

# The Predictive Factors of Subjective Recovery in First-episode Psychosis

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#### **OVERVIEW**

This thesis investigates subjective recovery from first-episode psychosis (FEP). Part 1 is a literature review, considering how recovery from FEP has been conceptualised and measured in the literature, including symptom reduction, functional improvements and subjective recovery. It considers the validity of applying such measures and concepts to individuals adjusting to the effects of a first episode of psychosis. Part 2 is an empirical paper investigating whether certain demographic and clinical variables are associated with subjective recovery in an FEP group. It considers whether objective measures of recovery such as symptom remission and improved functioning are associated with subjective recovery. Part 3 is a critical appraisal of conducting parts 1 & 2. It considers how the experience of conducting this study relates to wider research dilemmas.

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# PART 1

# LITERATURE REVIEW

# What do we mean by recovery from first-episode psychosis?

#### **ABSTRACT**

Conceptualisations of recovery from psychosis have evolved over time, from medically defined models of symptom reduction, to more recent definitions of subjective recovery. First-episode psychosis (FEP) individuals present as a group who are in the early stages of adjustment to the experience of a psychotic illness. Due to the typically early age of onset, they are also in the process of adjusting to major life and role changes. This paper addresses how recovery from FEP has been conceptualised and measured in the literature, and focuses on the validity of applying such measures and concepts specifically to an FEP group.

Key terms: First episode psychosis, subjective recovery, recovery and early intervention in psychosis.

#### Introduction

The long-term course following an initial psychotic episode is by no means one of a chronic illness, and there is now a considerable body of literature investigating recovery from early psychosis. However, various studies have conceptualised 'recovery' in many different ways with the conceptualisation and assessment of recovery falling along a continuum from more objectively to more subjectively based indicators of outcome (Jenkins, Strauss, Carpenter, Miller, Floersch & Sajatovic, 2005). Recovery from severe mental illness is also multi-faceted, however, most studies have often only looked at only one or two dimensions of recovery. These different conceptualisations will affect the rates of recovery encountered, and will also affect the focus of any treatment interventions provided. In the UK, the National Institute for Metal Health (NIMHE) has acknowledged that 'people have differing views of what recovery means, whilst the word is being included in common usage in mental health services, a clear understanding of what this means remains limited' (Department of Health, 2005). So, what exactly do we mean by 'recovery' and what is the most useful way of measuring this when assessing recovery in a first-episode psychosis group?

The broadening conceptualisation of recovery from psychosis

Over the course of the latter part of the 20<sup>th</sup> century, there has been a progressive broadening in the conceptualisation of recovery from serious mental illness. There has been a gradually emerging recovery vision that has developed in line with the changes occurring in mental health service delivery (Anthony, 1993). Institutions

that focussed narrowly on symptom alleviation have been replaced by community based services, attempting to provide more comprehensive services addressing people's multiple residential, social, vocational and educational needs. Over time there has also been a broadening in how psychosis itself is conceptualised, and this, in turn, has affected how recovery from psychosis is understood. The various definitions of recovery can be conceived of as being on a continuum, with three identifiable points (Fitzpatrick, 2002): (i) the medical model assumes mental illness is a disease and recovery would mean returning to the state prior to illness; (ii) the rehabilitative model assumes the illness is incurable but with effort the person can improve their quality of life; and (iii) the empowerment model which denies that psychosis has a biological foundation, but is due to psychological/psychosocial distress, and the person's response to this distress plays a crucial role in the subsequent course of their psychosis. This broadening in the conceptualisation of psychosis and recovery is acknowledged in official national health department guidance. In the U.S., the Commission for Mental Health, (2003) defines recovery by saying 'that for some people this will involve a complete reduction in symptoms, and in others it will be the ability to live a satisfying and productive life despite possible ongoing symptoms of illness'. In the U.K., the NIMHE acknowledges the difficulties in providing a definitive definition, and instead provides six definitions to include a breadth of meanings such as a return to wellness, achieving a personally acceptable quality of life, restoration, optimum quality of life and satisfaction (Department of Health, 2005).

First-episode psychosis

First-episode psychosis (FEP) has more recently become a discrete area of interest within psychosis research. This development is based upon the notion of a 'critical period' that may influence long-term course and outcomes (Spencer, Birchwood & McGovern, 2001). This has lead to a growing number of specialised services working to reduce the time between onset and treatment of symptoms, and to provide community-based treatment and support to young people with psychosis and their families, with an emphasis on maintaining normal social roles (Department of Health, 2001). Concomitant to the development of these specialist early intervention services, and in line with the aims of Evidence Based Practice, there has been a growth in research into people's outcomes from a first episode of psychosis. However, as with research into long-term psychosis, there remains considerable variety in the outcome measures used in attempting to assess recovery. A review of psychosocial treatments for FEP summarises many studies evaluating the effectiveness of multi-element treatments for early psychosis (Penn, Waldheter, Perkins, Mueser & Lieberman, 2005). Penn et al., (2005) grouped the various studies' collective findings into four positive domains of core outcome: symptoms; negative symptoms; relapse/hospitalisations; and social functioning/quality of life. They also noted individual studies using further outcome and recovery measures, including; reduction in levels of trauma; reduction in levels of aggression; reduction in incidence of selfharm; reduction in substance use; reduction in depression; reduction in suicidal behaviour; improvements in cognitive functioning; improvements in insight; and reductions in experienced levels of hopelessness. Menezes, Arenovich and Zipursky, (2006) also recently provided a systematic review of longitudinal outcome studies of FEP. In a summary of 37 studies the authors commented on the wide variety of outcome definitions used, some of these including: relapse; readmission;

hospitalisation time; Clinical Global Impression Scale; Brief Psychiatric Ratings Scale (BPRS); Positive and Negative Symptoms Scale (PANSS); employment; Global Assessment of Functioning Scale (GAF); Camberwell Assessment of Need; Social and Occupational Functioning Assessment Scale; compliance; social functioning; suicidal behaviour; quality of life; and living status. Of these measures, the majority fall towards the objective end of the continuum. However, there are some that have some subjective qualities, such as quality of life, and measures that assess the degree of hopelessness, although the use of subjective measures remains rare.

Services set up to work with FEP are in many ways a potential gateway to services working with established 'chronic' cases of psychosis. Unlike services working with largely chronic 'sufferers', FEP services encounter a wider variety of presentation, and therefore a wider variety of 'recovery'. With this in mind it is worth considering how a successful outcome can be evaluated with this client group, and the validity of the various definitions of recovery when used with this group.

#### **Outline**

This study will look at how recovery from FEP has been conceptualised and measured in the existing body of literature, and how this process has evolved. For clarity I have structured this review into three main sections based on categories of recovery suggested by the objective-subjective continuum model (Jenkins et al., 2005). Firstly, recovery has been conceived of as symptom reduction. I will only briefly summarise research in this area, as it represents a very large body of literature.

The interested reader can refer to (Menezes et al., 2006) for a review of longitudinal outcome studies of FEP. Secondly, I will review studies that included in addition other objective, yet non-symptom related measures of recovery that are often referred to as 'functional' recovery. Thirdly, this review will consider measures of 'subjective' recovery, including measures designed to be independent of symptoms and functioning.

Inevitably, there is much overlap in the literature between recovery research in FEP and longer-term psychosis. However, this review will attempt to focus on the validity of applying such measures and concepts specifically to an FEP group.

