was used to explore predictors of attitudes towards recovery.

### **7.4 Results**

#### *7.4.1 Descriptive statistics*

Scores on each measure are presented in Table 23. Overall explicit recovery attitudes were relatively high, indicating that most people had positive attitudes towards recovery from psychosis. Mean scores on the implicit attitudes test were around zero, indicating neutral implicit attitudes towards recovery.

The health professional sample had significantly more positive explicit recovery attitudes than the general public ( $t(136) = -3.852, p < .001$ ). Self-reported knowledge and experience of psychosis and recovery was significantly greater in the health professional sample ( $t(131) = -3.685, p < .001$ ). The general public endorsed significantly more 'other' causal attributions (i.e. coincidence/fate, self-induced, God's will) than health professionals ( $t(111) = -1.834, p < .05$ ).

There were no significant differences between the groups in their implicit attitudes towards recovery or biogenetic and psychosocial causal explanations of psychosis.

**Table 23: Descriptive statistics**

Measure	Scale	Total sample		Health		Lay	
		n	Mean (SD)	n	Mean (SD)	n	Mean (SD)
RAQ 7	7 to 35	140	28.78 (3.16)	69	29.78 (2.87)	69	27.80 (3.17)
Recovery IAT	-2 to +2	139	0.31 (0.95)	70	0.26 (0.92)	67	0.34 (0.98)
Self-reported knowledge and experience	0 to 16	146	7.73 (3.86)	75	8.84 (3.18)	71	6.56 (4.18)
<b>Causal explanations</b>							
Favour of biogenetic factors	-14 to +14	140	-1.64 (2.8)	69	-2.10 (3.37)	69	-1.23 (2.03)
Biogenetic causes	1-15	140	11.66 (2.18)	69	11.29 (2.69)	69	12.01 (1.49)
Psychosocial causes	1-15	140	13.31 (1.37)	69	13.39 (1.40)	69	13.25 (1.37)
Other causes	1-15	140	6.75 (2.77)	69	6.09 (2.45)	69	7.23 (2.80)

**Table 24: Relationships between measures**

	RAQ7			R-IAT			Knowledge and experience			Favour of BG over PS			BG			PS			Other		
	Total	Health	Lay	Total	Health	Lay	Total	Health	Lay	Total	Health	Lay	Total	Health	Lay	Total	Health	Lay	Total	Health	Lay
RAQ7	1.00	1.00	1.00																		
R-IAT	.005	-.069	.094	1.00	1.00	1.00															
Knowledge and experience	.435*	.397*	.368*	.055	.207	-.031	1.00	1.00	1.00												
Favour of BG over PS	-	-	-.179	-.167	-.224	-.136	-	-	-.191	1.00	1.00	1.00									
BG	.385*	.506*					.334*	.435*													
PS	-.268*	.384*	-.009	-.098	-.217	.59	-.270*	.387*	-.076	.876*	.919*	.740*	1.00	1.00	1.00						
Other	.359*	.483*	.256*	.185*	.125	.268*	.250*	.308*	.201	-	-	-	-	-	-.009	1.00	1.00	1.00			
	-.144	-.133	-.038	.049	.070	-.28	-.137	-.109	-.61	.644*	.650*	.679*	.196*	.298*							
										.191*	.224	.064	.189*	.191	.119	-.090*	-.174	.035	1.00	1.00	1.00

*Note:* Pearson correlations, 2 tailed; RAQ7= Recovery attitudes questionnaire 7, R-IAT= Recovery implicit association test; Knowledge and experience= self-reported knowledge and experience of psychosis and/or recovery; Favour of BG over PS = favour of biogenetic over psychosocial explanations of psychosis; BG = biogenetic causal explanations; PS= Psychosocial causal explanations; Other = other causal explanations (God's will, self-induced, fate/coincidence).

\*P<0.05, \*\*P<0.01

#### *7.4.2 Associations between attitudes, knowledge and experience and causal explanations*

As can be seen in Table 24, explicit attitudes towards recovery (RAQ7 scores) are significantly related to self-reported knowledge and experience of psychosis and recovery, as well as psychosocial and biogenetic causal explanations, with relatively positive (high scores on) recovery attitudes related to greater knowledge and experience and a greater preference for psychosocial causal explanations. The general public and health professional sample differed in some of the correlations between attitudes and causal attributions, therefore these results are reported separately for each group in Table 24. The differences between groups were significant according to Fishers *r*-to-*z* transformation for the correlations between: explicit attitudes and favour of biogenetic over psychosocial causal explanations ( $P < .05$ ); explicit attitudes and biogenetic causal explanations ( $P < 0.05$ ) and knowledge and experience and biogenetic causal explanations ( $P < 0.01$ ).

There was no significant relationship between preference for biogenetic causal explanations and explicit recovery attitudes in the general public. There was also a significant positive correlation between implicit attitudes toward recovery (R-IAT score) and psychosocial causal explanations in the sample as a whole. Although this relationship remained significant for the general public group, there was no significant relationship between implicit attitudes and psychosocial causal explanations for health professionals.

#### *7.4.3 Predictors of explicit attitudes towards recovery*

Significant correlations suggested that exploratory regression analysis would be useful to determine possible predictors of recovery attitudes. Variables were entered in three stages: firstly, self-reported knowledge and experience and beliefs about psychosocial causal explanations of psychosis (these variables were indicated as possible predictors by previous research); secondly, other beliefs about causal explanations (biogenetic and other causes); and finally personal and professional experiences and implicit attitudes towards recovery were entered. Variables were entered simultaneously at each stage.

As shown in

Table 25, self-reported knowledge/experience and beliefs about psychosocial causal explanations were significant predictors of explicit recovery attitudes. The first stage model was significant ( $F[2,134]=22.479$ ,  $p<.001$ ; adjusted  $R^2=.243$ ); having greater knowledge and experience of psychosis and recovery and greater beliefs about psychosocial causal explanations of psychosis predicted more positive explicit recovery attitudes. Adding biogenetic and other causal explanations of psychosis in stage 2 did not significantly improve the model ( $F[4,134]=12.122$ , ns; adjusted  $R^2=.249$ ). In stage 3, personal and professional experience of psychosis and recovery variables were added along with implicit attitudes towards recovery. This stage 3 model remained significant ( $F[9,134]=11.199$ ,  $p<.001$ , adjusted  $R^2=.407$ ) with only the psychosocial causal explanations and personal experience of psychosis variables remaining as significant predictors.

**Table 25: Multiple regression analysis: predictors of explicit recovery attitudes (RAQ7 score)**

		b	SEb	$\beta$
1	Constant	18.212	2.339	
	Self-reported knowledge and experience	.297	.064	.360***
	Psychosocial causal explanations	.626	.181	.270**
2	Constant	21.410	2.964	
	Self-reported knowledge and experience	.268	.066	.325***
	Psychosocial causal explanations	.584	.182	.251*
	Biogenetic causal explanations	-.166	.115	-.115
	Other causal explanations	-.072	.092	-.060
3	Constant	19.984	2.687	
	Self-reported knowledge and experience	.349	.251	.423
	Psychosocial causal explanations	.548	.167	.236**
	Biogenetic causal explanations	-.097	.105	-.067
	Other causal explanations	.024	.084	.020
	Personal experience of psychosis	-1.193	.412	-.366*
	Professional experience of psychosis	-.043	.421	-.016
	Personal experience of recovery	-.159	.384	.185
	Professional experience of recovery	.450	.341	-.062
	Implicit attitudes towards recovery	-.005	.233	-.002

### **7.5 Discussion**

The aim of this study was to explore attitudes toward recovery from psychosis, in the context of pre-existing beliefs about causal explanations and knowledge/experience of psychosis and recovery. In line with previous studies, health professionals were found to have generally positive views about recovery (Bedregal et al., 2006; Cleary & Dowling, 2009); however, attitudes towards recovery in the general public were less positive. Self-reported knowledge and experience of psychosis and recovery was significantly greater in health professionals compared to the general public. It may be that greater knowledge and awareness of recovery and psychosis is linked with more positive recovery attitudes.

Attributions of biogenetic and psychosocial causal explanations of psychosis were not significantly different between the two groups. The general public

endorsed more 'other'/'non-scientific' causal explanations than health professionals.

Results indicated strong associations between explicit positive attitudes towards recovery and a preference for psychosocial over biogenetic causal explanations. This was also true for implicit attitudes towards recovery; more positive implicit attitudes correlated with a greater preference for psychosocial causal explanations. Exploratory analysis suggested that predictors of recovery attitudes included participant's knowledge/experience of psychosis and recovery, and psychosocial causal attributions.

This study has a number of important clinical implications. Firstly, training of health professionals in the UK has focussed predominantly on a biogenetic approach of "schizophrenia is as an illness like others" (Read, Haslam, Sayce, & Davies, 2006), although research suggests that training including psychosocial approaches leads to reduced stereotyping (Walker & Read, 2002). Expert consensus suggests that successful CBT for psychosis requires the therapist to have a good understanding of recovery, with the assumption that experiences of psychosis are common and can be experienced by anyone during periods of extreme stress (Morrison & Barratt, 2010). In support of these findings, the present study suggests that training of health professionals should emphasise psychosocial causal explanations whilst promoting an understanding of recovery approaches.

Secondly, improving awareness of psychosis and recovery in the general public, using educational interventions targeting schools and colleges (Pinfold, Stuart, Thornicroft, & Arboleda-Flórez, 2005; Pinfold et al., 2003), could improve attitudes. The process of recovery does not happen in isolation; it happens within the context of families and communities. Knowledge and attitudes of the general public could have a huge impact on the lives of people who experience psychosis. Perhaps even more importantly, some of the young people in schools may go on to experience their first episode of psychosis; thus, changing public opinion regarding recovery and causation may benefit service users in terms of reducing public stigma and discrimination, as well as reducing the likelihood that they will internalise such stereotypes and attitudes.

The present study highlights the need for anti-stigma campaigns focussing on promotion of psychosocial explanations of psychosis. Expert consensus suggests the use of recovery-oriented messages as well as "see the person"



messages in future anti-stigma campaigns (Clement, Jarrett, Henderson, & Thornicroft, 2010). Biological models of schizophrenia, highlighting biochemical and inherited causalities, may be responsible for a “them and us” separation, with the general public believing that a ‘fixed’ genetic code or enduring chemical imbalance or “brain illness” is responsible, reducing any hope for recovery and possibly increasing stigma (Mehta & Farina, 1997). Promotion of psychosocial models of psychosis and recovery could improve attitudes and reduce stigma. A consequence of these improved attitudes towards recovery could be a greater sense of hope and optimism for those experiencing psychosis and their families, which in itself has been shown to be a vital component of user-defined recovery (Pitt et al., 2007c). An optimistic approach with an emphasis on psychosocial causation, may help both the general public and service users to view psychosis as a temporary reaction to past or current circumstances and life stresses, rather than a life-long illness that leads to inevitable decline and disability.

#### *7.5.1 Limitations and future research*

Despite the adequate sample size obtained, it is important to note that almost half of the health professional sample was from a psychology background. This may have influenced the results due the likelihood of more psychosocial training and beliefs. Similarly, participants were self-selecting and may have been biased towards those with an interest in psychosis or recovery. Recruiting a larger proportion of health professionals from more traditional medical backgrounds, including general practitioners, nurses and psychiatrists would be beneficial to compare different professions and establish if training in recovery should be tailored to particular roles. Sample sizes in the present study were not sufficient to carry out this analysis. Due to the number of statistical tests conducted, it is acknowledged that there is increased potential for type I error which could limit the robustness of findings.

In addition, the self-report questions used to measure knowledge and experience have not been used previously and are not considered a validated measure. However, for the purposes of exploring the links between attitudes and knowledge it was felt that the questions were sufficient.

Future research should explore the utility of the implicit association test to measure recovery attitudes. The present study did not find associations between the implicit and explicit measures. This may raise concerns about the

validity of the IAT; however, several studies have found no associations between implicit and explicit attitudes (Lincoln et al., 2008; Teachman & Brownell, 2001; Teachman BA, 2001). It could be argued that the lack of associations between implicit and explicit measures is due to the very nature of implicit attitudes being hidden or unwanted and therefore not reported explicitly. Further analysis of predictors of implicit attitudes were not conducted as part of this study, due to only one variable being weakly linked in zero-order correlations. Replication of the implicit methodology used in the present study would be recommended to validate the test and allow exploration of predictors of implicit attitudes.

## Chapter 8: Discussion

### 8.1 Outline of this chapter

This chapter will summarise the main findings from each of the five studies in this thesis, reflecting on the key emergent themes and wider implications of the research. The chapter will begin by providing the reader with an overview of the main aims and findings from the studies presented in the preceding chapters. Following this, the overarching themes which emerged from this thesis as a whole will be explored. In addition, the strengths and limitations of the research will be considered, along with summaries of the implications for clinical practice and future research. This thesis will conclude with a review of how this body of research has contributed to our understanding of recovery in psychosis.

### 8.2 Overview of aims and key findings

The overarching objective of this thesis was to increase our understanding of recovery in psychosis. In order to achieve this objective, five main aims were set. Each of these will be discussed below, along with the key findings. An overview of each study and the key findings can be seen in Table 26.

**Table 26: Overview of key findings from each study**

	<b>Study</b>	<b>Key findings</b>	<b>Key implications</b>
<b>Study 1</b>	User informed review of recovery measures	<ul style="list-style-type: none"><li>• RAS is the most valid and reliable tool.</li><li>• QPR is most user-friendly but requires psychometric validation.</li></ul>	<ul style="list-style-type: none"><li>• Feasible and valid measures of recovery are available</li><li>• QPR requires further psychometric evaluation</li><li>• Future studies needed to explore recovery outcome measurement over time.</li></ul>
<b>Study 2</b>	Psychometric properties of the QPR	<ul style="list-style-type: none"><li>• 15 item version of the QPR</li><li>• Scale consistent of one factor</li></ul>	<ul style="list-style-type: none"><li>• QPR as clinical utility as a measure of recovery</li><li>• Use of QPR recommended for routine practice</li></ul>
<b>Study 3</b>	Consultation on conceptualising recovery	<ul style="list-style-type: none"><li>• There is considerable overlap and consensus in service user conceptualisations of recovery</li></ul>	<ul style="list-style-type: none"><li>• Use of agreed items for service development and training of health professionals</li><li>• Identified user priorities for recovery</li></ul>

	<b>Study</b>	<b>Key findings</b>	<b>Key implications</b>
<b>Study 4</b>	Predictors of personal recovery	<ul style="list-style-type: none"> <li>Recovery scores predicted by negative emotion, positive self-esteem and hopelessness</li> </ul>	<ul style="list-style-type: none"> <li>Recovery interventions should target negative emotion</li> <li>Future research should examine predictors over a longer timeframe</li> </ul>
<b>Study 5</b>	Attitudes towards recovery	<ul style="list-style-type: none"> <li>Generally positive attitudes in health professionals and the general public.</li> <li>Psychosocial causal beliefs predicted more positive attitudes towards recovery</li> </ul>	<ul style="list-style-type: none"> <li>Training of health professionals should promote psychosocial causal explanations of psychosis</li> <li>Need to promote recovery awareness and psychosocial explanations in the general public</li> </ul>

**Aim one: To conduct a service user informed review of self-report style measures of personal recovery.**

The first aim of this thesis was to evaluate self-report style measures of personal recovery using a collaborative, standardised approach. Study one addressed this aim by inviting two service user consultants to join the author of this thesis and a clinician in the review process. This study identified six measures of personal recovery which met the stringent inclusion criteria: Recovery Assessment Scale (Giffort et al., 1995), Psychosis Recovery Inventory (Chen et al., 2005), Recovery Process Inventory (Jerrell et al., 2006), Stages of Recovery Instrument (Andresen et al., 2006), Questionnaire about the Process of Recovery (Neil et al., 2009) and the Illness Management and Recovery Scale (Mueser et al., 2006). After reviewing psychometric robustness, ease of administration, level of service user involvement during development and service-user acceptability, the Recovery Assessment Scale (RAS) was identified as the most acceptable and valid measure currently available. The Questionnaire about the Process of Recovery (QPR) was identified as being particularly user friendly and benefited from the collaborative approach with service users during the design stages of the measure. However, it was noted that the QPR had received less attention in the literature and therefore lacked further psychometric validation.

This study highlighted a total of 25 measures of recovery in the literature, demonstrating an acceptance of the recovery approach in both the academic

literature and health services. Despite this, it was also apparent that no 'gold standard' tool for measuring subjective recovery had been identified or used routinely in health services to date.

The review also found a number of themes which were common to the majority of subjective recovery measures. These themes included hope, goal orientation or purpose, confidence/empowerment, awareness/ understanding and help-seeking. These themes were found to be consistent with the literature on service user defined recovery.

This study was the first review of subjective recovery measures and provided a practical starting point for clinicians and academics when selecting the most appropriate measure for their needs. It was also the first review to incorporate service users on the reviewer panel and include their feedback in a structured way. This review contributes to the recovery literature by utilising a novel approach to evaluating recovery measures and providing information on both validity and acceptability to service users. It was hoped that publication of this review would facilitate awareness of the importance of recovery measurement and the benefits of collaboration with service users.

**Aim two: To examine the psychometric properties of one measure of personal recovery: the Questionnaire about the Process of Recovery (QPR).**

The aim of the second study was to further examine the psychometric properties of the QPR using a cross sectional sample. The first study reviewed measures of recovery and highlighted that the QPR was user friendly but lacked further investigation and validation. Based on this finding it seemed useful to conduct further analysis on the properties of the measure.

A cross sectional approach was used to gather data on the QPR and measures of associated factors including symptoms, hope, self-esteem, depression and functioning from over 300 individuals with experience of psychosis. The study found that the proposed two factor structure of the QPR was not supported. Instead, factor analysis suggested that the QPR is a uni-dimensional measure consisting of fifteen items, rather than the twenty-two items of the original version. Results indicated that the QPR is reliable, with high internal consistency and good test-retest reliability. As expected the QPR also

demonstrated good concurrent validity with other measures associated with recovery including self-esteem, depression, symptoms and hope. Regression analysis suggested factors which predicted recovery scores in this cross sectional sample, including hope, self-esteem and depression.

This study contributed to the current evidence base for the utility and validity of the QPR as a measure of subjective recovery for people with experience of psychosis. In agreement with the current literature (Ho et al., 2010; Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010; Morrison et al., 2013b), current subjective recovery scores were found to be associated with and even predicted by current self-esteem, hope and depression.

**Aim three: To consult a large group of service users about their definitions and conceptualisation of recovery in psychosis.**

The third aim of this thesis was to consult service users about what recovery means to them with the hope of achieving some level of consensus about defining and understanding recovery. Study 3 achieved this aim by utilising the Delphi methodology to consult over 300 'experts by experience' in three separate rounds. Results highlighted factors which were important to service users for defining recovery, understanding what helps and hinders recovery, and what shows that someone is recovering. Despite the current literature emphasising the idiosyncratic nature of service user defined recovery, this study found high levels of consensus (over 80% and as high as 90%) for several items indicating that there are commonalities across important areas of service user conceptualisations of recovery.

Results highlighted a central role for self-esteem and quality of life when defining recovery, as well as the importance of environmental factors (such as having a safe place to live) social support and personal understandings of mental health for facilitating recovery. Feeling lost, hopeless or isolated were found to be key elements which may hinder recovery whilst engaging in and enjoying activity alongside effective help seeking behaviours were felt to be factors which would show or demonstrate that someone is recovering.

This study is unique not only because it is the first to aim to reach consensus about recovery in psychosis, but also because it uses a large group of service users as the experts to be consulted. It provides an important contribution to

the literature on recovery and to the development of recovery orientated mental health services. It brings together all of the extant literature on recovery and refines this to factors which are important to the majority of service users.