#### 1. Symptom reduction as recovery in first-episode psychosis

A perhaps narrow, but frequently used, definition of recovery is that measured by a reduction in psychotic symptoms, such as hallucinations and delusional beliefs. This medical model of recovery views psychosis as a serious mental illness, that once diagnosed, will usually require medication for symptoms to remit and to remain symptom free. Definitions such as these do have clear face-validity as a measure of recovery from psychosis. It can be argued that ethically, symptoms such as persecutory hallucinations and paranoid delusions are distressing for many individuals, and their reduction is often appreciated (O'Toole, Ohlsen, Taylor, Purvis, Walters & Pilowsky, 2004).

Symptomatic outcomes of FEP

Symptom reduction is dominant in the outcome literature for any form of psychosis, including FEP. Of the 37 FEP studies (Menezes et al., 2006) reviews, symptom reduction is a feature of the majority of these. Measures of symptomatic recovery such as the PANSS and the BPRS, are also ubiquitous in service settings. Once stabilised on anti-psychotic medication, there is good evidence for favourable treatment outcomes in FEP based on this definition of recovery. Based on remission defined as a score of 3 or less for at least 2 weeks on any BPRS items: hallucinations, conceptual disorganisation, unusual thought content and suspiciousness, 72% of patients achieved rapid remission of symptoms at 3-month follow-up (Wade, Harrigan, Harris, Edwards & McGorry, 2006).

#### Limitations of symptom reduction

If symptom reduction as a definition of recovery is used alone, this would suggest that the vast majority of patients quickly achieve recovery, and there would remain little more to do. However, although approximately three quarters of individuals with first-episode psychosis showed symptom remission at 6 months, most (79.8%), failed to show functional recovery during the same time period (Tohen, Strakowski & Zarate, 2000). In a review of research into psychosocial treatments for FEP, Penn et al., (2005) conclude that despite symptomatic recovery, individuals with FEP tend to experience impairments in general social functioning (Addington, Young & Addington, 2003; Grant, Addington & Addington, 2001), quality of life (Gupta, Andreasen, Arndt, Flaum, Hubbard & Ziebell, 1997; Priebe, Roeder-Wanner & Kaiser, 2000), and occupational functioning (Svedberg, Mesterton & Cullberg, 2001).

This suggests that it is common for individuals who no longer experience psychotic symptoms to continue to feel they are unable to work or regain previous social roles.

Poor functioning despite symptomatic remission

As a result of social decline with the advent of psychosis a young person is likely to have been sidetracked from previous life goals. The young person may have lost jobs, lost friendships, or dropped out of school. Clearly, pharmacotherapy alone is not sufficient to prevent relapses or assure functional recovery from the consequences of acute psychosis. In such cases, considering symptomatic remission alone as the definition of recovery is inappropriate.

Equally, individuals who, to the 'objective' clinical observer, appear to be 'recovered', may not subjectively consider themselves to be so. This may be because: (i) they do not feel like the same person that they were before the experience of psychosis; (ii) they continue to use medication (Chen, Hui & Chiu, 2005) or other illness strategies; or (iii) they do not believe that it is possible for people with mental illness to get better (Whitwell, 1999, cited in Andresen, Oades & Caputi, 2003). There is likely to be a further link between engagement in social roles and general well-being, and this in turn may influence the course of the psychosis and treatment adherence.

Good functioning despite the continuing presence of symptoms

It is also worth considering the group of individuals who may continue to experience some psychotic symptoms such as auditory hallucinations, yet are able to return to work and lead relatively normal social lives (Romme & Escher, 2000). It is also possible that individuals may continue to experience psychotic symptoms without experiencing distress and manage without professional intervention (Johns & van Os, 2001). This group would not be considered to have 'recovered' using a definition of symptomatic recovery, and this highlights the limitation of using a purely medical model definition of recovery. This example serves to reiterate the need for a definition of recovery that accounts for the role of subjective distress as a result of symptoms.

Possible problems raised by reliance on adherence and 'insight'

The high rate of rapid remission of symptoms would seem to be largely dependent on adherence to anti-psychotic medication. Adherence is a significant problem, with many patients holding negative views about services' focus on medication, with over 50% of all patients demonstrating difficulties in adhering to prescribed medication (Fenton, Blyer & Heinsses, 1997). The assessment of 'insight', is usually based on whether the individual's understanding of psychosis concurs with that of medically trained mental health staff. While denial of mental illness may lead to non-compliance and subsequent relapse, acceptance can lead to pessimism, loss of self-efficacy and absorption of the pejorative stereotypes of mental illness (Birchwood, Todd & Jackson, 1998). First episode patients are often less aware of having an illness than multiple episode patients (Thompson, McGorry & Harrigan, 2001). Whilst most studies show better long-term outcomes for those with an integrative

recovery style, those with a sealing-over coping style actually had better short-term outcomes with regard to depression (Jackson, McGorry, Edwards, Hulbert, Henry & Francey, et al., 1998). This suggests that in the early stages of recovery from psychosis acceptance of an 'illness' may lead to depression, whereas denial may be protective.

Possible problems raised by conceptualising psychosis as 'illness'

A further criticism of relying solely on symptom reduction in determining recovery is that this is predicated on a medical model of psychosis, and recovery depends on psychosis being conceptualised as 'illness'. An alternative view is that mental illness can be conceptualised as severe emotional distress combined with the loss of a social role (Ahern & Fisher, 2001). If mental illness is a label, and not primarily based on biological status, recovery from FEP cannot be considered to have occurred without reference to emotional distress or social roles (Ahern & Fisher, 2001). Some patients and professionals would argue that psychotic experiences are meaningful events in the person's life (May, 2000; Reeves, 2000). For the service user the psychosis may be viewed as a coping reaction to trauma and conflict, whereas psychiatry may view the trauma as a trigger, rather than a cause, and be focussed on obliterating or controlling what they view as a brain disease (Reeves, 2000). Personal growth may be possible through the unusual experiences of psychosis, but the sedation of neuroleptics does not allow this growth to occur naturally, and might actually hinder a person from resolving traumatic experiences (Reeves, 2000).

#### Summary

In summary, a definition of recovery from FEP as symptom remission does provide good evidence of favourable outcomes, is widely used, and can relieve distress. It is reasonably concrete and operationalisable, and is manageable for both research and clinical outcome monitoring. Such a definition would not, however, be appropriate for either individuals who cope well with symptoms or individuals who have no current symptoms, but have not returned to previous social roles. A definition of recovery from FEP that relied solely on remission of symptoms would miss out on issues of functional recovery and of the individual's appraisal of their illness, which could both impact on overall outcome. It is based on the medical model of illness, and often relies heavily on 'insight' and medication adherence. The absence of both of these factors is common in those experiencing FEP. An over emphasis by clinicians on either of these factors could affect engagement, one of the key aims of specialist services.

#### 2. Other objective measures (functional recovery)

More recently it has been rare for symptom reduction alone to be considered as an adequate definition of recovery. Lieberman and Kopelowicz, (2005) claim to speak for many medically trained professionals when they define recovery from psychosis as a remission of symptoms *and* a return to pre-morbid levels of functioning. Whitehorn, Brown, Richard, Rui and Kopala, (2002) propose their criteria for defining recovery as five symptom dimensions and two functional dimensions. They recommend a battery comprising of: PANSS; GAF; Social and the Occupational

Functional Assessment scale. Measures assessing functional recovery are also widespread in the research literature. Of the 37 studies reviewed by (Menezes et al., 2006), 27 report outcomes of education/employment, 11 report functional recovery, and 31 report a mean rating from the GAF. These measures are also widely utilised in clinical outcome monitoring. Eighty percent of first episodes of psychosis occur between 16 and 30 years of age (Shiers & Lester, 2004), when individuals are at a critical time in their intellectual and social development, as reflected in the 'critical period' hypothesis (Birchwood, 2000). This theory has been a significant factor in service development focusing on functional recovery and therefore functional recovery would appear to be an important factor in assessing recovery within an FEP group.

#### Functional outcomes of FEP

An investigation of long-term follow-up 5-25 years after the initial episode, shows that about half of patients eventually recover, or have only mild impairment, based on a definition of sustained improvement in both symptoms and social/vocational functioning (Harding, 1988, cited in Robinson, Woerner, McMeniman, Mendelowitz & Bilder (2004); Harrison et al., 2001, cited in Robinson et al., 2004). When focusing on symptomatic and functional recovery in the early course of schizophrenia the overall rate of recovery remains low, and much lower than when measured by symptom remission alone. Robinson et al., (2004) found that symptom remission was achieved by 47.2% of their sample, with 25.5% achieving adequate social functioning for two years or more, but only 13.7% met both these criteria. Therefore for an FEP group symptom remission may be a reasonable short-term goal,

however, it might be expected that functional recovery would be slower to develop. Clinicians are likely to concur that recovery of social and occupational functioning requires a longer period of time than symptom reduction.

Poor employment outcomes are a consistent finding of research into first-episode psychosis (Gupta et al., 1997; Singh, Croudace, Amin, Kwiencinski, Medley, Jones et al., 2000). FEP studies show higher rates of unemployment compared with established cases of schizophrenia, with many individuals being already unemployed when making initial contact with services (Birchwood et al., 1992, cited Marwaha & Johnson, 2004), however they note that in these studies it was often unclear whether a premorbid or morbid employment rate was being described (Marwaha & Johnson, 2004). Over time there remains a substantial fall in employment rate, with a baseline rate of 52% dropping to 25% after one year, and with a baseline rate of 65% dropping to 49% at 2-year follow-up (Johnstone et al., 1986, cited Marwaha & Johnson, 2004). During these early years of recovery many FEP individuals become dependent on state welfare or family support. Findings such as these suggest that for an FEP group the short-term prognosis for functional recovery is not hopeful. Therefore, an over-reliance on functional measures of recovery may result in poor outcomes, and a sense of disappointment for all parties involved.

#### Adaptations needed for FEP

When predicting vocational recovery following a period of psychotic illness, the most consistent and strongest relationship established in the general psychosis literature is with pre-morbid social and occupational history. Functional outcomes

are therefore strongly influenced by the age of the client and the level of functioning achieved prior to the onset of psychosis. Younger clients who had not yet left home or developed a consistent work history appear in the research findings to have less success in recovering social and occupational functioning. However, due to their relatively young age, those recovering from a first-episode of psychosis are less likely to have a well-established pre-morbid social and occupational history and it may therefore be unrealistic to set a standard of 'a complete return to functioning' by which to measure their functional recovery. When evaluating functional recovery in an FEP group, it would be deceptive to rely too heavily on measures of employment. While employment is one outcome, this age range should also include the age-appropriate outcome of engagement in education. Young people might not have worked before becoming unwell, or may not view returning to work or education as a valued goal. Therefore, it is important to consider the baseline of functioning that the individual is expected to return to.

#### Functioning related to other factors in recovery

There is also wide recognition of an interaction between a client's engagement in meaningful activities, and improvements in other areas of recovery, such as symptoms, mood, preventing further relapses, promoting social inclusion and reducing discrimination. Evidence suggests that employment can lead to improvements in outcome for people with psychosis through increasing self-esteem, alleviating psychiatric symptoms and reducing dependency (Cook & Razzano, 2000, cited Marwaha & Johnson, 2004). Social roles and goals, particularly work, are highly prized by young people (Spencer et al., 2001). They provide a source of self-

esteem that can affect the psychosis itself (Warner, 2004), and the loss of social roles and goals has been linked to depression and suicidal thinking in psychosis (Birchwood et al., 2000b, cited Spencer et al., 2001). The experience of psychosis can exclude a young person from a sense of autonomy, employment and youth culture (Birchwood, McGorry & Jackson, 1997). A supportive social environment for recovering is one of the five essential treatment principles (McGorry, 1992, cited Young & Ensing, 1999). There is a consistent link between higher levels of social support and lower levels of psychological distress (Greenly, 1984, cited Young & Ensing, 1999). It seems plausible that these factors could contribute to a sense of hope, related optimism and self-sufficiency. In a review of research into the extent that work contributes to the recovery of people with schizophrenia, Marwaha and Johnson, (2004) found that working is correlated with positive outcomes in social functioning, symptom levels, quality of life and self-esteem. However, clear causal relationships between these factors have not yet been established.

As discussed above, there is also a complicated relationship between symptoms and functioning. In gaining employment following a psychotic episode, negative symptoms may be particularly important, independent of any relationship to positive symptoms, and substantial positive symptoms do not necessarily make employment impossible (Marwaha & Johnson, 2004).

#### Summary

In summary, a definition of functional recovery from FEP, measured by occupational status, has been widely used, usually in conjunction with symptomatic measures. It

addresses issues raised by the 'critical period' hypothesis, which are also known to be important to young people attending services and therefore can affect subjective recovery factors. However, largely due to the limited predictive power of pre-morbid functioning for individuals experiencing FEP, recovery measured this way is likely to be poor, and remains so during the period covered by specialist FEP services. This may make it an unrealistic goal for many, and an over-emphasis could lead to poor subjective outcomes. It is also important to consider education as an age-appropriate indicator of functioning with an FEP group.

#### 3. Subjective measures of recovery

The definition of subjective recovery is not a lack of evidence of illness, but rather a subjective attitude or orientation asserting that regardless of their state of illness or health, people can have hope, feel capable of expanding their personal abilities, and make their own choices (Resnick, Rosenheck & Lehman, 2004). It is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness (Anthony, 1993). From these various definitions it should be clear that a definition of recovery is not the same as a cure. With a definition such as this, it is possible to live a reasonably normal and full life, even though one *may* be vulnerable to relapse, or *may* even need to be treated with medication indefinitely.

Research into subjective recovery from psychosis

Research into the construct of subjective recovery from psychosis is at an early stage, and few papers have empirically investigated the components and processes involved. There are several narrative accounts of individual journeys of recovery (Forchuk, 2003; May, 2000; Ochocka, Nelson & Janzen, 2005; Ralph, 2000; Tooth, Kalyanasundaram, Glover & Momenzadah, 2003). These studies have suggested attributes and experiences that may be associated with a sense of progressing towards recovery include hope, destigmatisation, empowerment, self-acceptance, insight, awareness, collaboration with professionals, a sense of autonomy and self-control, and participation in self-help and consumer-run programs (Liberman & Kopelowicz, 2005). While these narratives provide valuable insight into achieving a sense of subjective recovery, often the language and terms used differs across the studies. This has lead to a call for an increase in the empirical investigation of the components of subjective recovery, and the socio-demographic and clinical factors related to it (Liberman & Kopelowicz, 2005).