**Aim four: To examine longitudinal predictors of subjective recovery scores.**

The fourth aim of this thesis was to investigate factors which may predict personal recovery over time. Study 4 addresses this aim using a longitudinal approach to assess personal recovery and associated factors in 110 participants at baseline and six months later. Results suggested that subjective recovery scores were predicted by negative emotion, positive self-esteem, hopelessness, and to a lesser extent by symptoms and functioning at baseline. Additionally, current recovery score was predicted by current hopelessness and positive self-esteem. Current recovery score was not predicted by past recovery scores after accounting for past symptoms and current hopelessness and positive self-esteem.

The strongest predictor of current negative emotion was past negative emotion, suggesting a trait-like interpretation. Current scores for symptoms, hopelessness and positive self-esteem were also found to predict negative emotion. The fact that negative emotion and recovery each have a distinct set of predictors supports the idea that recovery and negative emotion are distinct but related concepts.

Another interesting result from study 4 was that gender was found to be a significant predictor of recovery scores over time, with men having lower recovery scores than women. This suggests that different processes may be at work shaping the development of recovery beliefs of men and women over time. Gender did not predict recovery scores as baseline, or negative emotion at either time point, which suggests that the relationship between recovery and gender was not mediated by negative emotion. It is possible that other processes may explain these differences, for example sample selection may have played a part if males and females find their ways into services at different rates and at different stages of recovery.

This study enhances our understanding of recovery by demonstrating longitudinal relationships between recovery and associated factors. It is the first study to examine the role of negative emotion in relation to recovery in psychosis over time. It has highlighted a potentially important role for these two constructs, recovery and negative emotion, which appear to be related although distinct, as well as suggesting that the process of recovery may be different in men and women.

**Aim five: To examine attitudes towards recovery in psychosis in a sample of health professionals and the general public.**

The fifth aim of this thesis was to understand more about attitudes towards recovery in psychosis. It was important to consider the views of health professionals and the general public to get a complete picture of recovery attitudes. This study also examined factors which may be associated with attitudes, including causal beliefs about psychosis and knowledge or awareness of psychosis and recovery.

In accordance with the literature (Bedregal, O'Connell, & Davidson, 2006; Cleary & Dowling, 2009), health professionals were found to have generally positive attitudes towards recovery, although attitudes in the general public were found to be less positive. This study found a strong association between positive attitudes towards recovery and a preference for psychosocial over biogenetic causal explanations of psychosis; more positive implicit attitudes correlated with a greater preference for psychosocial causal explanations. Exploratory analysis also suggested that predictors of recovery attitudes included participant's knowledge/experience of psychosis and recovery, and psychosocial causal attributions.

The results of this study add to our understanding of general public awareness and attitudes towards recovery, as well as suggesting factors which may predict attitudes.

### **8.3 General discussion**

Although there were five distinct aims and studies within this thesis, the overarching objective was to improve our understanding of recovery in psychosis. When presented together, these findings form a body of research which appear to fall into four main themes addressing the overarching



objective. These themes are: conceptualising and defining recovery, measurement of recovery, relationships between psychological processes and recovery, and facilitating recovery. These themes will be discussed in more detail below.

### *8.3.1 Conceptualising and defining recovery*

A common theme throughout this thesis and the empirical literature is the need to define and conceptualise recovery in psychosis. As discussed in the introduction to this thesis, understandings of recovery have moved away from the more typical classifications of relapse and remission and towards a more service user defined recovery process. The existing literature has a wealth of qualitative studies and personal accounts of recovery with varying definitions and personal meanings (Deegan, 1988; Leete, 1989; Mead & Copeland, 2000; Pitt et al., 2007c; Ridgeway, 2001; Smith, 2000; Spaniol et al., 2002). Similarly, there are numerous policy documents which attempt to conceptualise recovery which are considerably broad in focus and vary throughout the documents (American Psychiatric Association, 2005; Department of Health, 2009; Mental Health Network NHS Confederation, 2012; National Institute for Mental Health in England, 2005; The Future Vision Coalition, 2010).

Commonly, an idiosyncratic approach is taken, with the implication that recovery is different for everyone (Pitt et al., 2007c). However, in order to facilitate effective service provision, a pragmatic approach to providing recovery orientated services is needed, and this requires some level of agreement regarding what recovery means to the majority of people. Identifying key overlapping or common elements of recovery definitions amongst service users is of central importance for effective recovery services.

The detailed review of the literature at the start of this thesis identified key themes of recovery such as hope, self-esteem, empowerment and quality of life. Similarly, study 1 reviewed measures of personal recovery and identified similar themes which appear to be of central importance to service user definitions of recovery: confidence/ empowerment, hope, awareness/ understanding, help seeking, goals/ purpose and support from others (Law et al., 2012). Additionally, study 2 of this thesis examined one measure of recovery, the QPR, and illustrated that the measure incorporates items with similar themes of recovery such as hope, meaning, empowerment, connectedness, identity and external support (Neil et al., 2009). An analysis of

factors associated with recovery scores on this measure identified strong correlations with symptom measures and questionnaires on self-esteem and hopelessness, which is again consistent with the current literature on service user defined recovery (Neil et al., 2009).

Although these themes are helpful for broader or more general conceptualisations of recovery, it is still difficult to identify which elements or themes are particularly important to service users, or to examine the multitude of definitions in the literature and determine which is the most acceptable and appropriate definition of recovery in psychosis for both service users and service providers. Personal accounts of recovery and qualitative studies exploring personal recovery have been present in the literature for almost three decades, and despite overlap in themes and conceptualisations of recovery, the view that recovery is an idiosyncratic process and is different for everyone (Pitt et al., 2007c) still appears to be the key message. Although this message is an important one, it seems clear that there are considerable areas of overlap in recovery in psychosis for most individuals, and understanding this overlap is essential for the development of recovery orientated services.

With this in mind, Study 3 brought together this broad range of definitions from the literature and presented them to a large group of service users, with the aim of reaching some level of consensus regarding which were the most important elements for defining recovery. A very high level of consensus (91%) was reached for two particular elements in defining recovery: "Recovery is the achievement of a personally acceptable quality of life" and "Recovery is feeling better about yourself". These two items suggest that according to service users the focus for recovery orientated services should be on quality of life and self-esteem. A further 17 items reached a high level of consensus (>80%) for defining recovery including items around being happy and satisfied, having meaning and purpose and knowing how to control symptoms.

This emerging theme of defining and conceptualising recovery in psychosis could have several important implications for clinical practice and future research. Firstly, the recovery themes and associated factors throughout this thesis replicate the existing literature and highlight the continued importance of concepts such as hope, self-esteem, goals and purpose and empowerment in recovery. In addition to this, the agreed definitions from the service user Delphi conducted in study 3, may act as a building block for services to promote a

service user defined and led recovery approach within services. Previously, services were adopting a recovery approach based a large number of studies and policy documents, all of which had varying conceptualisations of recovery. Following the consultation in study 3, it is possible to identify two key statements which a large number of service users agreed are essential to defining recovery. Using these statements, a more consistent approach to recovery orientated services would be possible, with the knowledge that this has been defined by service users adding meaning and ensuring acceptability. Working from these definitions will contribute to engagement and therapeutic relationships, guaranteeing that the service user voice has been heard. Previous research has suggested that this collaborative approach to developing and providing services is essential (Crawford et al., 2003).

Future research could examine the impact of utilising these service user definitions of recovery in clinical services and promoting awareness of methods used to agree them. Training packages for health professionals within services, and potentially service users themselves, which incorporate the agreed definitions of recovery as well as the methodology used could be trialled and evaluated as a package. Training packages would need to be easily accessible, possibly utilising web based formats and ideally delivered/designed collaboratively with service users and health professionals to facilitate maximum efficacy.

Another topic which was not been addressed within the scope of this thesis is possibility that recovery conceptualisations may differ through the course of mental health problems. For example, it may be that young people who experience a first episode of psychosis would have a different understanding of recovery than someone who was diagnosed ten or twenty years ago. Throughout the course of completing this body of work, discussions with a variety of service users have indicated this might be the case. Young people experiencing a first episode may not identify with the term 'recovery' or have the same long term goals of recovery. A future study, potentially using a similar Delphi methodology to study 3 could aim to consult a large sample of young people who are experiencing first episode psychosis or even those at risk of psychosis, to find out what they want from mental health services and whether a recovery approach is acceptable. This could then be compared with an established diagnosis group and results would allow services to be tailored towards the needs of their specific client groups.

Finally, conceptualising recovery is the first step towards providing recovery orientated services. In order to fully understand recovery it is important to consider relationships between recovery and other psychological factors. Following on from this, it will be necessary to understand more about how this conceptualisation could help with measuring recovery and facilitating recovery. This is discussed further in the remaining themes of this thesis.

### *8.3.2 Relationships between recovery and other psychological processes*

As well as demonstrating that recovery in psychosis is a distinct construct which can be conceptualised more generally than just an idiosyncratic process, this thesis has also highlighted that recovery appears to have strong relationships with other psychological processes. Understanding these relationships could facilitate a more holistic view of recovery which would be of benefit to services, health professionals and service users alike. Throughout this thesis, these studies and the associated literature have demonstrated the importance of negative emotion, optimism, self-esteem and locus of control in conceptualisations of recovery. These relationships are important to consider in the context of the existing literature.

#### *8.3.2.1 Negative emotion*

The literature suggests that emotion and affective changes are central to the development and maintenance of psychosis (Freeman & Garety, 2003; Garety et al., 2001; Smith et al., 2006). Based on this suggestion, it seems reasonable to assume that emotion also plays a key part in recovery in psychosis. This thesis provides support for this assumption, suggesting that emotion may mediate the relationship between experiences of psychosis and recovery. Clearly, if negative emotion perpetuates experiences of psychosis (Freeman & Garety, 2003; Garety et al., 2001; Smith et al., 2006), this will effect subjective recovery judgements by impacting on functioning and quality of life, as well as the individual's hope and self-esteem. Low recovery scores or beliefs could potentially create and maintain negative emotion, which could in turn contribute to the maintenance of psychosis. Understanding this relationship between recovery, psychosis and emotion could play a key part in recovery interventions.

Previous research has suggested that defeatist beliefs may mediate the relationship between negative affect, cognitive impairment and functioning

(Grant & Beck, 2009). Similar studies have found that asocial beliefs and negative expectancies predict poor social functioning (Beck, Grant, Huh, Perivoliotis, & Chang, 2013; Grant & Beck, 2010). Negative affect may increase pessimism and defeatist beliefs which could inhibit motivation, restrict functioning and consequently impair recovery. The findings in this thesis suggest that recovery interventions for psychosis should target negative emotion. This will be discussed further in 'facilitating recovery'.

#### *8.3.2.2 Locus of control and choice*

The Delphi consultation in study 3 also highlighted key psychological factors which are important to understand in relation to recovery. Control and choice was identified as an important area in recovery. Similarly, the previous literature has suggested that a more external locus of control is linked to fewer periods of recovery in both psychosis and depression (Harrow, Hansford, & Astrachan-Fletcher, 2009; Morrison et al., 2013b). Participants highlighted a need for personal control of their symptoms, but also for choice and control in relation to mental health treatment and decision making control in life more generally. It is important for recovery orientated services to consider the need for creating a greater sense of internal locus of control in these areas in order to promote recovery. This will be discussed further in the 'clinical implications' and 'facilitating recovery' sections.

#### *8.3.2.3 Causal beliefs*

Locus of control is also related to causal beliefs. Previous research has shown that biological causal attributions are often linked with beliefs that individuals with experience of psychosis have limited internal locus of control (Kent & Read, 1998). Although this thesis only examined causal beliefs of the general public and health professionals, understanding the relationships between causal beliefs, locus of control and recovery is important, particularly in light of service users highlighting that control of their own health, treatment and life generally is essential in facilitating recovery. There is potential for recovery interventions to create a greater sense of internal locus of control by promoting psychosocial causal attributions. Individuals who believe their experiences are genetically determined, or a result of chemical imbalances in the brain, are less likely to believe they have control over their mental health problems. The literature suggests that perceptions about illness are related to emotional problems and maladaptive coping skills (Barrowclough, Lobban, Hatton, & Quinn, 2001;

Lobban et al., 2004). A recent study investigating illness perceptions in relation to emotional dysfunction found similar results and suggested that clinical interventions should be recovery focussed (Watson et al., 2006). Moving away from perceptions of psychosis as a chronic and severe mental illness could improve wellbeing and emotional functioning, as well as creating a more internal locus of control and helping to reduce symptoms of psychosis.

#### *8.3.2.4 Self esteem*

Self-esteem has been identified by a number of studies in this thesis and in the psychosis literature more generally as being important in recovery (Barrowclough et al., 2003; Krabbendam et al., 2005; B. Smith et al., 2006). Research has also indicated that improved self-esteem is linked with reduction in negative symptoms and that cognitive behavioural interventions can specifically target and improve low self-esteem in people with experience of psychosis (Hall & Tarrier, 2003, 2004; Jones, Hansen, Moskvina, Kingdon, & Turkington, 2010). Study 4 of this thesis found that positive self-esteem at baseline was a significant predictor of recovery at time 2 (6 month follow up). This suggests that recovery orientated practice should include strategies (such as cognitive behavioural interventions) to improve self-esteem. Improving our understanding of the development and maintenance of psychosis in relation to self-esteem would be of benefit.

#### *8.3.2.5 Mapping onto the CHIME framework*

A recent review suggested the 'CHIME' framework of recovery: connectedness, hope, identity, meaning and empowerment (Leamy et al., 2011). The findings in this thesis map onto this framework and suggest psychological factors which may be related to these recovery processes. Social support and support from mental health services were highlighted in study 3 as key factors that would facilitate recovery in psychosis and these areas would map onto the recovery 'CHIME' process of connectedness. Hope and optimism have been emergent themes throughout this thesis and the existing literature. The identity process within the CHIME framework could be linked to self-esteem which was a significant factor in a number of the studies within this thesis. Meaning, goals and purpose were also identified in the Delphi consultation as being important facilitators of recovery and the review of recovery measures revealed that purpose and goals were a recurrent theme throughout the measures (Law et al., 2012). Finally, the CHIME framework includes empowerment. Choice and

locus of control clearly map onto this idea of empowerment. Health professionals could play a key part in developing more internal locus of control by empowering service users to be involved in decision making around treatment, as well as developing skills to enable control in daily life, which would have a direct impact on recovery.

### 8.3.3 *Measuring recovery*

A second theme to emerge from several studies within this thesis is the ongoing debate on the need to measure recovery, juxtaposed with the perceived difficulty in measuring subjective or service user defined recovery. As noted throughout this body of work, recovery is often seen as a process rather than an end point and as being idiosyncratic in nature, which creates difficulties in how we measure this individual process. As highlighted in study 1 there is a need to measure recovery and various tools have already been developed for this purpose (Law et al., 2012). The need to measure recovery is partly a result of the current ethos for service provision to be recovery orientated (American Psychiatric Association, 2005; Department of Health, 2009; Mental Health Network NHS Confederation, 2012; National Institute for Mental Health in England, 2005; The Future Vision Coalition, 2010), which in turn results in a requirement to evaluate the effectiveness of services in achieving recovery goals. However, service users have also placed emphasis on the need to develop measures which address factors that are important to them, and are personally acceptable in terms of language and content (Donnelly et al., 2011).

Study 1 reviewed 6 measures of personal or subjective recovery, highlighting the Recovery Assessment Scale (RAS) and the Questionnaire about the Process of Recovery (QPR) as particularly strong measures in terms of psychometric properties and/or acceptability to service users. However, the review also noted that the RAS has been used in several studies and has had further psychometric testing and development, whereas the (QPR) had previously had only limited psychometric testing and evaluation during the development phase (Law et al., 2012). Despite this lack of validation studies, the QPR is the only measure of its kind to be developed collaboratively with service users and in study 1, the QPR was noted as being particularly user friendly, relevant and easy to complete. Therefore, the QPR appeared to warrant further investigation of its utility and validity.

Study 2 went on to re-examine the psychometric properties of QPR, suggesting a revised 15 item, one factor version may be the most reliable and valid. In accordance with the initial study investigating the QPR (Neil et al., 2009), study 2 replicated findings that the measure demonstrated concurrent validity with associated measures and test-retest reliability. In addition to this, study 2 highlighted 7 items which did not have salient item loadings and appeared to lack face validity in terms of ambiguity of language and relevance to personal recovery (e.g. "I feel my experiences have made me more sensitive towards others" could be interpreted in several different ways due to the word 'sensitive' and is ambiguous in relation to whether this would be seen as a positive item for recovery or a negative one). Removal of these items resulted in a 15 item measure with one factor.

Building on the findings from studies 1 and 2, study 3 also addressed several important ideas about measurement of recovery by consulting a large group of service users using the Delphi method. Items from existing measures of recovery were collated into a single list. Service users were then asked to rate this list for the most important elements for 'what shows that someone is recovering'. There was a high level of consensus that engaging in and enjoying activities was important for recovery, as well as effective help seeking and feeling able to make good decisions in life. This suggests that these elements are important for the measurement of personal recovery.

All the studies in this thesis, and in the existing literature, have highlighted factors associated with and predictive of recovery. These include self-esteem, hope, quality of life and negative emotion (which included negative self-esteem and depression). It may be important for recovery measurement to include assessment of these associated factors, possibly alongside a service user informed measure of subjective recovery. Use of a recovery measure which has been collaboratively developed with service users may help initiate discussions around recovery, promote engagement and strengthen the therapeutic relationship between health professionals and service users. Indeed, previous research as suggested this is a potential strength of collaboratively developed measures (Neil et al., 2009).

Clearly, evaluation of recovery orientated services will depend of measurement of recovery related outcomes. This in turn will impact on the efficacy of such services, with improvement and service development being dependent on the



outcome measurement and evaluations. At the heart of this cycle of service commissioning, measurement, evaluation and development will be the requirement to ensure services are assessing recovery in a way that is acceptable and valid to service users who are essentially the client or consumer. The findings in this thesis suggest that use of a tool which was developed collaboratively with service users to measure subjective recovery, such as the QPR, would be the most effective approach. Results in this thesis and similar studies also suggest that measurement of factors associated with recovery, such as self-esteem, quality of life and hope, should also be considered as part of routine practice alongside the more typical functioning and symptom measures.

Another potential clinical implication surrounding measurement of recovery could be the use of a measure such as the QPR, as a Patient Reported Outcome Measure (PROM) with the possibility of standardised change scores. Utilisation of PROM's in mental health services could have positive impacts on patient care processes (Marshall et al., 2006) and to date, no recovery related mental health PROM's have been widely used and validated. Similarly, the items identified for 'what shows that someone is recovering' in study 3 as part of the Delphi consultation process, could be further investigated for validity as a measure of subjective recovery. This would require further research to test the structure of these items as measure using factor analysis, as well as examination of the concurrent validity with other similar measures such as the QPR. If these items were to form an effective measure of recovery in their own right, this could create a measure which has been fully informed by service user opinions.

Future research could test and evaluate the use of the 15 item version of the QPR in clinical services, and attempt to establish change scores within different clinical settings. It would be important to evaluate psychometric properties of the measure in these settings, including sensitivity to change, alongside gathering service user feedback on acceptability and validity. This would add weight to the potential use of the QPR or a similar measure of subjective recovery as a PROM in clinical services.

#### *8.3.4 Facilitating recovery*

As with most clinical psychology research, and indeed health research, the main goal of improving our understanding of a given topic is to better understand how we can help individuals with particular difficulties. The overarching aim of this thesis was to understand recovery in psychosis, and in doing so an emerging theme was around factors which could facilitate recovery. The existing literature, and the reviews within this thesis, all suggest factors such as hope, self-esteem and empowerment are important to recovery. Clearly, addressing these factors, as well as symptoms and associated distress are one approach to facilitating recovery. However, this thesis has highlighted a number of additional areas to consider which may also facilitate recovery.

Firstly, study 3 consulted a large group of service users about what helps and hinders recovery. Using the Delphi methodology, it was then possible to examine consensus around the items that participants felt were essential for helping recovery and in contrast, which items could hinder recovery. To date, this is the first time a large group of people with personal experience of psychosis have been asked for their views on recovery. The systematic approach used in this study allowed for a final list of items which achieved high levels of consensus to be produced. As discussed earlier, high levels of consensus were reached for environmental factors (such as a safe place to live), social support, internal locus of control and items focussing on personal understanding of mental health problems and recovery.

##### *8.3.4.1 Home environment*

Although the qualitative literature and personal accounts of recovery already suggest the importance of social support and personal understandings of recovery (Deegan, 1988; Leete, 1989; Mead and Copeland, 2000; Pitt et al., 2007; Ralph, 2000; Ridgeway, 2001), this study also highlights the importance of the home environment. It is a reasonable assumption that having a safe place to live, and a place that you like to live in, would be important for mental health and recovery. However, it is striking that 96% of the 385 participants in this study agreed that it was essential or important in recovery, which was the highest level of consensus for any of the items which facilitate recovery.

This clearly has significant implications for integrated clinical and social care services. As clinicians it is apparent that home environment and feelings of safety and security should be addressed in order to create a secure base to

work on other factors which may facilitate recovery, such as social support, engaging in activity and development of effective help seeking skills. This may mean that health professionals would discuss the service user's current feelings and concerns about their home environment and utilise a psychological approach to help manage these concerns and feelings. However, where it is not possible to establish this secure base due to the environmental context, it may be necessary to work with social care services to identify more acceptable home environments. Unfortunately, this would require considerable investment at the service planning stage, as well as potential costs of providing alternative living accommodation.

Other studies have also suggested the importance of appropriate housing for people with experience of psychosis, suggesting this as a possible area of intervention for community health services (Browne & Courtney, 2004, 2005). Development of schizophrenia has been linked to exposure to urban environments even after controlling for various confounders such as ethnicity and substance misuse (Van Os, Kenis, & Rutten, 2010). A recent meta-analysis found that an almost linear increase in incidence of schizophrenia with increase in urbanicity (Vassos, Pedersen, Murray, Collier, & Lewis, 2012). Clearly, environmental factors are of central importance when facilitating recovery in psychosis. Future research could investigate the feasibility of this approach, and conduct a cost benefit analysis of the long term effects of improving home environments on recovery in psychosis.

In addition to the more physical and pragmatic aspect of the home environment, it is also apparent that family relationships within the home may be important to consider. There is considerable evidence in the literature, particularly in relation to expressed emotion (EE), that family relationships predict outcomes following mental health difficulties (Barrowclough & Hooley, 2003; Barrowclough, Johnston, & Tarrier, 1994; Brewin, MacCarthy, Duda, & Vaughn, 1991; Butzlaff & Hooley, 1998; Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). Emotional over involvement, critical comments and hostility are just some of the behaviours and attitudes which characterise high expressed emotion (EE). Reviews and meta-analysis of studies investigating the role of EE in relapse suggested that EE was a robust predictor of relapse, with those living in high EE environments having a much higher risk of relapse (Barrowclough & Hooley, 2003; Butzlaff & Hooley, 1998). Perhaps most importantly, there is evidence that EE can be modified successfully using

psychosocial and family interventions (Barrowclough & Tarrier, 1990; Barrowclough et al., 1999; Tarrier & Barrowclough, 1990; Tarrier et al., 1988; Wearden et al., 2000). Working with families and carers of individuals with experience of psychosis within the community environment appears to be of key importance for a recovery approach.

#### *8.3.4.2 Psychological interventions*

Study 4 included a longitudinal approach to investigating predictors of recovery. The findings of this study are particularly important for facilitating recovery in clinical practice because they highlight key factors which predict subjective recovery over time. The results of the study indicated that negative emotion, positive self-esteem, hopelessness, and to a lesser extent by symptoms and functioning at baseline predict subjective recovery over time. Additionally, current recovery score was predicted by current hopelessness and positive self-esteem. This suggests that hopelessness, self-esteem and negative emotion should be targeted by clinical interventions, rather than a purely symptom and cognitive functioning approach. Interventions which aim to reduce negative emotion whilst promoting self-esteem and hope may be beneficial to promoting recovery. For example, strategies such as improvement of self-esteem (Hall & Tarrier, 2003) and reduction of internalised stigma (Lucksted et al., 2011) may be appropriate for recovery interventions.

NICE guidelines (National Institute for Health & Clinical Excellence, 2010) for the treatment and management of Schizophrenia recommend Cognitive Behaviour Therapy (CBT). However, a recent editorial on the future of CBT highlighted the need for the approach to evolve in light of our advancing understanding of the role of emotion in psychosis. Interventions which aim to reduce the distress associated with experiences of psychosis as well as improving emotional processing may be of benefit. A recent study found that a brief intervention called Emotional Processing and Metacognitive Awareness (EPMA) (Foster et al., 2010; Hepworth et al., 2011) was effective in reducing distress associated with delusions (Hepworth et al., 2011) by enhancing the emotional processing of experiences. It was suggested that worry may lead to distress by preventing emotional processing of upsetting experiences such as delusions.

Consideration of other factors which may improve quality of life and functioning should also be considered. For example, a current trial is investigating the impact of sleep on psychosis using a cognitive behavioural intervention for insomnia (CBT-I) (Freeman et al., 2013b). Early pilot studies of this approach have indicated improvements in sleep, as well as reduction in delusions, anomalies of experience, anxiety and depression (Myers et al., 2011). Emphasis in services should move away from purely symptom and functioning based approaches and towards a more psychosocial approach, which takes into account the key role of negative emotion on personal recovery outcomes.

Psychological interventions which may promote recovery are discussed in further detail in section 8.5 'implications for clinical practice'.

#### *8.3.4.3 Causal beliefs*

Study 5 investigated the impact of causal beliefs about psychosis and attitudes towards recovery. Understanding more about causal beliefs and attitudes could play a key role in facilitating recovery for people with experience of psychosis. Research suggests that biomedical causal beliefs about psychosis are linked to beliefs that individuals with psychosis have a more external locus of control and are dangerous and unpredictable (Angermeyer & Matschinger, 2004; Rusch et al., 2005). Similarly, biomedical causal attributions often go hand in hand with the belief that psychosis is severe and enduring, with poorer prognosis (Angermeyer & Matschinger, 1994). Consequently, biomedical causal beliefs are linked with increased stigma and desire for social distance (Rusch et al., 2005). On the other hand, psychosocial causal attributions are associated with less stigmatising beliefs, more optimistic prognosis and less desire for social distance (Lincoln et al., 2008).

The study in this thesis specifically investigated attitudes and causal beliefs in a sample of health professionals and the general public. In both groups, attitudes towards recovery were predicted by the participant's knowledge/experience of psychosis and recovery, and psychosocial causal attributions rather than biogenetic ones. Improving awareness and knowledge of psychosis and recovery could be an important step towards improving attitudes. Similarly, promotion of psychosocial causal attributions could lead to improved attitudes towards recovery. Training of health professionals in the UK and other countries has focussed predominantly on a biogenetic approach of "schizophrenia is as an illness like others" (Read et al., 2006). Previous research suggests that training

including psychosocial approaches leads to reduced stereotyping (Walker & Read, 2002) and the present study extends this finding to suggest that psychosocial approaches to training may also improve attitudes towards recovery.

Similarly this study has also highlighted that improving awareness of psychosis and recovery in the general public, using educational interventions targeting schools and colleges (Pinfold et al., 2005; Pinfold et al., 2003), could improve attitudes. Improving attitudes could play a central role in facilitating recovery. It is clear that social support is important in recovery and the process of recovery does not happen in isolation; it happens within the context of families and communities. Perhaps even more importantly, some of the young people in schools may go on to experience their first episode of psychosis; thus, changing public opinion regarding recovery and causation may benefit service users in terms of reducing public stigma and discrimination, as well as reducing the likelihood that they will internalise such stereotypes and attitudes. Future research could investigate the efficacy of psychosocially informed psychosis and recovery education packages for young people and communities and explore the impact of these on attitudes towards recovery.

As well as recognising the importance of attitudes and beliefs in health professionals and the general public, it is also important to consider the impact of recovery attitudes and causal attributions in individuals who experience psychosis. The causal beliefs of patients have also been linked to engagement and treatment response. Individuals who report a more psychological view of their difficulties are more likely to engage in CBT and have better outcomes, even after accounting for severity of their difficulties and insight (Freeman et al., 2013a). The studies in this thesis and the existing literature suggest that recovery orientated services and interventions should consider the relationship between causal beliefs and treatment engagement and outcomes. Promotion of psychological understandings of difficulties should facilitate engagement with interventions and be linked to more positive outcomes.

#### *8.3.4.4 Locus of control*

Freeman et al. (2013a) also demonstrated that beliefs around personal control were linked with more progress during the course of the CBT. The Delphi consultation in this thesis also highlighted that service users feel that control and choice is important for facilitating recovery. Recovery orientated services

and interventions should aim to facilitate a more internal locus of control. The literature suggests that internal locus of control is associated with fewer relapses and higher rates of recovery (Harrow et al., 2009; Morrison et al., 2013b). Facilitating treatment choice and empowerment via recovery service could be one approach. Additionally, in light of our advancing understanding of the importance of causal models, services could also promote more psychologically informed causal attributions which could in turn facilitate a more internal locus of control.

#### *8.3.4.5 Implications for future research and clinical practice*

The main clinical implications for facilitating recovery which have emerged from this thesis are the need to focus on and target recovery priorities from the service user perspective, alongside addressing factors such as locus of control, self-esteem, depression and hope as part of clinical practice. In doing so, clinical services can ensure they are tailored to understand and suit the needs of their client group. This will also promote positive relationships between service users and health professionals via the shared understanding of recovery goals. It is clear that emotion plays a key role in recovery outcomes suggesting a need to reduce depression and negative self-esteem, or conversely promote positive self-esteem and hope using psychologically informed practice. Future research could aim to combine these approaches to create a recovery intervention package. Developing this package collaboratively with services users and piloting within a range of services would be advantageous.

### **8.4 Strengths and limitations**

The methodologies employed throughout this thesis have a number of advantages and disadvantages that need to be considered before making any firm conclusions or generalisations from the findings. Whilst these are discussed in detail in each of the respective chapters of this thesis, it is acknowledged that a detailed critical analysis of methodology is not usually within the scope of a peer reviewed journal article, due to limited word counts. Therefore, the strengths and limitations of the approaches used throughout this thesis will be discussed.

#### 8.4.1 *Key strengths*

Firstly, the reviews and studies within this thesis when taken together as a single body of research utilise a 'multi-method' approach. This has included a structured user-informed review, cross-sectional and longitudinal methods, service user Delphi consultation, survey methods and a web based experimental task. The varied advantages of these methods contribute to the thesis as a whole, providing a converging, holistic investigation of the topic of recovery in psychosis. The cross-sectional studies allow for examination of concurrent relationships between recovery and associated factors such as hope self-esteem and negative emotion, whilst the longitudinal approach enables further investigation of the temporal relationships between these factors.

Perhaps one of the main strengths of this body of research is the emphasis on service user understandings of recovery. Although this strength is often present in the recovery literature, the author has attempted to combine this emphasis for service user involvement and service user defined recovery with the need for pragmatic conclusions that can be used to inform current practice and service delivery. All of the studies within this thesis were developed with input from a service user reference group who commented on the design, materials and conduct of the studies. In addition to this, two individuals with experience of psychosis were invited to collaborate on the review of subjective recovery measures. Similarly, the Delphi method was adapted in study 3 to use 'experts by experience' rather than the more typical use of key academics and clinicians in the field. It is hoped that this collaborative and service user informed approach has resulted in findings and conclusions which stay true to the service user led movement in recovery and would therefore be acceptable to service users, whilst also providing added value by interpreting and refining these principles in a way that can contribute to developing recovery orientated ,evidence based practice within mental health services.

In addition, the studies within this thesis have used a number of measures which encapsulate service user defined recovery, more traditional symptoms and functioning based recovery, and a range of psychosocial questionnaires which measure concepts which have been shown to be important in recovery such as self-esteem, hopelessness and depression. This has enabled a quantitative investigation of the concurrent associations between recovery and related concepts, as well as examination of the longitudinal relationships between these factors. It is fairly unique in the literature to find measures of



both neuropsychiatric and psychosocial variables, particularly in relation to recovery, which is a key advantage to the studies within this thesis.

Similarly, when taken as a collective body of research, this thesis has included samples of health professionals, the general public and individuals with personal experience of psychosis. A key benefit of including such a range of samples is the possibility of incorporating the often unique viewpoints of each group to provide an integrated, synthesised understanding of recovery. Recovery in psychosis does not happen in isolation; individuals with experience of psychosis are part of the wider community and are often in contact with mental health professionals. This means that each group should be considered as key stakeholders, and consequently their views should be taken into account to provide a comprehensive understanding of the topic.

#### *8.4.2 Limitations*

Despite the strengths and advantages listed above, it is also important to discuss some of the limitations of the studies which should be considered prior to making conclusions about this thesis and the implications for future theory and practice.

Firstly, although a range of methods have been utilised to investigate recovery from psychosis including examination of associations and temporal relationships between recovery and associated factors, there is a lack of investigation of causal relationships. Although the studies described in this thesis allow us to infer temporal and potential causal relationships, it is not possible to directly observe causality and direction of causality cannot be reliably established. This means it is not possible to determine whether decreased negative emotion leads to increased recovery scores or whether there is a more dynamic or bidirectional relationship.

Similarly, in study 5, we cannot confirm that causal explanations lead to particular attitudes towards recovery or whether the attitudes towards recovery lead to particular causal explanations. To confirm these types of questions, future research could include an experimental study or an interventional study which could target negative emotion directly and observe the impact of this intervention on recovery. Similarly, an intervention aimed at modifying causal beliefs could be tested and the impact on attitudes could be observed.

Another limitation to be considered is the participant samples within the studies and the methods used to recruit them. The samples used throughout this thesis

were essentially self-selecting which may have introduced bias. This could provide alternative explanations for the results found in this thesis. For example, in study 5 it could be that the health professionals and general public who chose to be involved were individuals who had a particular interest in recovery in psychosis, and hence had generally positive attitudes. The study did attempt to account for this possibility by asking about individual's experience and knowledge of recovery and psychosis, but only a small variance in knowledge and experience was observed within the health professional and general public groups. Similarly, study 3 may have attracted service users who had particularly strong views about recovery and a result were keen to be consulted. This may have reduced generalisability due to a lack of participants who had limited knowledge or less strong views on recovery.

Moreover, the samples in studies 2 and 4 often consisted of individuals referred by their care teams. This may have led to biases in the recruitment process, with care teams selecting individuals whom they believed were suitable or appropriate for the research studies. This would limit the generalisability of results. Similarly, as described in the methodology chapter of this thesis, recruitment was facilitated via two clinical trials which again could be seen as biasing the sample to individuals who are actively help seeking, able and willing to commit to a trial for a considerable number of months and are deemed suitable for a research trial by their care team. This could lead to a sample of participants with particular unique characteristics (such as motivated or high functioning individuals) and consequently reduce the generalisability of results.

Additionally, study 3 and 5 used a convenience sample with some data collected via a web based format. Whilst this approach has advantages in terms of practicalities such as efficiency, low burden for participants and potential for anonymity, it also eliminates the possibility of validating diagnosis with care teams, or checking job role and other demographics. Whilst anonymity is often viewed positively by participants and may allow more honest responses, it reduces control and validation of inclusion and exclusion criteria. Use of convenience sampling in study 5 was a particular limitation especially for the health professional group within the sample. This group primarily consisted of psychology and nursing professions. A more selective or purposive sampling could have enabled investigation of the attitudes of a range of health professionals, including psychiatrists and general practitioners. This could have

increased generalisability of results to other health professionals, as well as enabling comparisons to be made between different health professional groups.

A final limitation with respect to the samples used in this thesis was the lack of specific early intervention sample. The majority of participants in studies 2, 3 and 4 were recruited from community mental health teams, were aged over 35 or reported being given a diagnosis over 5 years ago. This suggests that the findings presented in this thesis are relevant only to those individuals with more longstanding experiences of psychosis. It could be that recovery in the early stages of psychosis, for example for those being supported by early intervention teams, is conceptualised quite differently. Although some individuals who took part in the studies within this thesis were recruited from early intervention teams, the groups were too small to allow any comparative analysis. Future research could aim to investigate the acceptability of the recovery approach to this group, and explore variations in understandings and priorities for recovery in this group compared with a more established diagnosis group.

An additional limitation throughout the studies within this thesis is the use of self-report measures. The literature suggests self-report measures can be prone to missing data (Fox-Wasylyshyn & El-Masri, 2005), for example if a participant doesn't understand the question or chooses not to answer due to distress or concerns around privacy. Furthermore, self-report measures are also limited by social desirability bias, where the participant may respond inaccurately in order to appear more socially acceptable (Holtgraves, 2004). As with the majority of psychological research, problems of demand characteristics (McCambridge, de Bruin, & Witton, 2012) and over or underreporting of results may also influence the results. Whilst the author acknowledges this is a potential limitation of the findings in the present thesis, this is often the case with psychological research.

The author also acknowledges the problem of using new measures which have not been previously validated. Study 5 used a novel adaptation of the implicit attitudes test to assess implicit attitudes towards recovery. The stimulus in this task were adapted from previous implicit tasks and steps were taken to pilot the task and ensure stimulus were appropriate. However, the very nature of implicit reaction time paradigms mean it is inherently difficult to assess validity. For example, new measures are usually used alongside other measures

assessing similar concepts so that concurrent validity can be examined. However, whilst lack of associations with other measures (such as the explicit attitudes measures) may indicate the test is unreliable or lacks concurrent validity, it could also mean that there are hidden or implicit attitudes which other measures are not sensitive too. For the purposes of study 5 it was an interesting addition to a basic attitudes and awareness survey. The findings of generally neutral attitudes towards recovery within the sample as whole, and strong associations between psychosocial causal beliefs and positive implicit attitudes suggests the measure may have some validity. Interestingly, although it is difficult to evidence the utility of the implicit association test as an accurate measure of implicit attitudes towards recovery, the author received a huge amount of interest from health professionals who wanted to know what the results showed about their recovery attitudes or feedback that the study 'made them think' about their own beliefs and attitudes. It may be that this computer task has utility as a training tool, to engage health professionals in conversations about recovery and associated beliefs.

As discussed earlier in thesis, longitudinal studies are essential to allow examination of relationships over time. Although the current thesis did include a longitudinal study, the follow up time was relatively short at six months. In order to fully understand relationships between recovery and associated factors, as well as factors which may predict recovery, future research should aim to include a longer follow up period.

In addition to the limitations discussed above, it is acknowledged that missing data may have limited statistical power, increased the possibility of type II error and resulted in a biased sample. Missing data was not imputed for any of the studies within this thesis; rather cases were deleted in SPSS where data was missing for 20% or more items on particular scale. In cases where less than 20% of items on a scale were missing, responses were pro-rated. Whilst acknowledging that this is a limitation of studies 2 and 4, it is also important to note that priorities must be with reducing participant burden and ensuring that all participation and responses to each question are voluntary. Longitudinal studies and research trials can be particularly high burden for participants, and this is a key ethical consideration for any such research.

Finally, as with any research all findings should be considered in light of the possibility that other unmeasured or observed variables could have an impact

on key 'outcome' measures. In the case of this thesis, there are other factors which could potentially have impacted on recovery beliefs, conceptualisations and outcomes such as insight into mental health problems, experience of stigma, social exclusion and other co morbid mental health problems amongst a wealth of other factors. Future research could build upon the findings of this thesis and incorporate other areas such as stigma and insight.

## **8.5 Implications for clinical practice**

Potential implications for clinical practice have been discussed throughout this thesis within the respective chapter for each study, and in the general discussion. An overview of these implications will be discussed below to allow the reader to consider the key implications from the thesis as whole.