#### Measures of subjective recovery

In line with evidence based practice, a variety of measures have been devised that attempt to assess the degree that an individual feels they have subjectively recovered from a severe mental illness. For a selection of such measures, the interested reader should refer to the Compendium of Recovery Measures (Campbell-Orde, Chamberlin, Carpenter & Leff, 2005). This compendium includes measures such as the Mental Health Recovery Measure (Young & Bullock, 2003), which aims to assess recovery independently of symptoms or symptom management. While many of the Compendium's measures are designed for broader mental health applications,

an additional measure is the Psychosis Recovery Inventory (PRI) (Chen, Tam, Wong, Law & Chiu, 2005), which is designed specifically for use with an FEP group, to assess the patient's own judgement of the extent of their recovery, and the basis upon which this judgement is made. There still exists considerable variety in the exact focus of subjective recovery with these measures. For example, there is variation in the inclusion of use of factors such as, medication, use of services, symptom management and insight.

#### Validity of subjective recovery

Psychotic experiences are meaningful events in the context of people's social lives. Rather than denying such experiences, the focus should be on reducing the debilitating nature of the experience so that people can freely get on with their lives (May, 2000). Even if medication is welcomed by the individual, and symptom remission is achieved, the recovering person faces a number of complex issues. These include the appraisal of the extent of their recovery, the appraisal of the risk of relapse, and making sense of the illness episode and its treatment (Chen, Tam, Wong, Law & Chiu, 2005). These appraisals can effect how the patient reacts to the illness and may impact on its course and outcome.

# Lack of use of subjective recovery measures in the research literature

At present, such measures do not appear to be widely used in longitudinal outcome studies. The systematic review of longitudinal outcome studies of FEP by Menezes et al., (2006), does not mention the use of any outcome variables that can be considered

to be a dedicated measure of subjective recovery. However, there is mention of some use of quality of life measures, and a measure of hopelessness. Quality of life has both an objective and a subjective component, with the subjective component referring to 'life-satisfaction' or 'happiness' while the objective component hinges on aspects of social functioning and environment (Bigelow, McFarland & Olsen, 1991 cited Caron, Lecomte, Stip & Renaud, 2005). Forchuk, (2003) reviews the literature for studies looking at subjective recovery in schizophrenia, and notes that there is generally a focus on the 'expert' assessing symptom severity using measures such as the BPRS and PANSS, and although the subjective experience is often commented upon as being clinically significant, it is frequently missed in terms of a formal measurement.

#### Rates of subjective recovery with FEP

There are very few published studies investigating rates of subjective recovery within this group. One such study that has used a dedicated recovery measure, used the Psychosis Recovery Inventory to assess the perceived extent of subjective recovery with a sample of 48 participants recovering from a first-episode of psychosis. The mean duration of illness within this sample was 19 months. In this group, 10% reported they felt fully recovered, 50% reported they felt they were recovered 75% or more, 71% reported they felt they were more than 50% recovered, and 19% considered themselves to have made a limited recovery of less than 50% (Chen, Tam, Wong, Law & Chiu, 2005).

## Subjective recovery related to other factors of recovery

It has been suggested that subjective recovery interacts with other objective aspects of recovery. For example subjective recovery has been conceptualised as a process rather than an end-point. Markowitz, (2001) suggests a model of the recovery process involving the three factors of symptoms, self-concept and life-satisfaction working in a reciprocal manner. This description of process suggests both symptom management, and the active engagement in 'meaningful' activity would benefit from increased levels of subjective recovery and also contribute to it. Liberman and Kopelowicz, (2005) speak of the subjective and objective factors of recovery being in a dynamic interaction with one another. Thus, the greater the person's symptomatic and functional improvement, the more one would expect subjectively experienced qualities such as hope, empowerment, self-responsibility, and autonomy to be in evidence. Mastery over symptoms, avoiding relapse and managing daily stresses, allows people to spend less time on their symptoms and more time pursuing personal goals. Thus illness management and recovery may be closely related (Resnick, Rosenheck & Lehman, 2004). Resnick, Fontana, Lehman and Rosenheck, (2005) hypothesise that 'important' objective goals such as participation in meaningful activity such as employment are critical in cultivating a recovery orientation.

There are very few empirical studies investigating the factors related to subjective recovery. One study has used multiple regression analyses based on a large sample (N=825), to identify client and service use variables associated with a recovery orientation based on a four factor model; life satisfaction, hope and optimism,

perceived knowledge about mental illness and services, and empowerment (Resnick, Rosenheck & Lehman, 2004). This was with a non-FEP sample with a diagnosis of schizophrenia and a mean age of 44.6 years, though this varied widely (+/- 12 years). The strongest overall relationships they observed were between lower severity of depressive symptoms and each of the four domains. The reported Beta values for each of the domains were small, ranging from -.14 to -.26, however these relationships were highly significant. Aside from this finding, they report that each of the four domains was associated with a somewhat different constellation of factors, which reinforces the complexity of the recovery orientation.

Resnick, Rosenheck and Lehman (2004) also comment on some other relationships observed, which they concluded to be important. Psychotic symptoms were found to have a small negative association with one of the four domains, life satisfaction. They suggest that the treatment of psychiatric symptoms is an important element of recovery. They also report that they found three 'medical' factors were associated with several of their domains of a recovery orientation: reduced symptoms; reduced side-effects of medication; and participation in family psychoeducation. They claim these are especially important as correlates of a recovery orientation, as it suggests that the polarity between the medical model and the subjective model may therefore be unfounded, and that the two approaches are mutually reinforcing. This research was of a cross-sectional design, so causal relationships cannot be determined. The researchers suggest a bi-directional relationship between recovery attitudes and positive clinical outcomes that are the goals of evidence based practice (Resnick, Fontana, Lehman & Rosenheck, 2005). This adds to the debate that objective and subjective measures of recovery may be linked rather than independent.

Contrary to this, it has been suggested that recovery does not require psychotic experiences to disappear (Reeves, 2000). Views such as this suggest that a sense of subjective recovery is possible independently of psychotic symptoms and other objective indicators of recovery. Recovery in this sense is more a case of the individual feeling in control and functioning well in terms of subjective goals, rather than being a victim of their symptoms.

Alternatively, Hatfield and Lefley, (1993) have conceptualised recovery in terms of adaptation at increasingly higher levels of personal satisfaction and interpersonal functioning. This suggests a possible hierarchy of recovery, beginning with symptom management, followed by rebuilding of functioning, and finally integrating the psychotic experience into the self to achieve a sense of subjective recovery. Based on this hierarchy, a sense of subjective recovery would be seen as the final stage of recovery. However, while a general trend may be helpful in thinking about overall recovery, it remains possible for each domain of recovery to be independent at the individual level.

The effect of insight and recovery style on subjective recovery

Despite the evidence presented above, suggesting objective and subjective measures of recovery as being mutually reinforcing, it would be possible for someone to feel completely subjectively recovered, while scoring poorly on objective symptomatic measure items such as grandiose delusions. With this in mind it may not be valid to rely on a measure of subjective recovery alone. This raises the question that a degree

of insight may be necessary for a measure of subjective recovery to be useful. First episode patients are often less aware of having a mental illness than multiple-episode patients (Thompson et al., 2001). It is suggested this may be a psychological defence, in that individuals deny illness, and therefore protect themselves from perceived stigma associated with psychosis. During recovery patients tend to either integrate their illness experiences into their wider life situation, or 'seal over', and keep them separate, so as to maintain their mental integrity. Patients who use an integrative style are characterised by a flexible thinking style, which incorporates psychosis into their wider life experience. These patients use these experiences as a new source of information about themselves and turn it into a positive situation rather than something that needs to be avoided. In contrast, patients who tend to seal over isolate their psychotic episode from the rest of their life and treat it as an inconvenient disruption. Thompson, McGorry & Harrigan, (2003) found that recovery style may be a useful predictor of outcome, with an integrative style associated with better outcomes and functioning at 12-months post-recovery based on three outcome measures at 12-month follow-up: BPRS, quality of life, and the Scale for the Assessment of Negative Symptoms. However, whilst most studies show better outcomes for those with integrative recovery style, (Jackson et al., 1998) demonstrated that those with sealing over coping style actually had better short-term outcomes, (i.e. less depression). This may be particularly pertinent for an FEP group who would generally fall in the short-term range. While under-recognition of the impact of an illness may lead to non-adherence, awareness of the full implications of an illness could overwhelm the coping capacity of the patient, which results in demoralisation and feelings of hopelessness (Birchwood, 1999, cited Chen et al., 2005).

Insight impairment is often considered from a relatively narrow clinician centred perspective as being a symptom of a psychotic disorder. Alternatively, insight in the recovery process has been conceptualised as a series of stages that are characterised by moments of clarity and insight into one's own psychopathology (Podvall, 1985, cited Young & Ensing, 1999). It is worth considering that insight is mentioned explicitly in some conceptualisations of subjective recovery, and is often clearly identifiable in the items of specific measures. Other measures go further and attempt to exclude this factor from their measures. However, it is difficult to ask about recovery, without making a statement indicating a reference point, and therefore implying a period of illness.

#### Problems with subjective recovery

Compared with objective measures, subjective recovery remains nebulous. This makes it trickier to empirically investigate, especially when researchers cannot agree on the factors involved, and the terminology used. Many studies have used grounded theory to generate terms/factors, and across the studies there are inconsistencies, where different words refer to similar concepts (Ochocka et al., 2005). Recovery may be an umbrella term for other factors already acknowledged such as destigmatisation, quality of life, and self-esteem. Resnick et al., (2004) reported life satisfaction as one of the four domains identified as relevant to a recovery orientation. Recovery may be something of a misnomer, and it has been questioned if 'recovery' is really 'adaptation' (Young & Ensing, 1999). Fitzpatrick, (2002) describes the various definitions of recovery as being on a continuum, and he himself believes that a more

helpful definition of recovery would fall somewhere between the rehabilitative model and the empowerment model.

## Potential benefits of focusing on subjective recovery

A consideration of subjective recovery explicitly broadens the focus of treatment approaches. It has been claimed that at present, treatment strategies focus too narrowly on symptom alleviation instead of addressing people's multiple residential, social, vocational and educational needs and wants (Young & Ensing, 1999). Considering subjective recovery allows for a more personal and unique process of changing one's attitude and values towards life. The concept of recovery holds out more hope for people with mental health challenges than the traditional medical model (Ochocka et al., 2005). Subjective recovery is positive, and gives hope for meaningful goal directed life, without need for symptom cure. Jacobson and Greenley, (2001) see hope as laying the groundwork for healing. There are narrative studies of recovery that have patients' descriptions of wellness and illness co-existing (Hamera, Pallikkathayil, Bauer & Burton; 1994, cited in Forchuk, 2003). Hope may be especially good for the FEP stage of any illness, as it would decrease despair and the sense that life was irreversibly ruined. Rates of suicide and depression are particularly high during the early years of psychosis (Power, 1999).

Subjective recovery issues such as hope, may impact upon engagement. The patient's own judgement of the extent of their recovery, and the basis upon which this judgement has been made, are important issues that need to be considered in the formulation of a management plan. Thus the treatment offered, and engagement with

it, will be affected by subjective recovery issues (Chen et al., 2005). Much research has focused on insight or compliance, and is oriented towards the perspective of the clinician, rather than that of the patient (Chen et al., 2005). A greater focus on subjective, patient centred recovery might enhance engagement, which is one of the key aims of services (Drury, 2000).

Measures such as the PRI (Chen et al., 2005) are designed to specifically address a number of closely related issues that are faced by patients as the psychotic symptoms subside. These include the appraisal of the extent of recovery and the possibility of relapse, making sense of the illness episode and its treatment. These are interconnected, and open to prior knowledge, personality, socio-cultural influences, illness experience and psycho-educational messages delivered by the intervention team. These factors have an impact on how the patient reacts to the illness and may consequently have an impact on future course and illness outcome. Whereas insight is from the clinician's perspective, subjective recovery is from the user's perspective. The experience of treatment initially received will significantly affect the course of engagement; first impressions last. Engagement has been shown to be a particular problem in early psychosis and it is one of the main aims of specialist services to improve this initial experience (Drury, 2000).

#### Summary

In summary, a definition of subjective recovery as recovery from FEP is rarely used clinically, although interest is growing. There is relatively little published research investigating the rates of subjective recovery, or the factors associated with

subjective recovery, particularly within an FEP population. Subjective recovery is phenomenological and more person centred and flexible in the issues it addresses than symptomatic and functional measures of recovery. Through this flexible quality it provides hope, and is therefore positive, and could increase engagement, particularly with FEP individuals who do not agree with an 'illness' model, or are reluctant to accept medication. The research there is suggests considerable variety in the extent to which individuals feel subjectively recovered at this early stage. Subjective recovery, however, is a somewhat vague, abstract concept, and this may make it difficult to measure and enhance. This could also make it less useful for research. If there is a need for 'insight', then FEP may prove a difficult group to use such measures with. In the meantime, debate continues as to whether subjective recovery may be largely dependent upon progress made with objective factors, whether it is interactive with objective factors, or whether it is relatively independent.

#### Summary and conclusion

This review suggests that recovery from FEP is not easy to define and there is no single ideal conceptualisation or way of measuring it. Recovery is multi-dimensional, and there is likely to be an interaction between the three areas discussed here. Therefore it may be more helpful to consider many aspects of recovery. FEP services will experience a wide variety of presentations of psychosis, which may mean that a more personalised version of recovery may be more helpful. Which definition is more useful, may vary across individuals. For example, a recovering individual may be symptom free but lacking in confidence, or may experience ongoing psychotic symptoms, while continuing to work. Definitions of recovery need to be able to take

account of such variety. A holistic consideration of recovery is necessary. Definitions of recovery should be congruent with the subjective goals of the individual. A definition of recovery needs to be achievable and to maintain hope for those who are working towards it. For example, due to the usual age of onset of early psychosis, it should also take account of pre-morbid baseline functioning and the effect this may have on goals. Research literature and clinical settings are presently dominated by objective psychiatric measures, and measures of subjective recovery are rare in both research and clinical settings. There is rhetoric that subjective recovery is an important focus, yet it does not yet appear to be evident in action.

Despite the apparent complexity of recovery, there is a need to strike a balance between considering the many varied dimensions of recovery, and having simple, manageable and practical measures, that can be utilised in both clinical and research settings. In order to increase the usefulness of the growing evidence base on recovery, it has been proposed by many that a multi-dimensional globally used definition of outcome is required, that enables comparison between studies and treatment interventions (Menezes et al., 2006). Rates of recovery are inherently dependent upon the definition used to measure it (Warner, 2004). It is important to remember that the measures employed will reflect the goals and philosophy of the service, and the interventions provided. Future research should focus on creating a more standardised definition of recovery so that studies can work together. It would then be better possible to identify the factors involved in promoting recovery.