### *8.5.1 Planning and commissioning recovery orientated services*

Key policy documents have demonstrated support, enthusiasm and optimism for recovery orientated services both in the UK and other countries (American Psychiatric Association, 2005; Department of Health, 2009; Mental Health Network NHS Confederation, 2012; National Institute for Mental Health in England, 2005; The Future Vision Coalition, 2010). Despite this drive for services to become more recovery orientated, there often seems to be a lack clarity and consensus about what exactly we mean by recovery and consequently, services provision is diverse and lacking equity. In order to move forward, it is necessary to adopt a more consistent approach to services with an agreed understanding of exactly what a recovery orientated service should look like. The Delphi study (study 3) has the potential to refocus and refine our understanding of recovery in psychosis. There were two key statements in this study which a large number of service users agreed are essential to defining recovery: "Recovery is the achievement of a personally acceptable quality of life" and "recovery is feeling better about yourself". The knowledge that this has been defined by a large group of service users adds meaning and ensures acceptability. Planning and commissioning of services by working from service user agreed definitions will contribute to engagement and therapeutic relationships, guaranteeing that the service user voice has been heard and lead to more acceptable and effective services. A collaborative approach to service development and planning is essential.

Another key point to arise from the studies in this thesis is the need for continued investment into integrated clinical and social care services. Home environment was demonstrated to have a key role in facilitating recovery. This suggests health care professionals may need to work with social care services to identify more acceptable home environments. Unfortunately, this would require considerable investment at the service planning stage, as well as potential costs of providing alternative living accommodation for those deemed to be living in particularly unsuitable environments. Further research and a cost benefit analysis would be advisable.

#### *8.5.2 Recovery orientated training for health professionals*

Training packages for health professionals within services, and potentially for service users themselves, which incorporate the agreed definitions of recovery could be trialled and evaluated as a package. Training packages would need to be easily accessible, possibly utilising web based formats and ideally delivered/designed collaboratively with service users and health professionals to facilitate maximum efficacy.

Study 5 suggested that, promotion of psychosocial causal attributions could lead to improved attitudes towards recovery. Training of health professionals in the UK and other countries has focussed predominantly on a biogenetic approach of "schizophrenia is as an illness like others" (Read et al., 2006). Previous research suggests that training including psychosocial approaches leads to reduced stereotyping (Walker & Read, 2002) and the present study extends this finding to suggest that psychosocial approaches to training may also improve attitudes towards recovery.

Equally, education and training packages which include the promotion of the conceptualisations of recovery as defined by the service users who took part in the Delphi consultation (study 3) should ensure consistency in the recovery approach and provide a firm basis for health professionals to work from.

#### *8.5.3 Recovery awareness training for the general public*

This thesis has also suggested that improving attitudes of the general public could play a central role in facilitating recovery. Individuals who experience psychosis are part of a wider community and it is clear that social support is

important in recovery. The process of recovery does not happen in isolation; it happens within the context of families and communities.

Study 5 within this thesis suggested that the general public have significantly less positive attitudes towards recovery than health professionals. This was linked with less knowledge and awareness of recovery in psychosis. Improving awareness and knowledge of psychosis and recovery could be an important step towards improving attitudes. Educational interventions targeting schools and colleges (Pinfold et al., 2005; Pinfold et al., 2003), could provide a logically starting point. Perhaps even more importantly, some of the young people in schools may go on to experience their first episode of psychosis; thus, changing public opinion regarding recovery and causation may benefit service users in terms of reducing public stigma and discrimination, as well as reducing the likelihood that they will internalise such stereotypes and attitudes.

#### *8.5.4 Recovery interventions: targeting negative emotion, improving quality of life, locus of control, self-esteem, and facilitating effective help-seeking*

Hopelessness, low self-esteem, external locus of control, and negative emotion have been highlighted in this thesis as potential targets for clinical interventions which are recovery orientated, rather than a purely symptom and cognitive functioning approach. Interventions which aim to reduce negative emotion whilst promoting self-esteem and hope may be beneficial to promoting recovery. Strategies such as improvement of self-esteem (Hall & Tarrier, 2003) and reduction of internalised stigma (Lucksted et al., 2011) for example, may lead to improved recovery outcomes. There is clearly a need to focus on and target recovery priorities from the service user perspective, alongside addressing factors such as control, self-esteem, depression and hope. In doing so, clinical services can ensure they are tailored to understand and suit the needs of their client group. This will also promote positive relationships between service users and health professionals via the shared understanding of recovery goals. Participants highlighted a need for personal control of their symptoms, but also for choice and control in relation to mental health treatment and decision making control in life more generally. It is important for

recovery orientated services to consider the need for creating a greater sense of internal locus of control in these areas in order to promote recovery.

It is clear that emotion plays a key role in recovery outcomes suggesting a need to reduce depression and negative self-esteem, or conversely promote positive self-esteem and hope using psychologically informed practice. A recent review suggests the future of interventions for psychosis lies in targeting one causal factor or mediator at a time (Garety & Freeman, 2013). Indeed, recent interventional trials targeting single factors such as worry (Foster et al., 2010) or reasoning biases (Waller, Freeman, Jolley, Dunn, & Garety, 2011) in patients with persecutory delusions have demonstrated encouraging results whilst current trials are targeting sleep in patients with psychosis (Freeman et al., 2013b) Emphasis in services should move away from a purely symptom reduction and cognitive functioning based approach and towards a more psychosocial approach, which takes into account the key role of negative emotion on personal recovery outcomes. Interventions should identify areas which are most distressing to service users, placing their experiences at the heart of therapy and targeting individual factors which may be mediating or maintaining the distress around particular experiences.

Effective help seeking behaviours were also highlighted by service users as being important in recovery. Factors such as being able to ask for help and knowing when to ask for help were essential. This is particularly important in early intervention in psychosis, where around a third of the duration of untreated psychosis is accounted for by poor help seeking (Birchwood et al., 2013). Interventions aimed at improving help seeking for depression and anxiety have been successful in promoting positive attitudes towards help seeking, although it is unclear whether this leads to help seeking behaviours (Gulliver, Griffiths, Christensen, & Brewer, 2012). Similar studies, perhaps incorporating peer/service user led interventions, for people with experience of psychosis would be beneficial.

#### *8.5.5 Evaluating recovery orientated services*

The final step in applying the recovery model to services is to ensure that we evaluate effectiveness of services by measuring recovery and recovery related outcomes. This would form part of a constant cycle of service development where services are planned and commissioned, implemented and evaluated



before further development and planning as necessary. At the heart of this cycle will be the requirement to ensure services are assessing recovery in a way that is acceptable and valid to service users who are essentially the client or consumer. The findings in this thesis suggest that use of a tool which was developed collaboratively with service users to measure subjective recovery, such as the QPR, would be the most effective approach. Results in this thesis and similar studies also suggest that measurement of factors associated with recovery, such as self-esteem, quality of life and hope, should also be considered as part of routine practice alongside the more typical functioning and symptom measures currently used.

Use of a Patient Reported Outcome Measure (PROM) with the possibility of standardised change scores should be considered. Utilisation of PROM's in mental health services could have positive impacts on patient care processes (Marshall et al., 2006) and to date, no recovery related mental health PROM's have been widely used and validated. The QPR could be considered for this purpose, or the items identified for 'what shows that someone is recovering' in study 3 as part of the Delphi consultation process, could be further investigated for validity as a measure of subjective recovery. This would require further research to test the structure of these items as measure using factor analysis, as well as examination of the concurrent validity with other similar measures such as the QPR. If these items were to form an effective measure of recovery in their own right, this could create a measure which has been fully informed by service user opinions.

## **8.6 Future research proposals**

Ideas for future research have been discussed throughout studies 1-5 and touched upon throughout this thesis. Several overarching future research ideas are apparent from this thesis as a whole, and these will be discussed in more detail below. More generally, this thesis and the current literature has highlighted that research into recovery should be collaboratively designed and carried out with service users and professionals. Indeed the Schizophrenia Commission (2012) highlighted the importance of service user involvement for recovery: "valuing their experiences and making their preferences central to a recovery focused approach adopted by all services". Similarly the British Psychological Society (2000) note that "service users should be acknowledged

as experts on their own experiences". A key point for future research will be to continue working with service users in designing and conducting research that will help improve mental health services.

#### *8.6.1 Developing and evaluating recovery orientated training packages for health professionals*

One of the clinical implications arising from this thesis is the need for better and more widespread recovery orientated training which includes a variety of approaches to understanding the causes of psychosis, with particular emphasis of psychosocial causes. Study 5 suggested that this type of training may be helpful in promoting more positive attitudes toward recovery in psychosis.

However, this would need further research to design and implement such a training package, before evaluating efficacy in improving awareness and attitudes towards recovery. Working collaboratively with service users and health professionals to develop a package of training which incorporated the findings from the Delphi consultation about conceptualisations of recovery, along with information about causality in psychosis would be the first stage of such a research proposal. This could be followed up by piloting the packages to determine the most effective and accessible formats to achieve the learning objectives.

Evaluation of this training package would require assessment of knowledge, beliefs about causality and attitudes both before and after such a package of training. Quantitative and qualitative exploration of feedback from the training would be essential to develop the most effective training.

#### *8.6.2 Developing and evaluating recovery awareness packages for the general public*

Similarly, this thesis has highlighted a potential lack of knowledge and awareness in the general public about psychosis and recovery. Improving awareness and knowledge of the topic in the general public, for example using educational interventions targeting schools and colleges (Pinfold et al., 2005; Pinfold et al., 2003), could improve attitudes. Improving attitudes of the general public could play a significant role in facilitating recovery.

Further assessment of what the general public understand about recovery in psychosis, and particularly what young people know, could be hugely important

for developing communities which are positive about recovery. We know that some of these young people may go on to experience a first episode of psychosis, so early awareness training which promotes the possibility of recovery and facilitates positive, normalising attitudes towards recovery in psychosis could be instrumental in fostering their own recovery at a later date.

Again, further consultation with the general public and particularly young people would be recommended to inform the development of awareness and education programmes. Research could consider how to make this information easily accessible, such as using school and college programmes as an access point, or using visual and web based formats. Evaluating awareness and education packages and determining whether they have an impact on attitudes towards recovery in psychosis would be an interesting and potentially valuable research exercise. Randomly assigning groups of young people to receive either the recovery in psychosis awareness package, or an alternative control package, followed by assessment of attitudes in the two groups would demonstrate whether such an approach could impact on attitudes. It would also be interesting to investigate whether this would have an impact on early help seeking by young people who experience psychosis, possibly by presenting the two groups with hypothetical vignettes of a young person experiencing psychosis-like symptoms and asking what actions they would recommend to that young person. If a small scale study were to demonstrate a positive impact on young people's attitudes and awareness, or increase the likelihood of early help seeking, training packages could be rolled out amongst a bigger group of young people, with a programme of ongoing development and evaluation.

### *8.6.3 Exploring recovery in young people*

Another point which has been touched upon throughout this thesis, is the possibility that recovery conceptualisations differ through the course of mental health problems. For example, a young person experiencing a first episode may not identify with the term 'recovery' or have the same long term goals of recovery. A future study, potentially using a similar Delphi methodology to study 3 could aim to consult a large sample of young people who are experiencing first episode psychosis or even those at risk of psychosis, to find out their priorities and preferences for mental health services and whether a recovery approach is acceptable to this group. This could then be compared

with an established diagnosis group and results would allow services to be tailored towards the needs of their specific client groups. Additionally, qualitative studies could be used to generate information from young people who have experience of psychosis about what they understand about recovery or indeed how they would like to conceptualise the goal of their contact with services. It may be conceptualisations and priorities would overlap considerably with the findings in this thesis, although in all likelihood there will be at least some subtle differences between what young people want compared with adults or those with more long standing mental health problems. Issues around identity, stigma and social functioning may be even more significant to this age group. Qualitative explorations, potentially using a grounded theory approach, could be a useful starting point. Following this, a more widespread consultation perhaps via young people in contact with early intervention teams to examine goals and priorities would be beneficial, and could potentially inform a model for what a recovery orientated approach might look like for this client group, allowing more tailored services to be provided.

#### *8.6.4 Recovery focussed Patient Reported Outcome Measures (PROMs)*

One of the key points to emerge throughout the studies in this thesis is the requirement for recovery orientated service to evaluate their performance using appropriate recovery focussed measures which have been developed collaboratively with service users. Study 1 and 2 of this thesis put forward a case for use of the Questionnaire about the Process of Recovery (QPR) to be used as a Patient Reported Outcome Measure (PROM) with the possibility of establishing standardised change scores. Utilisation of PROM's in mental health services could have positive impacts on patient care processes (Marshall et al., 2006) and to date, no recovery related mental health PROM's have been widely used and validated. Future research should test and evaluate the use of the 15 item version of the QPR in a larger sample and perhaps its routine use within clinical services. This could help to establish normalised scores and standardised change scores within different clinical settings. It would be important to evaluate psychometric properties of the measure in these settings, including sensitivity to change, alongside gathering service user feedback on acceptability and validity. Use of the measure in future clinical trials could also provide information to further validate the psychometric properties, adding weight to the use of the QPR or a similar measure of subjective recovery as a PROM in clinical services.

As noted earlier, those looking to improve measurement of recovery in services could also consider using the items from 'what shows that someone is recovering' in the study 3 Delphi consultation process. This would require further research primarily to test the structure of these items as measure using factor analysis, as well as examination of the concurrent validity with other similar measures such as the QPR in a large sample. If these items were to form a valid and reliable measure of recovery in their own right, this could create a measure which has been developed using opinions from a large group of service user.

#### *8.6.5 Developing and evaluating recovery based interventions*

Finally, the primary aim of improving our understanding of recovery in psychosis should always be to improve services and interventions which may help people to recovery. A significant future research proposal could be to utilise the information contained in this thesis about recovery and the associated factors and predictor to inform a recovery based intervention. A recovery based intervention should aim to reduce negative emotion whilst promoting internal locus of control, self-esteem and hope. Strategies such as improvement of self-esteem (Hall & TARRIER, 2003) and reduction of internalised stigma (Lucksted et al., 2011) along with a psychological approach to reducing negative emotion would be necessary.

Any research proposal would need to consider developing this package collaboratively with services users and clinicians, and piloting within a range of services. Evaluation of this type of intervention could be small scale in the first instance, possibly using a case series approach to develop and pilot an intervention with a small number of participants and gain qualitative feedback. The aim would then be to move to a pilot randomised controlled trial to examine feasibility and conduct a preliminary exploration of the efficacy of such an intervention. Outcome measures could include the QPR and well as other areas identified by service users as important to recovery, such as hope, control, self-esteem and depression.

## **8.7 Conclusions**

Throughout this body of work it is apparent that the key feature of the recovery approach in psychosis is the need to consider and listen to service users, putting them at the heart of future research and clinical services, and recognising them as experts on their own experience. Embodiment of the recovery approach can empower service users and create an inherent optimism within clinical services. However, it is clear that this optimism is sometimes tainted by ambiguity about the recovery conceptualisation and concerns around how this approach can be utilised in services and how we can demonstrate its efficacy. It is hoped that this thesis has added to the current recovery knowledge base by attempting to find a balance between the ideology of the service user orientated and led recovery movement, and a pragmatic approach which can be effectively adopted within clinical services. This has included reaching consensus about what recovery means to individuals with experiences of psychosis, so that health professionals and clinical services can ensure they have shared understandings and expectations with service users. This thesis has also attempted to determine some of the key psychological processes in recovery, including the importance of causal beliefs, locus of control and negative emotion. Finally, recommendations for the measurement of recovery have been included to enable services to collaboratively monitor progress and outcomes. The work within this thesis is a starting point for future explorations of recovery in psychosis.

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## **Appendix 1: Questionnaire about the Process of Recovery (QPR)**

### **The Process of Recovery Questionnaire (the QPR): Guidelines for Clinicians, Researchers and Service Users for the uses, administration and scoring of the QPR**

*Developed by: Sandra Neil, Liz Pitt, Martina Kilbride, Anthony Morrison, Sarah Nothard, Mary Welford and William Sellwood in collaboration with The Bolton Salford and Trafford Service User Steering Committee*

**What is the QPR?** The QPR is a 22-item measure developed from service users' accounts of recovery from psychosis in collaboration with local service users. The idea of the QPR is to ask people about aspects of recovery that are meaningful to them. The QPR is reliable and valid and is strongly associated with general psychological wellbeing, quality of life and empowerment all of which are crucial in recovery from psychosis. There are two subscales: 1) intrapersonal tasks involved in recovery and 2) interpersonal factors that facilitate recovery (see below).

#### **What are the applications of the QPR?**

- **Clinical practice:** Because the QPR asks about aspects of recovery that are important to service users this measure could help to facilitate communication and engagement. The QPR may be used to illustrate to people that other individuals progressed to achieve similar goals and this positive message might instil hope, which is crucial to recovery.
  - The QPR could be used both as a tool for setting goals for individual outcomes and as a measure of achievement of these individual goals. For example, the QPR could be used to help people open up, give them structure and offer a focus for individual goals they could work towards and then be used to track progress and provide evidence of this.
  - The sensitivity of QPR is currently being evaluated, to assess the QPR's use as a measure of service effectiveness and as a routine outcome measure.
- **Research:** It is suggested that researchers could use the QPR to expand and add to the evidence base in the area of recovery

**How do I administer the QPR?** The service users involved in the development of the QPR suggest that before administering the QPR clinicians or researchers using this measure should ensure that:

- All service users who are asked to complete the QPR are given general information (as above) about the measure and are provided with an explanation as to why they are being asked to complete this questionnaire, such as “It is hoped through asking you to complete this measure that we can identify the areas in your life where things are going well and also any areas where you might be having difficulties.”
- All service users must give their written or verbal consent to complete the QPR
- The QPR should where possible be completed with another professional or person with whom they can discuss any issues raised.
- The QPR should be used judiciously and responsibly by clinicians, and service users who are in crisis and / or very distressed **should not** be asked to complete the QPR
- The QPR should not be used in a sterile manner, but rather as a vehicle to facilitate discussion about individual goals.

**How do I score the QPR?** The QPR has 22 items each scored on a 4-point scale (0= disagree strongly, 1=disagree, 2=neither agree nor disagree, 3=agree, 4=agree strongly). The intrapersonal subscale includes items; 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 18, 19, 21, 22. The interpersonal subscale includes items: 14, 15, 16, 17, 20 (highlighted in grey on the QPR). Higher scores are indicative of recovery. However, those involved in developing this measure suggest that subscale or total scores should not only be added to give total recovery scores, but the QPR should be used as described above e.g. as a tool for engagement, setting goals relative to the individual and as a measure of outcome for these.

**PLEASE TURN OVER THE PAGE AND CONTINUE OVERLEAF**

## The Process of Recovery Questionnaire (QPR)

[15/10/2007- Version 1]

We developed this questionnaire in order to understand more about the process of recovery; what's helpful and what's not so helpful.

Everyone is different and there will be differences for everyone. The items on this questionnaire were developed through a process of interviewing service users about their recovery journeys. We hope that by filling in this questionnaire you will help us find out information that is important to you and your own recovery. Not all factors will be important to you, since everyone is different. This questionnaire is not intended to be used to impose anything against your wishes.

If you would like to fill in the questionnaire, please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements by putting a tick in the box which best describes your experience.

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
1. I feel better about myself					
2. I feel able to take chances in life					
3. I am able to develop positive relationships with other people					
4. I feel part of society rather than isolated					
5. I am able to assert myself					
6. I feel that my life has a purpose					
7. My experiences have changed me for the better					
8. I have been able to come to terms with things that have happened to me in the past and move on with my life					
9. I am basically strongly motivated to get better					
10. I can recognise the positive things I have done					
11. I am able to understand myself better					
12. I can take charge of my life					
13. I am able to access independent support					
14. I can weigh up the pros and cons of psychiatric treatment					
15. I feel my experiences have made me more sensitive towards others					
16. Meeting people who have had similar experiences makes me feel better					
17. My recovery has helped challenge other peoples views about getting better					
18. I am able to make sense of my distressing experiences					
19. I can actively engage with life					
20. I realise that the views of some mental health professionals is not the only way of looking at things					
21. I can take control of aspects of my life					
22. I can find the time to do the things I enjoy					

**Thank you for completing this questionnaire**

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## **Appendix 2: Psychotic Symptom Rating Scales (PSYRATS)**

### DELUSIONS: SCORING CRITERIA

#### **1. AMOUNT OF PREOCCUPATION WITH DELUSIONS**

How much time do you spend thinking of your beliefs?  
- all the time / daily / weekly etc.?