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# PART 2 EMPIRICAL PAPER

## **ABSTRACT**

While there is much research into symptomatic and functional recovery from first-episode psychosis (FEP), there is little published research into subjective recovery in FEP. Therefore, it is presently unclear which factors relate to promoting a sense of subjective recovery in this group. Sixty people, between 1-3 years from first contact with an early intervention service, were assessed on measures of subjective recovery, psychiatric symptoms, functioning and demographic variables. Regression analysis demonstrated that depression was negatively associated with subjective recovery. Positive psychotic symptoms and functioning were not found to be associated with subjective recovery. These results suggest that depression is an important factor to consider when attempting to promote subjective recovery in an FEP group.

## INTRODUCTION

Psychosis is the term used to describe a group of severe mental disorders that are commonly characterised by symptoms such as hallucinations, delusions, cognitive dysfunction, and disturbances in the individual's ability to recognise reality and their own emotional responses. These symptoms often combine so that the individual's functioning is seriously impaired (Warner, 2004). Forms of psychosis range from brief isolated episodes to more chronic, prolonged illnesses, characterised by multiple episodes and periodic increases in the above mentioned symptoms.

# First-episode psychosis

First-episode psychosis (FEP) is of particular interest due to the theory of there being a 'critical period' in early psychosis, which may influence long-term course and outcomes (Spencer, Birchwood & McGovern, 2001). As 80% of first episodes of psychosis occur between 16 and 30 years of age (Shiers & Lester, 2004), these individuals are at a critical time in their intellectual and social development. Within this group, there is a particular risk of secondary effects such as disruptions to relationships, work and education. These secondary effects, can in turn hamper recovery, and contribute to a deteriorating course of illness. Aims in the management of FEP are to reduce the time between onset of psychotic symptoms and effective treatment, to accelerate remission through effective biological and psychosocial interventions, to reduce the individual's adverse reactions to the experience of psychosis and to maximize functioning (Edwards, McGorry & Pennel, 2000). Recovery from early psychosis has hence been prioritized by the Department of

Health plan's aims to set up dedicated early intervention in psychosis services across the UK (Department of Health, 2000).

## Recovery from psychosis

Definitions of recovery from psychosis can be thought to fall along a continuum from more objectively to more subjectively based indicators of outcome (Jenkins, Strauss, Carpenter, Miller, Floersch & Sajatovic, 2005). The most commonly used definitions of recovery are symptomatic remission and functional recovery. Recently the concept of recovery from psychosis has broadened to include models of subjective recovery. A typical definition of this is 'the reconstruction of a new and valued sense of self and purpose, fostering hope, insight, social support, and spirituality' (Deegan, 1988). Definitions of recovery such as this do not require that all suffering has disappeared, or that all symptoms have been removed, or that functioning has been restored (Kelly & Gamble, 2005). The National Institute for Mental Health in England (NIMHE) has published a guiding statement on recovery (Department of Health, 2005). In this they recognise that there are differing views of what recovery means, and propose a series of broad definitions that conceptualise recovery as a personalised shift from a negative focus on a troubling event towards an empowered, hopeful viewpoint, where positive restoration, rebuilding and reclaiming control of one's life can occur. Despite this promotion of subjective recovery in mainstream mental health services, research into both rates of subjective recovery, and the factors contributing to it, is presently limited.

# Rates of recovery from FEP

# Symptomatic recovery from FEP

The use of anti-psychotic medication has demonstrated good results in achieving symptomatic remission. For example, once stabilised on anti-psychotic medication treatment, 72% of patients achieved rapid remission of symptoms at 3-month follow-up (Wade, Harrigan, Harris, Edwards & McGorry, 2006). However, measuring recovery by symptom remission alone does not account for the secondary effects of psychosis, as detailed above.

# Functional recovery from FEP

Functional recovery, as objectively measured by social and occupational functioning, has also been used to measure recovery. Studies have shown rates of functional recovery fall behind those of symptomatic recovery, and this gap is especially pronounced during the years immediately preceding a first-episode (Marwaha & Johnson, 2004). For example, five years after an initial episode of psychosis, only 25.5% had adequate social functioning for two years or more, and only 13.7% met the criteria for both symptomatic remission and social functioning. (Robinson, Woerner, McMeniman, Mendelowitz & Bilder, 2004).

# Subjective recovery from FEP

There are very few studies investigating rates of subjective recovery in FEP. One such study used a dedicated recovery measure, the Psychosis Recovery Inventory, to

assess the perceived extent of subjective recovery with a sample of N=48, and a mean duration of illness of 19 months. In this group, only 10% reported they felt fully recovered, 50% reported they felt they were recovered 75% or more, 71% reported they felt they were more than 50% recovered, and 19% considered themselves to have made a limited recovery of less than 50% (Chen, Tam, Wong, Law & Chiu, 2005).

# A possible interaction of objective and subjective factors

The recovery movement has been proposed as an alternative to the bio-medical view of mental illness, with many writers stressing that subjective recovery can occur despite the presence of psychiatric symptoms (Jacobson & Greenly, 2001; Reeves, 2000). However, some writers have also suggested an interaction between objective and subjective factors of recovery. For example Markowitz (2001), talks of symptoms, self-concept and life satisfaction affecting each other in a reciprocal manner. Likewise, Liberman and Kopelowicz, (2005) believe that most, if not all, of the subjective attributes of recovering from schizophrenia are influenced by the progress being made by individuals, whereby the greater the person's symptomatic and functional improvement, the more one would expect subjectively experienced qualities such as hope, empowerment, self-responsibility, and autonomy to be in evidence. Social roles and goals, particularly work, are highly prized by young people (Warner, 2004). They provide a source of self-esteem, which in turn can affect the psychosis itself, and their loss has been linked to depression and suicidal thinking in psychosis (Birchwood, Todd & Jackson, 1998). An example of subjective factors influencing objective outcomes is suggested by Chen et al., (2005) when he claims it is important to consider the individual's capacity for hope and other subjective recovery factors as these will impact on the effectiveness of any treatment plan.

## Factors related to achieving a sense of subjective recovery

A number of qualitative studies have investigated narratives of subjective recovery (Tooth, Kalyanasundaram, Glover & Momenzadah, 2003; Ralph, 2000; Forchuk, 2003; Ochocka, Nelson & Janzen, 2005). Based upon these studies, several attributes and experiences that may be associated with individuals who are progressing towards recovery have been suggested. These include hope, destigmatisation, empowerment, self-acceptance, insight, awareness, collaboration with professionals, sense of autonomy and self-control, and participation in self-help and consumer-run programs. While these studies provide valuable insight into achieving a sense of subjective recovery, the language and the terms used often differs across the studies. To date, there are very few quantitative empirical studies investigating factors related to subjective recovery. One study used multiple regression analyses based on a large sample (N=825) to identify client and service use variables associated with a recovery orientation based on a four factor model including: life satisfaction, hope and optimism, perceived knowledge about mental illness and services, and empowerment (Resnick, Rosenheck & Lehman, 2004). This study was with a non-FEP sample of clients who had received a diagnosis of schizophrenia, and who had a mean age of 44.6 years, though this varied widely (+/- 12 years). The strongest overall relationships observed were between lower severity of depressive symptoms and each of the four domains. Resnick et al., (2004) reported Beta values for each of

the domains that were small ranging from -.14 to -.26, however these relationships were highly significant. Aside from this finding, the authors report that each of the four domains was associated with a somewhat different constellation of factors, including age, gender, ethnicity, income, paid employment, and being in receipt of various mental health services, which reinforces the complexity of the recovery orientation. As an additional point they also highlight that they found three 'medical' factors; reduced symptoms; reduced side-effects of medication; and participation in family psychoeducation; which were associated with several of their domains of a recovery orientation. They claim these are especially important as correlates of a recovery orientation, as it suggests that the treatment of psychiatric symptoms is an important element of recovery, and the polarity between the medical model and the subjective model may therefore be unfounded.

# What factors predict subjective recovery in an FEP group?

Most of the research investigating subjective recovery from psychosis thus far has been conducted with people with long-term psychosis. With chronic forms of psychosis individuals are likely to have lived with their illness for a considerable time, whereas with FEP there has been less time to adjust. It is not known at this stage how a sense of subjective recovery changes over time, nor what factors are associated with a sense of subjective recovery at the various stages of illness/recovery. There may be characteristics particular to this group that affect which factors are related to a recovery orientation. For example, first-episode individuals have been shown to be less aware of their illness than multiple episode individuals (Thompson, McGorry & Harrigan, 2001). As a starting point it is worth

considering whether the factors already known to be related to a recovery orientation in a non-specific psychosis sample, will also hold true for an FEP group at this early stage of recovery. For example, to what degree do the objective measures typically focussed upon in EIS treatment (symptom reduction and functioning), relate to subjective recovery (Liberman & Kopelowicz, 2005; Markowitz, 2001; Resnick, Fontana, Lehman & Rosenheck, 2005).

## **Summary**

One previous study has empirically demonstrated that greater levels of subjective recovery are associated with lower levels of depression in a sample of people with long-term psychosis. To date, however, factors associated with subjective recovery have yet to be explored with an early psychosis population. The critical period hypothesis emphasises there is a particular need to understand and foster all aspects of recovery with young people in the early stages of psychosis so as to minimise the risk of further toxic secondary effects. An individual's capacity for hope and other subjective recovery factors are also likely to impact on the effectiveness of treatment interventions (Chen et al., 2005). There is some theoretical speculation in the literature that there may be an interaction between objective and subjective factors of recovery, or that subjective recovery is a judgement based on reference to progress made towards objective goals, however, again this has yet to be established.

This study therefore seeks to redress these gaps, and explicitly seeks to examine the following research questions:

## Research aims

- 1) What factors predict greater levels of subjective recovery in people who have experienced FEP?
- 2) Is there a correlation between objective, and subjective, recovery factors in people who have experienced FEP?

## Hypotheses

- 1) Lower levels of depression and anxiety will predict subjective recovery.
- 2) Positive symptoms of psychosis will not predict subjective recovery.
- Engagement in paid employment and/or education will predict subjective recovery.

## **METHOD**

# **Participants**

All data collection was carried out through an Early Intervention Service (EIS), in London during a six-month period between September 2006 and March 2007. The caseload of this service was divided so that a proportion was contained within a specialist 'stand-alone' EIS, and the remainder were treated within 'augmented' Community Mental Health Teams (CMHTs). For this study, the majority of participants were recruited from the caseload of the 'stand-alone' EIS team (N=54),

and this was supplemented by a smaller number of EIS clients who were being treated in the parallel running 'augmented' CMHTs (N=7).

# Recruitment from the 'stand alone' team

Within the stand-alone EIS, a continuous sample of clients accepted by the service during a two-year period from 16/3/04 to 15/3/06, were identified and approached to take part in the study, (N=99). This meant, that at the time of data collection, all prospective participants would have experienced a period of between one and three years since first coming into contact with specialist early intervention in psychosis services.

Of the 99 clients from the 'stand-alone' EIS approached to participate in the study, 45 either did not respond or declined participation. Table 1.1 summarises a breakdown of the reasons for non-participation.

## Recruitment from the augmented teams

The participants recruited through the 'augmented' CMHT route also fell within this two-year window. However, due to logistical constraints, it was not possible to approach all clients within a continuous sample. As a result this sub-group should be considered to be somewhat of a supplementary opportunity sample. It was decided that despite the lack of control in obtaining this sub-set, the benefits of increasing the sample size outweighed any threats to the validity of the overall sample.

**Table 1.** Breakdown of potential participants approached, reasons for non-participation, and rates of eventual participation

Sample	N
Total from EIS eligible	99
Interviewed	54
Out of area	9
Opted out of all research at intake	2
Not contactable	9
Disengaged	3
Refused	15
Too ill (care co-ordinator's opinion)	4
DNAed (Agreed to participate, however repeated efforts to interview failed)	3

Note: An additional N=7 obtained via augmented teams.

A total of 61 individuals were eventually interviewed. However, one case had to be rejected due to concerns about the validity of the data, which indicated a clear response bias. This resulted in a complete, useable dataset of N=60.

The stand alone and augmented sub-samples were compared for significant difference on their scores on the main outcome measure, Mental Health Recovery Measure (MHRM). Statistical analysis indicated no significant difference between the two samples. The two groups were combined for all further analyses.

## **Procedure**

# Efforts made to recruit

All 99 potential participants from the stand alone EIS were initially approached via their designated care co-ordinators. The care co-ordinator would briefly explain the aims of the research and ask if a researcher could meet with them to answer any further questions. Care co-ordinators could decline to arrange contact if they felt their client was too unwell at that time. If this was the case, follow-up contact with the

care co-ordinator was made throughout the six-month data collection period to establish whether the client's mental state had adequately improved. For those potential participants classed as disengaged with the EIS, an information sheet was sent to their last known address, and, where possible, this was followed-up with a phone call inviting them to participate. Care was taken to ensure that all 99 potential participants were given adequate opportunity to take part, and this often involved repeated attempts to contact them, with efforts ceasing only after considerable time had elapsed or an explicit refusal to participate.

## Interview procedure

All participants gave written informed consent to take part in the study. Interviews took place at the EIS service base, on hospital wards or in clients' homes, and took approximately one hour. An interpreter was provided for two clients where English comprehension was felt to be poor. All participants were paid £15 for their time and contribution.

Each interview was conducted by one of three members of the research team, comprising two trainee clinical psychologists and one assistant psychologist. All of the researchers received formal training in administering the Positive and Negative Symptom Scale (PANSS) and six initial interviews were each rated by two researchers independently, to enable comparison of the PANSS ratings, and to allow for necessary standardisation of the rating procedure. These six initial interviews also provided opportunity to pilot use of the other measures in the battery.

#### Measures

A number of quantitative measures were included in the interview battery, which were to be used in the current study as well as a number of separate studies (see appendix for a full list of these measures). In addition to these measures, standard demographic information was also collected, both at the interview, and from patients' files. All measures except the PANSS were self-report, and generally consisted of Likert scale responses or the provision of yes/no responses to a series of statements.

Mental Health Recovery Measure (MHRM), (Young & Bullock, 2003)

The Mental Health Recovery Measure (MHRM), (Young & Bullock, 2003), is a self-report instrument designed to assess the subjective recovery process for individuals with serious mental illness. It achieves this without relying on the measurement of symptoms or symptom management. Its content is based upon a specific model of metal health recovery that is grounded in the recovery experience of persons with psychiatric disabilities (Young & Ensing, 1999). It was developed using qualitative grounded theory analysis of the recovery narratives of eighteen mental health service users. The MHRM consists of 30 items, each based on a 5-point Likert scale that ranges from "strongly disagree" (0) to "strongly agree" (4), with a mid-point of 2 for "not sure". Each item asks the interviewee to rate the degree to which they agree or disagree with a statement related to their recovery, e.g. 'I still grow and change in positive ways despite my mental health problems'. The measure comprises six subscales as follows: overcoming stuckness; self-empowerment; learning and self-

redefinition; basic functioning; overall well-being; new potentials; and advocacy enrichment. Two additional items specifically address the role of spirituality in the recovery process. While it is possible to derive subscale scores, for the purpose of the current study the main focus of the measure is on using the total MHRM score as an overall assessment of self-reported recovery. The total scale has a theoretical range from 0-120. The available norms for the MHRM indicate a mean total score of approximately 80 with a standard deviation of 20.