0. No delusions, or delusions which the subject thinks about less than once a week.
1. Subject thinks about beliefs at least once a week.
2. Subject thinks about beliefs at least once a day.
3. Subject thinks about beliefs at least once an hour.
4. Subject thinks about delusions continuously or almost continuously.  
Subject can only think about other things for a few seconds or minutes.

#### **2. DURATION OF PREOCCUPATION WITH DELUSIONS**

When the beliefs come into your mind, how long do they persist?  
-Few seconds/minutes/hours, etc.?

0. No delusions
1. Thoughts about beliefs last for a few seconds, fleeting thoughts
2. Thoughts about delusions last for several minutes
3. Thoughts about delusions last for at least one hour
4. Thoughts about delusions usually last for hours at a time

3. **CONVICTION** (at the time of interview)

**RECORD FOR EACH DELUSION**

At the present time how convinced are you that your beliefs are true? Can you estimate this on a scale from 0 – 100, where 100 means that you are totally convinced by your beliefs and 0 being that you are not convinced at all?

0. No conviction at all
1. Very little conviction in reality of beliefs, less than 10%
2. Some doubts relating to conviction in beliefs, between 10-49%
3. Conviction in belief is very strong, between 50 – 99%
4. Conviction is 100%

4. **AMOUNT OF DISTRESS**

Do your beliefs cause you distress?  
How much of the time do they cause you distress?

0. Beliefs never cause distress
1. Beliefs cause distress on the minority of occasions.
2. Beliefs cause distress on less than 50 % of occasions
3. Beliefs cause distress on the majority of occasions when they occur between 51-99% of time
4. Beliefs always cause distress when they occur

5.

**INTENSITY OF DISTRESS**

When your beliefs distress you, how severe does this feel?

0. No distress
1. Beliefs cause slight distress
2. Beliefs cause moderate distress
3. Beliefs cause marked distress
4. Beliefs cause extreme distress, couldn't be worse

6.

**DISRUPTION TO LIFE CAUSED BY BELIEFS**

How much disruption do your beliefs cause you?

-Do they prevent you working or carrying out a day-time activity?

-Do they interfere with your relationships with family or friends?

-Do they interfere with your ability to look after yourself, e.g. washing, changing clothes, etc?

0. No disruption to life, able to maintain independent living with no problems in daily living skills. Able to maintain social and family relationships (if present)
1. Beliefs cause minimal amount of disruption to life, e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.
2. Beliefs cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills.
3. Beliefs cause severe disruption to life so that hospitalisation is usually necessary. The patient is able to maintain some daily activities, self-care and relationships whilst in hospital. The patient may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.
4. Beliefs cause complete disruption of daily life requiring hospitalisation. The patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

DELUSIONS: SCORE SHEET

ID Number \_\_\_\_\_ Timepoint \_\_\_\_\_ Date \_\_\_\_\_  
\_\_\_\_\_

SCORE

1. AMOUNT OF PREOCCUPATION
  
2. DURATION OF PREOCCUPATION
  
3. CONVICTION
  
4. AMOUNT OF DISTRESS
  
5. INTENSITY OF DISTRESS
  
6. DISRUPTION

## AUDITORY HALLUCINATIONS: SCORING CRITERIA

### 1.

#### **FREQUENCY**

How often do you experience voices? e.g. every day, all day long etc.

0. Voices not present or present less than once a week (specify frequency if present)
1. Voices occur for at least once a week
2. Voices occur at least once a day
3. Voices occur at least once an hour
4. Voices occur continuously or almost continuously i.e., stop for only a few seconds or minutes

### 2.

#### **DURATION**

When you hear your voices, how long do they last, e.g. for a few seconds, minutes, hours, all day long?

0. Voices not present
1. Voices last for a few seconds, fleeting voices
2. Voices last for several minutes
3. Voices last for at least one hour
4. Voices last for hours at a time

3.

**LOCATION**

When you hear your voices, where do they sound like they're coming from?  
-inside your head and/or outside your head?  
-if voices sound like they are outside your head, whereabouts do they sound like they are coming from?

0. No voices present
1. Voices sound like they are inside head only
2. Voices outside the head, but close to ears or head. Voices inside the head may also be present.
3. Voices sound like they are inside or close to ears and outside head away from ears
4. Voices sound like they are from outside the head only

4.

**LOUDNESS**

How loud are your voices?  
Are they louder than your voice, about the same loudness, quieter or just a whisper?

0. Voices not present
1. Quieter than own voice, whispers.
2. About same loudness as own voice
3. Louder than own voice
4. Extremely loud, shouting

5. **BELIEFS RE-ORIGIN OF VOICES**

**RECORD FOR EACH VOICE:**

What do you think has caused your voices?

-Are the voices caused by factors related to yourself or solely due to other people or factors?

If patient expresses an external origin:

- How much do you believe that your voices are caused by ..... (add patient's contribution) on a scale from 0-100 with 100 being that you are totally convinced, have no doubts and 0 being that it is completely untrue?

0. Voices not present
1. Believes voices to be solely internally generated and related to self
2. Holds a less than 50% conviction that voices originate from external causes
3. Holds 50% or more conviction (but less than 100%) that voices originate from external causes
4. Believes voices are solely due to external causes (100% conviction)

6. **AMOUNT OF NEGATIVE CONTENT OF VOICES**

**RECORD FOR EACH VOICE**

Do your voices say unpleasant things or negative things?

- Can you give me some examples of what the voices say? (record these examples)
- How much of the time do the voices say these types of unpleasant or negative items?

0. No unpleasant content
1. Occasional unpleasant content
2. Minority of voice content is unpleasant or negative (less than 50%)
3. Majority of voice content is unpleasant or negative (50% or more)

4. All of voice content is unpleasant or negative

**7. DEGREE OF NEGATIVE CONTENT**

**RECORD FOR EACH VOICE**

(Rate using criteria on scale, asking patient for more detail if necessary)

0. Not unpleasant or negative
1. Some degree of negative content, but not personal comments relating to self or family e.g. swear words or comments not directed to self, e.g. “the milkman’s ugly”
2. Personal verbal abuse, comments on behaviour e.g. “shouldn’t do that or say that”
3. Personal verbal abuse relating to self-concept e.g. “you’re lazy, ugly, mad, perverted”
4. Personal threats to self e.g. threats to harm self or family, extreme instructions or commands to harm self or others and personal verbal abuse as in (3)

**8.**

**AMOUNT OF DISTRESS**

Are your voices distressing?

- How much of the time?

0. Voices not distressing at all
1. Voices occasionally distressing, majority not distressing (<10%)
2. Minority of voices distressing (<50%)
3. Majority of voices distressing, minority not distressing (□ 50%)
4. Voices always distressing



**9. INTENSITY OF DISTRESS**

When voices are distressing, how distressing are they?

-Do they cause you minimal, moderate, severe distress?

-Are they the most distressing they have ever been ?

0. Voices not distressing at all
1. Voices slightly distressing
2. Voices are distressing to a moderate degree
3. Voices are very distressing, although subject could feel worse
4. Voices are extremely distressing, feel the worst he/she could possibly feel

**10. DISRUPTION TO LIFE CAUSED BY VOICES**

How much disruption do the voices cause to your life?

-Do the voices stop you from working or other daytime activity?

-Do they interfere with your relationships with friends and/or family?

- Do they prevent you from looking after yourself, e.g. bathing, changing clothes, etc?

0. No disruption to life, able to maintain social and family relationships (if present)
1. Voices cause minimal amount of disruption to life e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.
2. Voices cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills.
3. Voices cause severe disruption to life so that hospitalisation is usually necessary. The patient is able to maintain some daily activities, self-care and relationships whilst in hospital. The patient may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.
4. Voices cause complete disruption of daily life requiring hospitalisation. The

patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

**11. CONTROLLABILITY OF VOICES**

-Do you think you have any control over when your voices happen?

-Can you dismiss or bring on your voices?

0. Subject believes they can have control over the voices and can always bring on or dismiss them at will
1. Subject believes they can have some control over the voices on the majority of occasions
2. Subject believes they can have some control over their voices approximately half of the time
3. Subject believes they can have some control over their voices but only occasionally. The majority of the time the subject experiences voices which are uncontrollable
4. Subject has no control over when the voices occur and cannot dismiss or bring them on at all.

AUDITORY HALLUCINATIONS: SCORE SHEET

ID Number \_\_\_\_\_ Timepoint \_\_\_\_\_ Date \_\_\_\_\_

1. FREQUENCY
2. DURATION
3. LOCATION
4. LOUDNESS
5. BELIEFS RE-ORIGIN OF VOICES
6. AMOUNT OF NEGATIVE CONTENT OF VOICES
7. DEGREE OF NEGATIVE CONTENT
8. AMOUNT OF DISTRESS
9. INTENSITY OF DISTRESS
10. DISRUPTION
11. CONTROL

**Appendix 3: Beck Hopelessness Scale (BHS)**

<b>Statement</b>	<b>True</b>	<b>False</b>
1. I look forward to the future with hope and enthusiasm	T	F
2. I might as well give up because there is nothing I can do about making things better for myself.	T	F
3. When things are going badly, I am helped by knowing that they can't stay this way forever.	T	F
4. I can't imagine what my life would be like in ten years.	T	F
5. I have enough time to accomplish the things I want to do.	T	F
6. In the future, I expect to succeed in what concerns me most.	T	F
7. My future seems dark to me.	T	F
8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person.	T	F
9. I just can't get the breaks, and there's no reason I will in the future.	T	F

10. My past experiences have prepared me well for the future.	T	F
11. All I can see ahead of me is unpleasantness rather than pleasantness.	T	F
12. I don't expect to get what I really want.	T	F
13. When I look ahead to the future, I expect that I will be happier than I am now.	T	F
14. Things just don't work out the way I want them to.	T	F
15. I have great faith in the future.	T	F
16. I never get what I want, so it's foolish to want anything.	T	F
17. It's very unlikely that I will get any real satisfaction in the future.	T	F
18. The future seems vague and uncertain to me.	T	F
19. I can look forward to more good times than bad.	T	F
20. There's no use in really trying to get anything I want because I probably won't get it.	T	F

## Appendix 4: The Self Esteem Rating Scale (SERS)

### SERS

Name \_\_\_\_\_

ID # \_\_\_\_\_

This questionnaire is designed to measure how you feel about yourself. It is not a test, so there are no right or wrong answers. Please answer each item carefully and accurately as you can by using the following scale:

- 1 = Never**
- 2 = Rarely**
- 3 = A little of the time**
- 4 = Some of the time**
- 5 = A good part of the time**
- 6 = Most of the time**
- 7 = Always**

1. \_\_\_ I feel that others do things much better than I do.
2. \_\_\_ I feel confident in my ability to deal with people.
3. \_\_\_ I feel that I am likely to fail at things I do.
4. \_\_\_ I feel that people really like to talk with me.
5. \_\_\_ I feel that I am a very competent person.
6. \_\_\_ When I am with other people, I feel that they are glad I am with them.
7. \_\_\_ I feel that I make a good impression on others.
8. \_\_\_ I feel confident that I can begin new relationships if I want to.
9. \_\_\_ I feel ashamed about myself.
10. \_\_\_ I feel inferior to other people.
11. \_\_\_ I feel that my friends find me interesting.
12. \_\_\_ I feel that I have a good sense of humor.
13. \_\_\_ I get angry at myself over the way I am.
14. \_\_\_ My friends value me a lot.
15. \_\_\_ I am afraid I will appear stupid to others.
16. \_\_\_ I wish I could just disappear when I am around other people.
17. \_\_\_ I feel that if I could be more like other people then I would feel better about myself.
18. \_\_\_ I feel that I get pushed around more than others.
19. \_\_\_ I feel that people have a good time when they are with me.
20. \_\_\_ I wish that I were someone else.

## Appendix 5: Calgary Depression Scale for Schizophrenia (CDSS)

Interviewer: Ask the first question as written. Use follow up probes or qualifiers at your discretion.. N.B. The last item (9) is based on observations of the entire interview.

**1. DEPRESSION: How would you describe your mood over the last two weeks? Do you keep reasonably cheerful or have you been very depressed or low spirited recently? In the last two weeks how often have you (own words) every day? All day?**

**0. Absent**

- 1. Mild:** Expresses some sadness or discouragement on questioning.
- 2. Moderate:** Distinct depressed mood persisting up to half the time over last 2 weeks: present daily.
- 3. Severe:** Markedly depressed mood persisting daily over half the time interfering with normal motor and social functioning.

**2. HOPELESSNESS: How do you see the future for yourself? Can you see any future? - or has life seemed quite hopeless? Have you given up or does there still seem some reason for trying?**

**0. Absent**

- 1. Mild:** Has at times felt hopeless over the last two weeks but still has some degree of hope for the future.
- 2. Moderate:** Persistent, moderate sense of hopelessness over last week. Can be persuaded to acknowledge possibility of things being better.
- 3. Severe:** Persisting and distressing sense of hopelessness.

**3. SELF DEPRECIATION: What is your opinion of your self compared to other people? Do you feel better, not as good, or about the same as other? Do you feel inferior or even worthless?**

**0. Absent**

- 1. Mild:** Some inferiority; not amounting to feeling of worthlessness.
- 2. Moderate:** Subject feels worthless, but less than 50% of the time.
- 3. Severe:** Subject feels worthless more than 50% of the time. May be challenged to acknowledge otherwise.

**4. GUILTY IDEAS OF REFERENCE: Do you have the feeling that you are being blamed for something or even wrongly accused? What about? (Do not include justifiable blame or accusation. Exclude delusions of guilt.)**

**0. Absent**

- 1. Mild:** Subject feels blamed but not accused less than 50% of the time.
- 2. Moderate:** Persisting sense of being blamed, and/or occasional sense of being accused.
- 3. Severe:** Persistent sense of being accused. When challenged, acknowledges that it is not so.

**5. PATHOLOGICAL GUILT: Do you tend to blame yourself for little things you may have done in the past? Do you think that you deserve to be so concerned about this?**

**0. Absent**

- 1. Mild:** Subject sometimes feels over guilty about some minor peccadillo, but less than 50% of time.
- 2. Moderate:** Subject usually (over 50% of time) feels guilty about past actions the significance of which he exaggerates.
- 3. Severe:** Subject usually feels s/he is to blame for everything that has gone wrong, even when not his/her fault.

**6. MORNING DEPRESSION: When you have felt depressed over the last 2 weeks have you noticed the depression being worse at any particular time of day?**

**0. Absent:** No depression.

- 1. Mild Depression:** present but no diurnal variation.
- 2. Moderate Depression:** spontaneously mentioned to be worse in a.m.
- 3. Severe Depression:** markedly worse in a.m., with impaired functioning which improves in p.m.

**7. EARLY WAKENING: Do you wake earlier in the morning than is normal for you? How many times a week does this happen?**

**0. Absent:** No early wakening.

- 1. Mild:** Occasionally wakes (up to twice weekly) 1 hour or more before normal time to wake or alarm time.
- 2. Moderate:** Often wakes early (up to 5 times weekly) 1 hour or more before normal time to wake or alarm.
- 3. Severe:** Daily wakes 1 hour or more before normal time.

**8. SUICIDE: Have you felt that life wasn't worth living? Did you ever feel like ending it all? What did you think you might do? Did you actually try?**

**0. Absent**

- 1. Mild:** Frequent thoughts of being better off dead, or occasional thoughts of suicide.
- 2. Moderate:** Deliberately considered suicide with a plan, but made no attempt.
- 3. Severe:** Suicidal attempt apparently designed to end in death (i.e.: accidental discovery of inefficient means).

**9. OBSERVED DEPRESSION: Based on interviewer's observations during the entire interview. The question "Do you feel like crying?" used at appropriate points in the interview, may elicit information useful to this observation.**

**0. Absent**

- 1. Mild:** Subject appears sad and mournful even during parts of the interview, involving affectively neutral discussion.
- 2. Moderate:** Subject appears sad and mournful throughout the interview, with gloomy monotonous voice and is tearful or close to tears at times.

**3. Severe:** Subject chokes on distressing topics, frequently sighs deeply and cries openly, or is persistently in a state of frozen misery if examiner is sure that this is present.

## Appendix 6: Personal and Social Performance Scale (PSP)

Please rate the patient on his/her level of functioning during the reference period (e.g. **past month** or **last seven days**) Consider what the person is doing, taking into account if she needs help or prompting by others. Only for activities that she has not the possibility of doing where she lives, consider what she would be able to do in a different setting.

Because area a, b, c include many subareas, give the score to each area taking into account the **worst** functioning during the period in the relevant **best** subarea. For area a, subareas are work or study and other socially useful activities (e.g. housework, voluntary work, “useful” hobbies as gardening); for area b, subareas are relationship with partner (only if the patient has a partner and usually lives with him/her, elsewhere ignore) , family relationships, social relationships; for area c, subareas are personal hygiene, care of one’s look and way of dressing.

Other areas (different from the main four areas) (e.g. self-management of the disorder, interests and information, instrumental activities as phoning, travelling) may be taken into account to define the score inside each 10 points interval.

If there was a recent crisis, we may want to give two scores, one for the crisis period (e.g. last seven days) and one for the month before the beginning of the crisis.

There 4 main domains of functioning considered in this scale are a) Personal and social relationships; b) socially useful activities, including work and study; c) self-care; d) disturbing and aggressive behaviours.

There are tow different sets of operational criteria to judge the degree of difficulties:  
One for the **a-c** areas and one specific to the **d** area.

### Degrees of severity areas a-c

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>i) Absent</li> <li>ii) Mild, defined here as known <b>only to someone who is very familiar</b> with the person</li> <li>iii) Manifest, but not marked, difficulties <b>clearly noticeable by everyone</b>, but not interfering substantially with the person’s ability to perform his/her role in that area, given the person’s socio-cultural context, age, gender and educational levels</li> <li>iv) Marked, difficulties interfering heavily with role performance in that area; however,, the person is still able to do something without professional or social help, although inadequately and/or occasionally; if helped by someone, he/she may be able to reach the previous level of functioning</li> <li>v) Severe, difficulties that make the person unable to perform any role in that area, if not professionally helped, or make the person to have a harmful influence; however,, there are no survival risks</li> <li>vi) Very severe, impairments and difficulties of such intensity to endanger the person’s survival. Suicide risk should be taken into account only as much as suicide rumination interferes with social functioning.</li> </ul> | <ul style="list-style-type: none"> <li>i) Absent</li> <li>ii) Mild, corresponding to mild rudeness, unsociability or whingeing</li> <li>iii) Manifest, such as speaking too loudly or speaking to others in a too-familiar manner, or eating in a socially unacceptable manner</li> <li>iv) Marked, insulting others in public, breaking or wrecking objects, acting frequently in a socially inappropriate but not dangerous way (e.g. stripping or urinating in public) <u>not occasionally</u></li> <li>v) Severe, frequent verbal threats or frequent physical assaults, without intention or possibility to severe injuries <u>not occasionally</u></li> <li>vi) Very severe, defined as aggressive acts, aimed at or likely to cause severe injuries <u>not occasionally</u>.</li> </ul> |
|---|--|

### Degrees of severity area d



The disturbing behaviour has to be considered only occasionally if it has taken place only 1 in the preceding week or 1-2 times in preceding month **and** mental health professionals and caregivers believe that it is very unlikely to happen again in the next six months. If the disturbing behaviour is judged “occasional” the score should be decreased by 1, e.g. severe becomes marked. An injury has to be considered “severe” if it would need to be treated in an emergency department if available.

The following table may be used to score the severity of problems in each main area.

	Absent	Mild	Manifest	Marked	Severe	Very Severe
1) Socially useful activities, including work and study	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Personal and social relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Self-care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Disturbing and aggressive behaviours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Personal and Social Performance Scale (PSP) –

#### Overall score instructions on the basis of the four main areas scores

100-91	Excellent functioning in all four main areas. He/she is held in high consideration for his/her good qualities, copes adequately with life problems, is involved in a wide range of interests and activities.
90-81	Good functioning in all four areas, presence of only common problems and difficulties.
80-71	Mild difficulties in one or more of the areas a-c.
70-61	Manifest, but not marked difficulties in one or more areas a-c or mild difficulties in d. For area a include here sheltered work, if the performance is good.
60-51	Marked difficulties in only one area a-c or manifest difficulties in d.
50-41	Marked difficulties in two or three of the areas a-c, or severe difficulties <u>in only one</u> area a-c <u>without</u> marked difficulties in the other two; no marked difficulties in d.
40-31	Severe difficulties <u>only</u> in one area a-c <u>and</u> marked difficulties in at least one of the other two; or marked difficulties in d.
30-21	Severe difficulties in two areas a-c; or severe difficulties in d, even if severe and marked difficulties in the areas a-c are absent.
20-11	Severe difficulties in <u>all</u> areas a-c; or very severe difficulties in d, even if severe difficulties in area a-c are absent. If the person react to external prompts, the suggested scores are 20-26; if not, they are 15-11.
10-1	Lack of autonomy in basic functioning with extreme behaviours but without survival risk (scores 6-10) or with survival risk, e-g- death risk due to malnutrition, dehydration, infections, inability to recognise situations of marked danger (scores 5-1).

5) Overall score |\_\_|\_\_|\_\_|

#### 1.12. Summary meaning of PSP total score

71-100:	These ratings reflect only mild difficulties
31-70:	These ratings reflect varying degrees of disability
0-30:	These ratings reflect functioning so poor that the patient requires intensive support or supervision.

## **b) INSTRUCTIONS TO THE PSP RATERS TO COLLECT THE REQUIRED INFORMATION**

*This section reports the questions to be asked by the rater to himself/herself to assess his/her knowledge about the patient. If this knowledge is insufficient, the questions should be directed to the patient himself/herself and/or to (other) mental health professionals and/or to relatives and other caregivers.*

### **INTRODUCTION**

#### **1. If the questions are asked to P. P stands for the person or patient to be assessed**

Good morning. I am .... I would like to ask you some questions about the problems you may have in your daily life, specially about those problems you have had in the last (*reference period, for instance in the “thirty days” if the person has a chronic stabilized disorder*). This will help us to better understand your needs and your treatment. I am interested to learn not only about the problems or difficulties you have had, but also the things you have been able to manage and achieve. Of course everything you will say will be protected by professional confidentiality and will never not be discussed with people who are not professionally involved in your treatment unless you give your consent, not even with your relatives. The information may be used for research purposes, but your identity will never be disclosed.

If the rater suspects that P is unable to answer the questions, he/she may assess his/her mental lucidity with the following questions:

*Can you tell me where we are? Why did you come here? How old are you? When were you born? What day of the week is today? What time of the day is it? What is your doctor name here? (NB Paranoid ideation or lack of insight are not a reason non to ask the questions you need to ask; however, in this case also other sources of information have to be tapped; psychotic patients tend to overestimate their social functioning).*

#### **2. If the questions are asked to a caregiver. P stands for person or patient to be assessed.**

Good morning. I am .... I would like to ask you some questions about the problems P (*for instance “your son”*) have in his/her daily life, especially about the problems he had in the last (*reference period, for instance in the “thirty days” if the person has a chronic stabilized disorder*). This will help us to better understand his needs and his treatment. I am interested to learn not only about the problems or difficulties he/she may have had, but also about the things he/she has been able to manage and achieve. Of course everything you will say will be protected by professional confidentiality and will not be discussed with people who are not involved a professionally interested in your treatment, non even with P (*for instance “your son”*), unless you ask us to do so. The information may be used for research purposes, but P’s identity and your identity will never be disclosed.

**3. If the questions are asked to a (other) mental health professionals . P stands for person or patient to be assessed.**

Good morning. I am .... I would like to ask you some questions about P's (say P name) functioning in his/her daily life, especially about the problems he/she may have had in the last ... (reference period, for instance in the "thirty days" if the person has a chronic stabilized disorder). I understand that you have had the opportunity to observe him and to speak to him/her. I am interested to know not only about his/her problems or difficulties, but also about the things he/she has been able to manage and achieve. The information may be used for research purposes, however in this case P's identity will never be disclosed.

**4.If the questions are asked by the rater to himself/herself. P stands for person or patient to be assessed.**

Please ask yourself the following questions about P and seek further information if you do not know the answers. Take into account not only the answers to questions but also your observations.

*The following questions are addressed to P; the construction should be changed according to the introductions above if they were addressed to relatives or health professionals. The questions are only example and not all have to be asked. Stop when you have sufficient information to make the ratings on the 0-5 scales.*

*Rate the worst functioning during the reference period in the best subarea for each area a-c (in area b, the subarea "relationship with partner" has to be considered only if P has a partner and usually lives with the partner).*

**a) SOCIALLY USEFUL ACTIVITIES, INCLUDING WORK AND STUDY**

**a1) Work or study**

In the last.... (reference period) did you work? (or "Have you been to school?").

*If yes: Where? How many days? How many hours a day? Have you had difficulties at work (at school), for instance with the other workers (students) or your manger (teachers)? Have you been punctual?*

**a1) Socially useful activities**

Apart from work, did you do something that other people may find useful? For instance, did you help with a household task (cleaning the house, tidying things up, cooking)? Did you help to organize something or with gardening or sewing? Have you done some voluntary work?

**If uncertain between mild and manifest, ask: *How many people have noticed that you have had some problems at work (or study)?***

**b) PERSONAL AND SOCIAL RELATIONSHIP**

**b1) Do you have a partner (a spouse, or a boy/girl friend)? *If yes: Do you live together? How do you get along? Do you speak to each other? Do you have commons plans?***

**b2) Family (different from partner)**

In the last.... (reference period) have you been in touch with any of your relatives? How often have you seen them? Did you get along well or did you have problems? Do they help you? Do you help them?

*If P lives in a residential facility: During leave from the residence or when your relatives came to visit you, did you get on well with them?*

### **B3) Social relationships**

How often did you go out to meet other people? Do you like meeting and speaking with other people? Do you do things together with other people? Do other people like you? How many friends have you got? Are they patients or workers of the mental health service? Do you have somebody who can help you when you need it?

**If uncertain between mild and manifest: *How many people have noticed that you have some difficulties in social relationships?***

### *c) SELF CARE*

#### **c1) Personal hygiene**

*In the last.... (reference period) how often have you taken a shower or a bath? Did you wash alone or did somebody remind or help you? Have you cleaned your teeth every day?*

#### **c2) Care of one's appearance**

*For men without a beard: Do you shave regularly? For women: Have you used a little make up, at least on special occasions? Have you gone to a hairdresser?*

#### **c3) Way of dressing**

*In the last ... (reference period) did you always put on clean clothes? Did you ever go out in pyjama or not properly dressed? Did you ever dress in a way that people might find unusual for the period of the year or the weather?*

*If the person being asked is not P: Did people ever complained that P had a bad smell?*

**If uncertain between mild and manifest: *How many people have noticed that you were not perfectly clean and rather grubby?***

### **d) DISTURBING AND AGGRESSIVE BEHAVIORS**

#### **d1) Disturbing behaviour**

*In the last.... (reference period) did you behave in a way that some people may have thought rude or insensitive? Did you take something belonging to others without asking permission? While drunk, did you do something that could annoy others? Did you ever do something strange that other people may have found worrying? Did you speak to loudly or have your record player or the TV too loud? Did you keep asking other people for money or gifts? Did you complain often about your condition?*

**If uncertain between mild and manifest: *How many people have noticed that you were behaving in disturbing way for others?***

#### **d1) Destructive and aggressive behaviour**

*In the last.... (reference period) did you ever lose control of your temper? Did you shout at anybody? Did you throw or destroy objects? Did you hit or hurt anybody? How severe was it? Did you really want to hurt them? How often did it happen? Do you think that is going to happen again in the near future?*

**If uncertain between mild and manifest: *How many people have noticed that you have some difficulties in self control?***

## Appendix 7: Recovery Attitudes Questionnaire (RAQ-7)

### RECOVERY ATTITUDES QUESTIONNAIRE (RAQ-7)

Recovery is a process and experience that we all share. People face the challenge of recovery when they experience the crises of life, such as the death of a loved one, divorce, physical disabilities, and serious mental illnesses. Successful recovery does not change the fact that the experience has occurred, that the effects are still present, and that one's life has changed forever. Rather, successful recovery means that the person has changed, and that the meaning of these events to the person has also changed. They are no longer the primary focus of the person's life (Anthony, 1993).

We are interested in measuring your beliefs about the concept of recovery from mental illnesses. Please read each of the following statements and using the scale below mark the rating that most closely matches your opinion.

	SA Strongly Agree	A Agree	N Neutral	D Disagree	SD Strongly Disagree
1. People in recovery sometimes have set backs. ....	SA	A	N	D	SD
2. To recover requires faith. ....	SA	A	N	D	SD
3. Stigma associated with mental illness can slow down the recovery process. ....	SA	A	N	D	SD
4. Recovery can occur even if symptoms of mental illness are present. ....	SA	A	N	D	SD
5. Recovering from mental illness is possible no matter what you think may cause it. ....	SA	A	N	D	SD
6. All people with serious mental illnesses can strive for recovery. ...	SA	A	N	D	SD
7. People differ in the way they recover from a mental illness. ....	SA	A	N	D	SD

**Thank you for taking the time to fill out the questionnaire.**

Please direct any comments or questions to:  
John Steffen or Hillary Wishnick at (513) 558-3324  
Hamilton County Recovery Initiative Research Team (HCRI-RT)

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Supported by the Office of Program Evaluation & Research, Ohio Department of Mental Health  
Sponsored by the Multidisciplinary Program Consortium, A Center for Training & Research in Serious Mental Illness

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## Appendix 8: Causal Attributions Questions

(taken from online study, please note item numbers were sequential for the entire study)

There are many factors which could cause or contribute to a person experiencing psychosis.

Please indicate to what extent you agree each of the following items could be a cause of a person's experiences of psychosis:

12). Coincidence or fate

strongly agree  agree  neutral  disagree  strongly disagree

13). Disorder of the transmitters in the brain

strongly agree  agree  neutral  disagree  strongly disagree

14). Stress

strongly agree  agree  neutral  disagree  strongly disagree

15). Self causation (eg. lack of willpower, immoral behaviours etc.

strongly agree  agree  neutral  disagree  strongly disagree

16). Damage to the brain

strongly agree  agree  neutral  disagree  strongly disagree

There are many factors which could cause or contribute to a person experiencing psychosis.

Please indicate to what extent you agree each of the following items could be a cause of a person's experiences of psychosis:

17). Trauma

strongly agree  agree  neutral  disagree  strongly disagree

18). Problems during childhood

strongly agree  agree  neutral  disagree  strongly disagree

19). Genetic inheritance

strongly agree  agree  neutral  disagree  strongly disagree

20). Religious or spiritual cause eg. God's will

strongly agree  agree  neutral  disagree  strongly disagree

21). Substance misuse (drugs or alcohol)

strongly agree  agree  neutral  disagree  strongly disagree

## Appendix 9: Screen shots of the Recovery Implicit Association Test

**Recovered** **Not recovered**

Place your left index finger on the 'E' key and your right index finger on the 'I' key of your keyboard. Words representing the categories at the top will appear one-by-one in the middle of the screen. When think the item belongs to a category on the left, press the 'E' key; when you think the item belongs to a category on the right, press the 'I' key. Items belong to only one category. If you make an error, an X will appear - fix the error by hitting the other key.

This is a timed sorting task. GO AS FAST AS YOU CAN while making as few mistakes as possible.

This task will take about 5 to 10 minutes to complete.

Press the SPACE BAR to begin.

**Recovered** **Not recovered**

**Unhealthy**

Recovered

Not recovered

Well

Recovered

Not recovered

or

Psychosis

See above, a new category now appears together with one of the previous categories you saw. Remember, each item belongs to only one group. For example, if the categories psychosis and recovered appeared on the separate sides above - words related to psychosis would go in the psychosis category, not the recovered category.

Use the E and I keys to categorize items into the three groups left and right, and correct errors by hitting the other key.

Press the SPACE BAR to begin.



Recovered  
or  
Psychosis

Not recovered

Normal

Recovered  
or  
Psychosis

Not recovered

Hearing things

Recovered  
or  
Psychosis

Not recovered

Normal

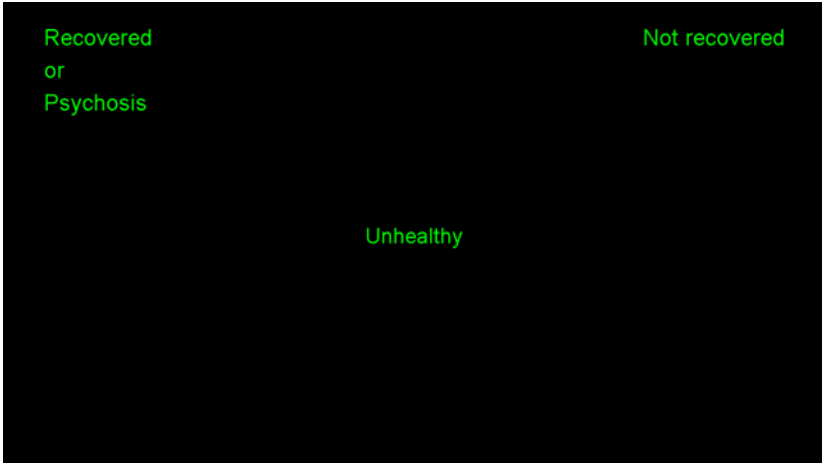
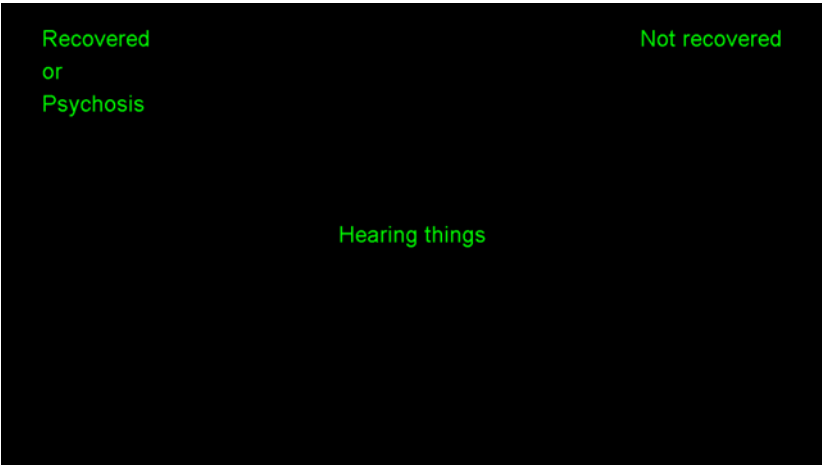
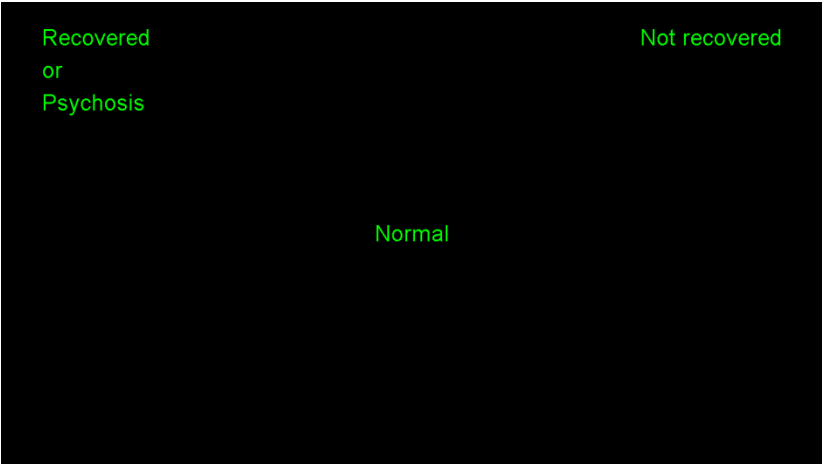
Recovered  
or  
Psychosis

Not recovered

Sort the same three categories again. Remember to go as fast as you can while making as few mistakes as possible.

Use the E and I keys to categorize items into the three groups left and right, and correct errors by hitting the other key.

Press the SPACE BAR to begin.



Recovered

Not recovered

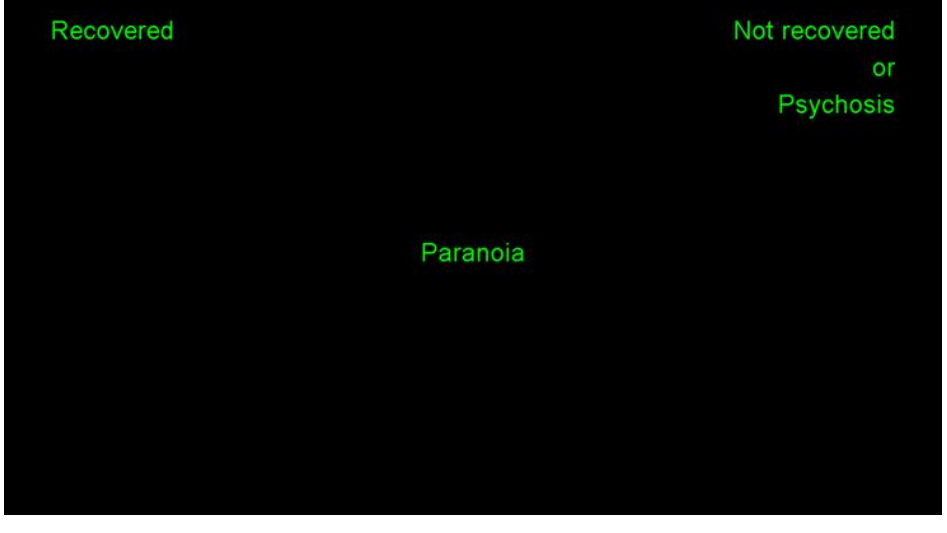
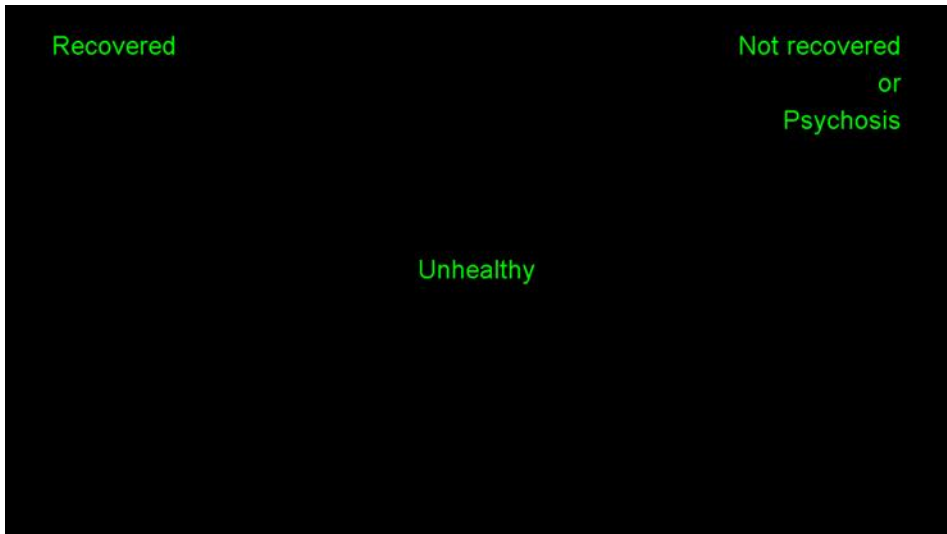
or

Psychosis

See above, the three categories now appear together in a new configuration. Remember, each item belongs to only one group.

Use the E and I keys to categorize items into the three groups left and right, and correct errors by hitting the other key.

Press the SPACE BAR to begin.



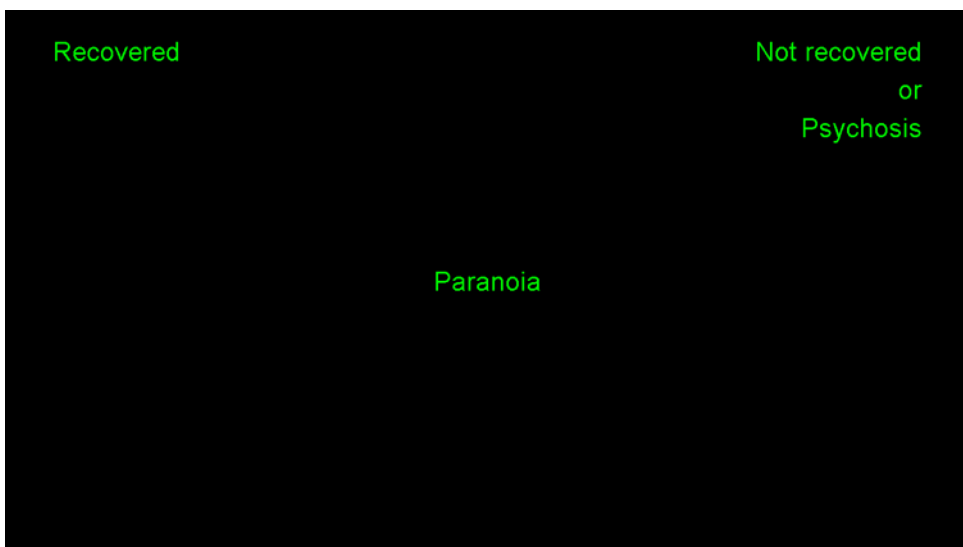
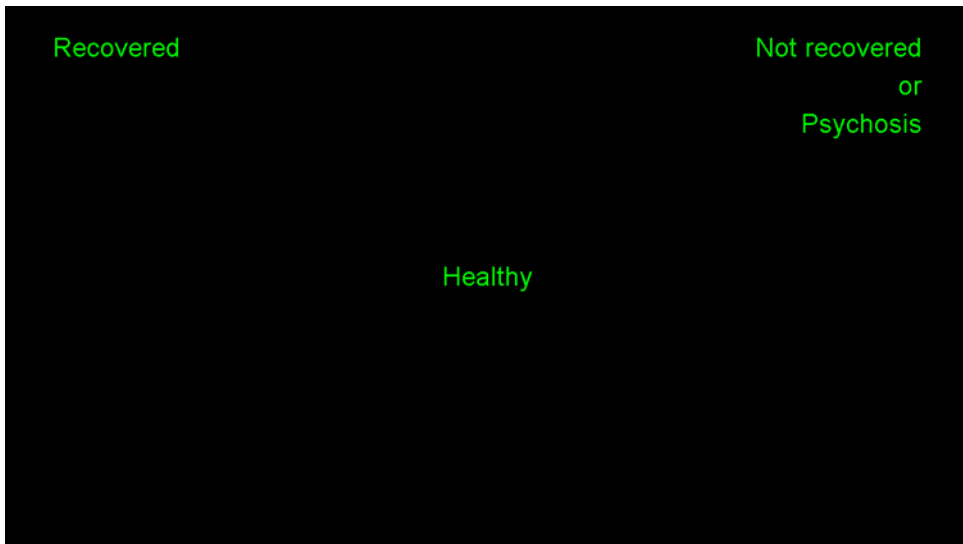
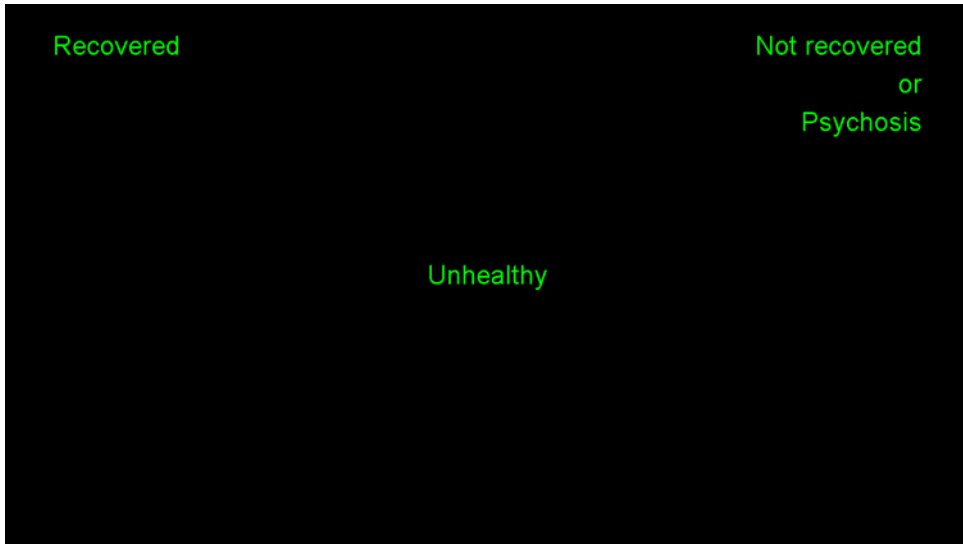
Recovered

Not recovered  
or  
Psychosis

Sort the same three categories again. Remember to go as fast as you can while making as few mistakes as possible.

Use the E and I keys to categorize items into the three groups left and right, and correct errors by hitting the other key.

Press the SPACE BAR to begin.



## Appendix 10: Recovery programme project 1 PIS (data used in study 2 & 4)

A study to investigate the psychometric properties of the  
Subjective Experience of Psychotic Symptoms Scale PIS Version 2 20/11/2008



**Greater Manchester West**  
Mental Health NHS Foundation Trust

### Participant Information Sheet

#### **Study Title: A study to investigate the psychometric properties of the Subjective Experience of Psychotic Symptoms Scale**

You are being invited to take part in a service user defined research study. This information sheet explains why the research is being done and what it involves. Please read this information carefully and discuss it with others if you wish. Feel free to ask if there is anything that is not clear or you would like more information about. Please take time to decide whether or not you wish to take part.

#### **Who is organising the study?**

This project is one of five projects undertaken within the 'Recovery Programme' of research run by Professor Tony Morrison and Professor Gill Haddock of the University of Manchester. The research team members you may meet are a service user researcher (e.g. Jason Price) or a research assistant (e.g. Lisa Wood).

#### **What is the study about?**

The study aims to assess the reliability and validity, i.e. the usefulness of the newly developed measure assessing symptom change in psychosis, called the Subjective Experience of Psychotic Symptoms Measure (SEPSS for short). The SEPSS was created, as there are no measures currently available that assess' experiences of psychosis that have been designed and developed by service users.

To create the SEPSS we talked to around 40 service users across the North West. We listened to their experiences and asked them to rate symptom changes that were important to them.

To test the usefulness of this scale, the research involves 3 stages:

- Stage 1: We are asking a service user group to comment on the presentation and readability of the scale. This will allow us to assess the accessibility of the scale.
- Stage 2: Then it will be compared to 8 other measures, all completed by service users. This will allow us to compare the SEPSS to other measures related to psychosis, recovery and emotions.
- Phase 3: Lastly, we are asking mental health staff to rate 10 anonymous audiotapes of service users completing the SEPSS. This is to prove that the measure is reliable across raters.

We need you to take part in stage 2.

#### **Who will be taking part?**

To make sure that this scale is useful we need to talk to around 75 service users from the North West area. We would like to talk to a broad range of people, aged 18 – 65 who have experience of psychosis and experienced delusions and/or hallucinations currently. You have been asked to take part because of your own experiences of psychosis. Sharing your experiences will help us make sure that the SEPSS is of benefit to all service users.

Also 5 – 10 mental health staff, including service user researchers will be recruited to take part in stage 3. They will be between the ages of 18 – 65 and be working as a mental health professional from a North West NHS Trust.



### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you agree to take part, you will be given a copy of this participant information sheet and we will ask you to complete a consent form. You are free to withdraw at any time and do not need to give a reason. If you do withdraw, this will not affect any help or treatments you are getting.

### **What will it involve for me?**

To see how useful our new measure is, we have to compare it with other measures of psychosis, emotions and recovery. This will let us see how this new measure works against other measures and to see how results are the same or different. This will involve three sessions:

**Visit 1:** Firstly, we will go through an information sheet with you. This will just talk about some personal details such as date of birth, ethnicity, and first contact with mental health services etc. Then we will then go through the new measure with you. It involves answering around 50 questions on a questionnaire about your experiences and what aspects are important to help them recover. This should only take about 20 minutes. We will also go through eight other measures with you, so we can compare results. These involve three standardised interviews and five self-completion questionnaires, these measures may take up to an hour and a half to complete. These interviews and questionnaires will touch on things about your experiences of psychosis, recovery and your emotions. The whole session should take a total of about an hour and fifty minutes.

**Visit 2:** We may also like to return after one to two weeks, and go through the SEPSS again. This should take around 20 minutes.

**Visit 3:** We would also like to return for a third time after around 3 months to go over everything we did in visit 1 except for the personal information sheet. This will take about an hour and forty-five minutes.

We would also like to audio record the sessions if you consent to us doing so. This is for two reasons, firstly to make sure the measure is reliable, as we have to get a number of mental health professionals to rate us administering the scale to people. However, they will not know who has completed the scale, as it will all be anonymous. Secondly, some of the interviews need scoring, so we need to record the interviews to make sure they have been scored correctly. If you do not want us to audio tape your assessment you can still take part.

All the information you give will be strictly confidential. However there are two exceptions to this. Firstly, the University of Manchester and Greater Manchester West Mental Health NHS Foundation Trust may access the raw data or personal information to check we are meeting their standards of practice. Also, if during the course of the interviews, you express an intention to harm yourself or others. In such circumstances your care coordinator would be informed.

As stated before, we are part of the 'Recovery Programme' of research and there are 4 other projects within this research. If you are interested we could pass your contact details to other projects but we will ask your permission first.

If you consent, we would also like your permission to look at your medical notes, to get your diagnosis.

The results and any published findings will also be anonymous; your name will not be quoted.

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

For each stage, we will give you £5 as a token of our appreciation. So if you take part in all stages, you will receive £15 in total. The creation of a meaningful measure may lead to the improvement of healthcare service in the future. You may find it an enjoyable experience being involved in such work.

It is possible that talking about your personal experiences may result in some distress. The people interviewing you will be sensitive to this as they themselves may have personal experience of mental distress. You will have the opportunity to discuss any concerns at the end of the interview and you are

free to withdraw from the process at any point. We will check if there are any concerns you wish to raise and, if necessary, you will be able to talk to one of the clinical psychologists who are a member of the research team.

#### **What do I do if something goes wrong?**

The study does not have any 'medical' interventions. You will only be asked to rate some set questions. 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.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Manchester, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

The University of Manchester has cover for no fault compensation for bodily injury, mental injury or death where the injury resulted from a trial or procedure you received as part of the trial. This would be subject to policy terms and conditions. Any payment would be without legal commitment. (Please ask if you wish more information on this).

The University would not be bound to pay this compensation where the injury resulted from a drug or procedure outside the trial protocol or the protocol was not followed.

However, if you wish to make a formal complaint, you should contact the University Research Office on: 0161 275 7583.

#### **What will happen to the results of the research?**

If you participate in the study you will be given a summary of the results. The findings will also be presented to a range of mental health professionals and service users with the aim of increasing the understanding of service users perceptions of psychotic symptoms and their measurement. The findings will be published in mental health journals and other publications read by mental health professionals and service users.

#### **Further Information**

If you want any further information or have any questions, please ask the researchers.

Lisa Wood and Jason Price  
Greater Manchester West Mental Health NHS Foundation Trust  
Psychology Services  
Bury New Road  
Prestwich  
Manchester  
M25 3BL

Tel: 0161 772 4350 or e-mail: [jason.price@gmw.nhs.uk](mailto:jason.price@gmw.nhs.uk)  
[lisa.wood@gmw.nhs.uk](mailto:lisa.wood@gmw.nhs.uk)

## Appendix 11: Recovery Programme project 2: phase 2 PIS (data used in study 2 & 4)

Understanding Recovery In Everyday Life: An Experience Sampling Study PIS Version 6 Service Users.  
20.12.2011

Greater Manchester West  
Mental Health NHS Foundation Trust



### Participant Information Sheet – Part 1

**Study Title:** *Understanding Recovery In Everyday Life: An Experience Sampling Study*

You are being invited to take part in a research study. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information about. Take time to decide whether or not you wish to take part.

#### Who is organising and funding the research?

This study is funded by a grant from the National Institute for Health Research. It is one of five projects undertaken within the 'Recovery Programme' of research organised by Greater Manchester West Mental Health NHS Foundation Trust. The programme is run by Professor Tony Morrison in collaboration with staff from the Universities of Manchester, Lancaster and Bangor. This project is led by Professor Richard Bentall from the University of Bangor.

#### Why is the study being done?

Research has shown that many factors involved in finding out if people are recovered from psychosis seem to vary. We are interested to find out whether it may be to do with change in how we think, our mood, beliefs, or unusual experiences, how able we are to find meaning or satisfaction in everyday life, or how constant or stable our feelings about these things are.

In this study we will be using the following methods to find out about the things described above:

1. An informal interview and some questionnaires measuring symptoms or experiences and ways of thinking including a measure of *past childhood trauma*, a short computerised task and some questions about recovery.
2. A six day long diary with questions about ways of thinking, activities and recovery in day-to-day life.
3. A telephone interview once three months after the initial visit asking about recovery, followed by a final visit at six months to complete the interview about experiences and questions about recovery again.

The study will require you to agree to participate in each of these stages. It is hoped that the results from the study will help us tell which factors may be important in recovery from psychosis in future.

### **Why have I been asked to take part?**

We are inviting people to take part in the research who have experience of psychosis, are aged 16-65, and live in the North West of England. We are hoping for 120 people to take part in this study. Your Care Coordinator has agreed for us to approach you.

### **Do I have to take part?**

It is up to you whether or not you decide to take part. If you agree to take part you will be given a copy of this information sheet and be asked to sign a consent form. If you do decide to take part you can leave the study at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

### **What will happen / what will it involve for me?**

A researcher will see you for either one session lasting approximately 2 and a half hours, or on two separate occasions each for about one and a quarter hours to go through a series of questionnaires, some that you complete yourself and some that he/she reads out to you. The questions you will be asked are about yourself, your experiences including potentially sensitive experience of childhood trauma, your current mental health, your views about your thoughts and emotions and experiences of recovery.

We will try to make appointments at times that suit you. You can choose whether you wish to be interviewed in your own home, at a treatment service or at a local venue of your choice.

Following this you will be asked to complete a structured diary for 6 days. This involves using a device that will beep at random intervals throughout the day. When the device beeps you will be required to answer a set of questions. You will be required to carry the device with you. The emphasis is on how you go about your everyday life. It is important that you do things the same way that you would do without the device. There will be ten beeps, therefore sets of questions to be answered per day. At the end of the six days the researcher will see you again to collect the device and discuss how you found it.

Following this the researcher will contact you by telephone once 3 months after the initial appointment to go through some questions about recovery. This should not take longer than 20 minutes per phone call. At 6 months the researcher will visit you for the final time to complete some questions again about your experiences of psychosis and judgements about recovery.

As stated before, we are part of the 'Recovery Programme' of research and there are 4 other projects within the programme. If you are interested we could pass your contact details to other projects, but we will ask your permission first. If you do agree to take part in another study, we will, with your consent, use some of the information from the questionnaires in this study for the other ones.

You will be given £10 in cash on completion of the first battery of measures and £20 on completion of the diary part of the study as a token of appreciation for taking part. After the 6 month stage you will receive an additional £10.

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

The information we get from this study may help us to plan other studies in which we investigate how different kinds of psychological treatment help people recover. This may help us to improve services for people with psychosis and help them to recover. People often welcome the opportunity to talk about their experiences and it is possible you may benefit emotionally from participating in this study. However, it is possible that talking about your personal experiences may result in some distress. We will check if there are any concerns you wish to raise and, if necessary, you will be able to talk to a clinical psychologist who is a member of the research team.

**What if there is a problem?**

Any complaint in relation to the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

**Will my taking part be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

If the information in part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.



## Participant Information Sheet – Part 2

### What will happen if I don't want to continue with the study?

If you wish, you can withdraw from the study at any time without giving a reason. We will need to use the data already collected to complete the study and also retain your identifiable information.

### What do I do if something goes wrong?

If you have any questions or concerns you are welcome to ask the researchers or advisors whose contact details are listed at the end.

If you are harmed by taking part in this research study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then in the first instance please contact:

Mr Hefin Francis, School Manager, School of Psychology, University of Wales, Bangor, Adeleidad Brigantia, Penralt Road, Gwynedd, LL57 2AS  
Tel: 01248 388339  
e-mail: [h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)

### Will my taking part be confidential?

If you agree to take part in the study, any information you give the researcher will be kept strictly confidential and will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. Your name will not appear on any of the forms, you will be assigned a study number instead. All information about your identity will be stored separately from data gathered during the study. All data may be held for up to 10 years before it is destroyed. This is following recommendation by the Medical Research Council. Any information you give to the researcher will not be shared with anyone outside the research team without your consent, unless the researcher feels that either yourself or others are likely to be harmed.

If you agree to take part, we will need to look at your medical notes to check that you are suitable for the study. If you are under the care of a mental health NHS Trust, a copy of your consent form will be copied into your usual medical notes and this copy may

be reviewed by the Trust Clinical Audit Department to confirm that you have given written informed consent.

We will ask for your consent to audio record some of the assessments. These recordings are made to ensure that the researchers keep to the same research format and to help us with scoring the assessments.

*You may decline permission for us to use the audio recorder at any time and still take part in the study.*

### **What will happen to the results of the research study?**

If you take part in the study you will be informed of the overall results by post. The findings will be presented to a range of mental health professionals and service users. It is intended that the results of the study will be published in a scientific journal.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent party called a Research Ethics Committee in order to protect your safety, rights, well-being and dignity.

### **Further Information**

If you would like any further information or have any questions about the study, please contact:

James Dudley, Assistant Psychologist (Research)  
Greater Manchester West Mental Health NHS Foundation Trust, Psychology Services,  
Bury New Road, Prestwich, Manchester, M25 3BL  
Tel: 0161 772 3634  
e-mail: [james.dudley@gmw.nhs.uk](mailto:james.dudley@gmw.nhs.uk)

If you would like any other general advice or information about taking part in research, please contact:

Jonathan Roberts, Patient Advisory and Liaison Services (PALS),  
Greater Manchester West Mental Health NHS Foundation Trust, Bury New Road,  
Prestwich, Manchester, M25 3BL  
Freephone: 0800 587 4793  
e-mail: [pals@gmw.nhs.uk](mailto:pals@gmw.nhs.uk)

## Appendix 12: Recovery Programme project 3: STAR-T PIS (data used in study 2 & 4)

Participant Information Sheet

Version 4 2/11/10



### Participant Information Sheet

#### Study Title: Self-help Therapy and Recovery Trial (STAR-T)

You are being invited to take part in a research study. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully. We can go over it in more detail when we meet if you like. You can also discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information about. Take time to decide whether or not you wish to take part.

#### Why is the study being done?

The study aims to look at the benefits of a new Recovery Guide+Support for people with psychosis. We would also like to find out about processes involved in recovery from psychosis.

#### Who will be taking part?

We are hoping for 120 people to take part in this study. Participants will all have experience of psychosis, and will need to be aged 18-65, live in the North West of England, and be in contact with mental health services.

#### Why have I been asked to take part?

We are inviting you to take part because you have experience of psychosis. Your keyworker has agreed for us to approach you, or we have spoken to you at a voluntary group.

#### Do I have to take part?

It is up to you whether or not you decide to take part. If you do decide to take part you will be given a copy of this information sheet and be asked to sign a consent form. If you decide to take part you can leave the study at any time without giving a reason. If you decide to leave at any time, or not to take part, this will not affect any of the treatment you usually receive or the standard of care.



**Assessments:** These will involve meeting with a research assistant at a location convenient for you. You will speak to the researcher about your experiences, thoughts and feelings and also fill out some questionnaires. Each assessment visit should take approximately 1 ½ hours to complete. If you prefer we can complete the assessments over two visits instead. You will be able to have a break during the visits if you wish.



**Your decision:** You will meet with a therapist or other researcher who will speak to you about your options. There will be 4 options on offer:

1. You can choose to receive the 'Recovery Guide + low support therapy'
2. You can choose to receive the 'Recovery Guide + high support therapy'
3. You can choose to carry on with your treatment as usual and not receive any extra therapy
4. If you decide that you do not mind which type you receive, you can be 'randomised'. This means that the option you receive will be chosen at random after you have agreed to take part. The random selection is made by a computer, by chance.

For more information about these choices, please see the ['What are my options?' leaflet](#)



**Recovery Guide + support:** You receive your choice of support (high or low) plus treatment as usual, just treatment as usual, or the option you were randomised to receive. This will last about 9 months. Any support will be in addition to your treatment as usual.



**Assessments:** At the end of the 9 months, you will see a researcher again to do the assessments. If you completed a Recovery Guide+Support option, you may also be asked about how you found this. You will also complete the assessments one last time at the end of the study, 15 months after you joined the project. So, in total there will be 3 sets of assessments to complete (at the beginning of the project, at 9 months and at 15 months).

**Reimbursement:** As a token of our appreciation, you will receive £10 for each assessment set you complete.

**What are the good things and bad things about taking part?**

This project will help us to see how useful the Recovery Guide+Support is for people. It will also allow us to understand recovery from psychosis and the impact of giving people choice about their treatment. This may help us to improve services for people with psychosis and help them to recover.

We don't expect any disadvantages but it is possible that talking about your experiences may cause some distress. We will check if you have any concerns. If you wish, you will be able to talk to a clinical psychologist to discuss what to do next and what support is available. We can also speak with your clinical team if you wish.

**What do I do if something goes wrong?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to help or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to [research-governance@manchester.ac.uk](mailto:research-governance@manchester.ac.uk).

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester and NHS but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

The University of Manchester has cover for no fault compensation for bodily injury, mental injury or death where injury has resulted from a trial or procedure you received as part of the trial. This would be subject to policy terms and conditions. Any payment would be without legal commitment. (Please ask if you wish to have more information on this). The University would not be bound to pay this compensation where the injury resulted from a drug or procedure outside the trial protocol or the protocol was not followed.

**Will my taking part be confidential?**

If you agree to take part in the study, any information you give the researcher will be kept strictly confidential. We will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. Your name will not appear on any of the forms, we will give you a study number instead. Any information you give to the researcher will not be shared with any staff without your consent, unless the researcher feels that either yourself or others are likely to be harmed.

If you agree, we will contact your GP and other appropriate professionals to let him/her know that you are taking part in the study. We will also need to look at your medical notes to check there is nothing that would prevent you from taking part in the project, and to see what treatments you have previously received. As you are under the care of a mental health NHS Trust, we are required to put a copy of your consent form into your usual medical notes. This copy may be reviewed by the Trust Clinical Audit Department to confirm that you have given written informed consent.

We will ask for your consent to audiotape some of the assessments. These recordings are made to make sure that the researchers keep to the same research format and to help us understand more about what happens in therapy and assessment.

*You may decline permission for us to use the tape recorder at any time and still take part in the study.*

We will also ask for your consent to record the therapy sessions, if you receive the Recovery Guide+Support. These recordings are made to make sure that you receive the best support possible.

You may decline permission for us to record therapy sessions at any time and still take part in the study.

### What will happen to the results of the research study?

If you take part in the study you will be informed of the results. The findings will be presented to a range of mental health professionals and service users. It is hoped that the findings will improve mental health services. We also aim to publish the results of the study in a scientific journal.

### Who is organising and funding the research?

This study is funded by a grant from the National Institute for Health Research. It is organised by Greater Manchester West Mental Health NHS Foundation Trust, in partnership with a number of other NHS trusts. The research is being done in collaboration with staff from the University of Manchester.

### Further Information

If you would like any further information or have any questions about the study, please ask the trial manager:

Samantha Hartley  
Division of Clinical Psychology  
University of Manchester  
Zochonis Building, 2<sup>nd</sup> Floor  
Brunswick street  
Manchester  
M13 9PL

Tel: 0161 275 8497

Email: [samantha.hartley@manchester.ac.uk](mailto:samantha.hartley@manchester.ac.uk)

If you would like any other advice or information about taking part in research, please contact:

Jonathan Roberts  
Patient Advisory and Liaison Services (PALS)  
Greater Manchester West Mental Health NHS Foundation Trust  
Bury New Road  
Prestwich  
Manchester  
M25 3BL

Freephone: 0800 587 4793

E-mail: [pals@gmw.nhs.uk](mailto:pals@gmw.nhs.uk)

## Participant Information Sheet – Part 1

**Title of project:** Cognitive Behavioural Suicide Prevention for Psychosis (CBSPP)

*We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.*

### **Introduction – What is this research about?**

Many people during recovery from their illness are overcome with feelings of sadness and hopelessness which may lead to thoughts or attempts at suicide. Feelings of 'not wanting to go on' can be very distressing for the individual and also their friends and family and can also interfere with their hopes and goals for the future. The aim of this research is to test out in a clinical trial a psychological treatment which aims to reduce the vulnerability to such distress and to reduce such obstacles to achievement in the future.

### **Why have I been chosen?**

We are inviting people into the trial who have experience of psychosis, who currently have contact with a mental health team and who have had previous suicide attempts or current suicidal ideas. In total we aim to recruit 60 participants. You have been referred to us by your Care-Coordinator.

### **Do I have to take part?**

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

### **What will happen to me / what will I have to do if I take part?**

If you decide to take part, it will involve first of all filling in a number of questionnaires, which will ask you about your thoughts, feelings, and events in your life, and also talking to a research assistant about some of your experiences. You will then be asked to talk to a research assistant about things leading up to previous suicide attempts or current suicidal thoughts. This will be audio taped so that the researcher can look for any common themes. The tapes will be kept in a locked cabinet and destroyed at the end of the study. In total this will take around 2 ½ hours and can be done over two or more sessions.

You will be asked to do the same again after 3 and 6 months. Your clinical notes will also be examined to assess for any changes during the course of the trial.

Sometimes we don't know which way of treating individuals is best. To find out, we need to compare different treatments. We put people into groups and give each group a different treatment. The results are compared to see if one is better. To try to make

sure the groups are the same to start with, each patient is put into a group by chance (randomly). Half of the people who agree to take part will be offered a psychological treatment in addition to their usual care and treatment, the remaining half will receive their usual care without any additional treatment.

If you are in the group receiving the psychological treatment, it will consist of 2 weekly sessions for 12 weeks (each session will last for about 1 hour) with a clinical psychologist. The sessions will focus on processes that are thought to make people more resilient to suicide and hopelessness. This will include the therapist helping you to; control what you pay attention to, remember positive memories, remember when you have successfully solved problems, and to change the way you think about things that have happened to you in the past. You will then be asked to give us feedback of your experience of the treatment.

#### **Expenses and payments**

You will receive a payment of £5 when you have completed the questionnaires and interview. You will then receive a further £5 when you complete the questionnaires and interview after 3 months, and again at 6 months. However, you will not receive any additional payments for attending therapy sessions.

#### **What are the alternatives for treatment?**

You can access treatment in the usual way, via your care team, regardless of whether you take part in this research trial or not.

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

It is hoped that this intervention could have the real possibility of reducing distress self-harm and risk of suicide. However, it is possible that talking about some of these issues may be upsetting.

#### **What will happen when the research study stops?**

When the study ends, if you were one of the people who received therapy, your therapist will discuss with your care team any relevant information that may help with your continuing care. You will no longer be able access the treatment that you had in the research trial, but you will continue to receive your usual care.

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

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

#### **Will my taking part in the study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence

## Appendix 14: Study 3: Delphi study PIS

### HOW IS CONFIDENTIALITY MAINTAINED?

You will not be asked to provide your name or any personal information when you take part in this study. If you choose to provide an e-mail address so that we can contact you about the second stage of the study, this email address will be stored separately from your responses to ensure that your answers are completely anonymous. We will provide instructions about how to set up a new free anonymous email account if you prefer not to use your personal email address.

All of the anonymized data will be stored on a password-protected encrypted computer for at least 5 years after completion of the research. Data will be handled and stored in accordance with the Data Protection Act of 1998. Only researchers involved in the project will have access to the study database.

### WHERE WILL THE RESEARCH BE CONDUCTED?

We think that most people will take part in this study online by clicking on the link so participation is possible on any device which has an internet connection. However, if you do not have access to a computer and are happy to provide an alternative method of contact (eg. Postal address), a paper copy of the survey can be sent to you with a return envelope provided.

### COMPLAINTS

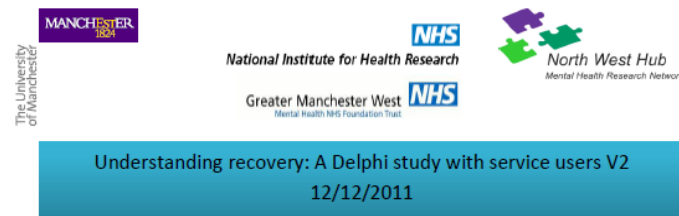
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or by email to [research-governance@manchester.ac.uk](mailto:research-governance@manchester.ac.uk)

This project has been approved by the NRES Committee East Midlands

### WHERE CAN I OBTAIN FURTHER INFORMATION IF I NEED IT?

If you require any further information about this study, please contact Heather Law on:

0161 772 3672 or at [heather.law-2@postgrad.manchester.ac.uk](mailto:heather.law-2@postgrad.manchester.ac.uk)



## WHAT DOES RECOVERY MEAN TO YOU?

<http://www.psych-sci.manchester.ac.uk/projects/12327>

Service users should be  
acknowledged as  
“EXPERTS  
on their  
own experiences”

(British Psychological Society, 2000)

## Background

### **PSYCHOSIS**

The word psychosis describes a common set of experiences including hearing voices, seeing things, unusual thoughts and unusual beliefs (eg. believing that you have special powers or are receiving messages from the television). Many people will have these experiences to some degree, but for some people experience of psychosis may interrupt or disturb daily activities or cause distress. When this happens, people sometimes refer to these experiences as symptoms.

### **RECOVERY**

In society we often use the word recovery to describe 'a return to feeling well' after illness. In the context of mental health the word recovery has recently become more common place and many mental health services are adopting a "recovery approach". Despite this, it is not often clear what we mean by recovery or what services are trying to achieve with a 'recovery approach'.

### **ASKING THE EXPERTS**

Service users and people with personal experience of psychosis should be recognised as "experts by their experiences". However, so far no one has asked a large number of people with experience of psychosis to share their views. Therefore, as part of a larger project entitled "Understanding recovery from psychosis", this web based study will consult people with personal experience of psychosis and ask them what recovery is and what it means to them.

### **WHO IS CARRYING OUT THE PROJECT?**

The study is part of the Recovery Programme of research which is funded by the National Institute for Health Research. It is being carried by researchers at Greater Manchester West Mental Health NHS Foundation Trust and the University of Manchester. It is also supported by the Mental Health Research Network.

### **DO I HAVE TO TAKE PART?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to complete an online/paper consent form. If you decide to take part and then later change your mind, you can withdraw without giving your reasons. However, please note that withdrawal from the study is possible only up to the point at which your responses are submitted. Your responses are recorded anonymously and will not be identifiable after submission.

### **WHAT WILL I BE ASKED TO DO IF I TAKE PART?**

You will be asked to provide a few details about yourself, (age, gender, location) and either your diagnosis or your own description of your experiences. You will also be asked if you would like to provide an email address, so we can contact you about the second stage of the survey.

#### **Stage 1**

- Rate a list of statements according to how important and relevant you think the statements are to understanding what we mean by the term recovery.
- You will also be given the opportunity to add to or amend this list of statements.

The list of statements will look like a questionnaire or survey, and you will simply select your response for each statement like the example below:

#### ***Recovery is about making sense of experiences of psychosis***

Essential	Important	Do not know / depends	Unimportant	Should not be included
1	2	3	4	5

When the results of stage one are returned, we will look to see which statements the majority of people agree are important and relevant to defining recovery. These will automatically be included in the final statement list. Those which people agree are *not* important or relevant will not be included.

#### **Stage 2**

Using the responses from the first stage, any statements which people didn't agree on, or any newly added items, will be used to create a second survey, with a similar format to the first survey.

If you agree to take part in the second stage, we will send you this amended list of statements in a survey and ask you to rate them again.

This type of two stage survey is often used to consult experts on a variety of topics, and is a useful way of asking lots of people for their opinions and then trying to decide where those opinions are similar and how this can be used to further our understanding of the topic.

## Appendix 15: Study 5 PIS

The University  
of Manchester

MANCHESTER  
1824

Project no  
11289

### School of Psychological Sciences

#### Participant Information Sheet

**Title of project: Exploring attitudes toward recovery in psychosis- a web based study**

You are being invited to take part in an online research study. Before you decide whether to take part or not, it is important that you understand why the research is being done and what it will involve. Please take some time to read the following information carefully and to decide whether or not you wish to take part. If you would like more information or have any questions, just get in touch with us using the email address at the end of this page.

The word psychosis describes a common set of experiences including hearing voices, seeing things, unusual thoughts and unusual beliefs (e.g. believing that you have superhuman powers or are receiving messages from the television). Many people will have these experiences to some degree, but for some people experience of psychosis may interrupt or disturb daily activities or cause distress. When this happens, people sometimes refer to these experiences as symptoms.

In society we often use the word recovery to describe 'a return to feeling well' after illness. In the context of mental health the word recovery has recently become more common place, and as well as including the idea of feeling well, it often incorporates themes of empowerment and hope about ones future.

As part of a larger project entitled "Understanding recovery from psychosis", this web based study will explore people's beliefs, attitudes and knowledge about the concept of recovery in psychosis.

#### **What will I be asked to do if I take part?**

If you agree to take part you will be asked to provide a few details about yourself, to complete a brief computer based word sorting task and to answer a short survey on attitudes towards recovery. Overall, taking part in this study should take no longer than 25 minutes.

We will ask a few details about you, including your age, gender, occupation, location (region of the UK) and whether you have personal or professional experience of psychosis and/or recovery in psychosis. You will not be asked to divulge any more detailed personal information and you are under no obligation to answer any questions if you would prefer not to. You will also be asked if you would like to be entered into a prize draw for a £20 shopping voucher and whether you would be happy to be contacted about research on this topic in the future. To enter this draw or take part in future research, you will need to provide a contact email address (this is optional and is used to notify the winner of the prize draw and/or contact you about further research).

The computer based task should last around five minutes and involves sorting words relating to recovery and psychosis into categories by pressing a left or right key. This task is timed, so you will be asked to sort the words as quickly as possible, and you will be prompted if you make a mistake. The word sorting task includes a variety of words relating to psychosis and recovery, including some words which may not be appropriate or acceptable to you personally. These words have been included in the



**Appendix 16: Recovery programme project 1 Consent form (data used in study 2 & 4)**

SEPSS testing consent form Version 2 12.01.2009



**Greater Manchester West**  
Mental Health NHS Foundation Trust

**CONSENT FORM**

Client Identification Number for this study: .....

Title of Project:

~ A study to test the Subjective Experiences of Psychotic Symptoms Scale (SEPSS)~

Name of Researcher: Lisa Wood

Name of Participant:

- 1. I confirm I have read and understand the participant information sheet (PIS) dated 14.10.08. (version 1) for the above study 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 agree to take part in visit 1 outlined on the PIS.
- 4. I agree to take part in visit 2 (in 1 – 2 weeks time) outlined on the PIS
- 5. I agree to take part in visit 3 (in three months time) outlined on the PIS.
- 6. For the purpose of the study, I agree to the research team having access to my medical notes.
- 7. I consent to the use of audio recording if necessary.
- 8. I consent to my name being passed to other projects in the 'Recovery Programme' for possible participation
- 9. I consent to my GP being informed about my involvement in this research project

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

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

## Appendix 17: Recovery Programme project 2: Consent form (data used in study 2 & 4)

Understanding Recovery In Everyday Life: An Experience Sampling Study - consent v4 20.12.2011  
service users



### CONSENT FORM

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

Title of Project: *Understanding Recovery In Everyday Life: An Experience Sampling Study*

Name of Researcher:

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet (PIS) dated 20/12/2011 (version 6.0) for the above study 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 agree to take part in the study and agree to the necessary contact as outlined on the PIS once three months after initial assessment by telephone, and a face-to face session 6 months following initial assessments).
4. I give my consent for assessment sessions to be tape-recorded where necessary.
5. I give my consent for my name to be passed to other projects within the 'Recovery Programme' for possible participation in other studies
6. I give my consent for anonymised information gathered in this project to be shared with other projects within the 'Recovery Programme', should I choose to participate in other projects.
7. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the individuals from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
8. I understand that my information will remain confidential unless there are concerns about the safety of myself or others, in which case this information will need to be passed on to an appropriate person.

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

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix 18: Recovery Programme project 3: STAR-T Consent form (data used in study 2 & 4)**

*1 copy for service user; 1 for researcher; 1 to be kept with medical notes* Version 3 02/11/10



**CONSENT FORM**

Client Identification Number for this study: .....

Title of Project: Self-Help Therapy and Recovery Trial (STAR-T)

Name of Researcher:

Name of Participant:



Please initial box

- 1. I confirm that I have read and understood the information sheet dated 02/11/10 (version 4) for the above study and have had at least 24 hours to consider it and been given 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 agree to take part in the study.
- 4. I give my consent for assessment sessions to be audio-recorded.
- 5. I give my consent for therapy sessions to be audio-recorded.
- 6. I give my consent for my GP and other appropriate professionals to be informed about my participation in the study.
- 7. I give my consent for my medical notes to be reviewed by a researcher in the study.
- 8. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 9. I give my consent to be asked to participate in an interview about my experiences in the project. If I agree to participate in the interview, I give my permission for this to be audio-recorded and direct quotes from the interview to be published.
- 10. I give my consent for my name to be passed on to other projects in the Recovery Programme for possible participation in other studies, and for information to be shared across projects if I do take part.

_____ Name of Service user	_____ Date	_____ Signature
_____ Name of Person taking consent	_____ Date	_____ Signature
_____ Name of Researcher	_____ Date	_____ Signature



**Appendix 19: Recovery programme project 4: CBSP Consent form (data used in study 2 & 4)**

The University of Manchester

**MANCHESTER**  
1824

Application Ref: 08/H1012/97, 06/03/2014, Version 2

Study  
Number

Consent form

Title of Project: Cognitive Behavioural Suicide Prevention for Psychosis (CBSPp)

*The participant should complete the following part of this sheet him/herself*

	please delete as necessary and initial
1. I Have read the Participant Information Sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	YES/NO Initials:.....
2. I understand the aims of the study and what I will be asked to do if I take part	YES/NO Initials:.....
3. I understand that I do not need to take part in the study and if I do enter I am free to withdraw:-  * at any time  * without having to give a reason for withdrawing  * and without detriment to myself	YES/NO Initials:.....
4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the research team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	YES/NO Initials:.....
5. I agree to my interviews being tape recorded	YES/NO Initials:.....
6. I agree to take part in this study	YES/NO Initials:.....
7. I agree to my GP being notified about my involvement in this study	YES/NO Initials:.....
8. If I withdraw from the study, I agree that the data already collected can be retained and used.	YES/NO Initials:.....

Name of participant: ..... Signed: ..... Date: .....

Name of researcher: ..... Signed: ..... Date: .....

Project researchers: Natasha Snelson & James Kelly  
Project supervisor: Prof Nicholas Tarrier