# Positive and Negative Symptom Scale

The Positive and Negative Symptom Scale (PANSS) (Kay, Fiszbein & Opler, 1987), is a clinician rated 30-item rating instrument evaluating the presence/absence and severity of positive, negative and general psychopathology symptoms commonly associated with psychosis. All 30 items are rated on a 7-point scale (1=absent; 7=extreme). The PANSS provides three subscale scores (positive symptoms, negative symptoms, and general psychopathology symptoms) based on the summing of individual items related to each sub-scale. It also provides an overall score.

# Additional data

Additional demographic information was obtained at the interview or from the participants' medical files. For the purpose of this study these included gender, age, ethnicity, length of time in the early intervention service, and current employment/educational status. As employment status resulted in more than the two categories necessary for statistical analysis, these were later collapsed to provide a

binary variable that represents whether the individual was in paid employment/education or not.

## Design

A cross-sectional, correlational design was used to determine which factors predicted higher levels of subjective recovery within this sample. The criterion variable was the total score on the MHRM (0-120), and potential predictor variables examined were: PANSS anxiety score (1-7); PANSS depression score (1-7); PANSS general psychopathology symptoms sub-scale score (1-112); PANSS delusions score (1-7); PANSS hallucination score (1-7); PANSS positive symptoms sub-scale score (1-49); PANSS negative symptoms scale score (1-49); a binary measure of whether the participant is in paid employment/education or not (0/1); gender (0/1); age in years at the time of interview; and length of time in service in months.

## Sample size considerations

This current study was predominantly explorative as there is no known previous research upon which to base an accurate prediction of effect size. Based on projected recruitment (N=60), it was expected that it would be possible to enter up to four predictor variables into the final regression equation. It is acknowledged that this would only enable the detection of large effect sizes, however, it was anticipated that this would be sufficient for an exploratory study.

## **Statistical Analysis**

Statistical Analysis was conducted using the Statistical Package for the Social Sciences for windows, version 11.5 (SPSS11). All variables were checked for normality to ensure that they met the criterion for parametric tests, and were adjusted as necessary. Variables were checked for outliers that might unduly influence the patterns observed, and were removed where appropriate. An independent samples t-test was conducted to assess any significant differences in scores on the MHRM across the two sub-samples (stand alone & augmented sub-samples). The final 'cleaned' data set was then entered into a bivariate correlation matrix to identify significant relationships between the criterion variable (total MHRM score), and the predictor variables. Finally, the correlations found at the univariate level guided which variables would be worth observing at the multivariate level in the regression models, to find a model of best fit which would predict a proportion of the variance in the criterion variable (MHRM)

## **Ethical Considerations**

All prospective participants were informed that their participation was voluntary and that they were free to withdraw at any time, without needing to provide a reason, and without their medical care or legal rights being affected. All interview data was treated as confidential, and this would only be breached if there were concerns about self-harm or harming another person. Interview records and data were stored confidentially. All participants were provided with contact details of the research team so they could follow-up any questions at a later date, if they so wished.

Ethical approval for this study was obtained from the Camden & Islington NHS ethics board.

## **RESULTS**

# Sample demographics

Table 2 shows a summary of the demographic information of the final sample. It can be seen that the sample contains exactly twice as many males as females. Approximately half of the sample were of 'white' ethnicity and half consisted of other ethnic groups, the largest of which was 'black'. The mean age was close to 26 years, and the mean time in service was close to 1 year 9 months. The upper and lower extremes for both these variables was restricted by service inclusion criteria. The majority of participants were living in the community at the time of interview, while a small proportion were inpatients. The majority of participants had completed compulsory schooling, while two-thirds were unemployed at the time of interview.

## **Data Analysis**

The intended criterion variable (MHRM), was found to be normally distributed. All the remaining variables, however, were not normally distributed, and were found not to be normalisable using transformations. Additionally, the PANSS individual item data was found to be restricted in its range (i.e. although the scale ranges from 1-7, only scores of 1-4 had been used in practice). Due to these factors, non-

parametric statistics were performed for all variables involved in the correlation analyses.

Table 2. Summary of demographic data of final sample

Demographic variable	N	(%)
Gender		
Male	40	66.7%
Female	20	33.3%
Ethnicity		
White British	22	37%
White Irish	1	1.7%
White other	7	11.7%
Mixed white/black African	1	1.7%
Mixed other	1	1.7%
Asian Bangladeshi	4	6.7%
Asian other	1	1.7%
Black or Black British Caribbean	4	6.7%
Black or Black British African	9	15%
Other Black groups (inc 'Black British')	7	11.7%
Chinese	1	1.7%
Other ethnic group	2	3.3%
Age at time of interview in years		
Minimum	19	-
Maximum	36	-
Mean age	25.97 (SD 4.57)	-
Number of months in EIS at time of interview	,	
Minimum	12	-
Maximum	35	-
Mean	20.9 (SD 6.81)	-
Mental health act status at time of interview	,	
Community	51	(85%)
Hospitalised (voluntary)	3	(5%)
Hospitalised (sectioned)	6	(10%)
Age at leaving full-time education in years		` ,
(N=55)		
Minimum	10	-
Maximum	28	_
Mean	17.9 (SD 3.47)	-
Employment status	, ,	
Paid employment	8	(13.3%)
Training/education	10	(16.7%)
Unemployed	39	(65%)
Other	3	(5%)

# Comparison of MHRM scores from main EIS sample and 'augmented' sample

An independent samples t-test was conducted on the total MHRM scores obtained from the 'stand alone' and 'augmented' sub-samples, to check if they differed significantly, and should therefore not be considered as a whole in any subsequent analysis. The 'stand alone' sample N = 53, mean = 83.36, SD = 15.03, and the 'augmented sample' N = 7, mean = 76, SD = 18.19. There was no significant difference between the 'stand alone' and 'augmented' sub-samples on total MHRM scores (t = 1.189, df = 58, p = 0.239, two-tailed). This suggests that the two groups did not differ significantly on the MHRM, and it was reasonable to group them in all further analysis.

## Gender and MHRM

An independent samples t-test was conducted to investigate any potential effect of gender on the total MHRM scores, (t = .957, df = 58, p = 0.343, two-tailed). This result suggested that the two groups did not differ significantly.

# Functioning and MHRM

An independent samples t-test was conducted to investigate any potential effect of functioning on the total MHRM scores, (t = 1.003, df = 58, p = 0.320, two-tailed). This result suggested that the two groups did not differ significantly.

## Overall scores on the MHRM

The distribution of total MHRM scores within the sample is represented in figure 1. The mean score obtained on the MHRM was 82.5, with a standard deviation of 15.44. The minimum score of any individual was 33, and the maximum was 112. The available norms for the MHRM indicate a mean total score of approximately 80 with a standard deviation of 20 (personal communication with author). The mean of this sample appears to be in keeping with the norms established in wider research.

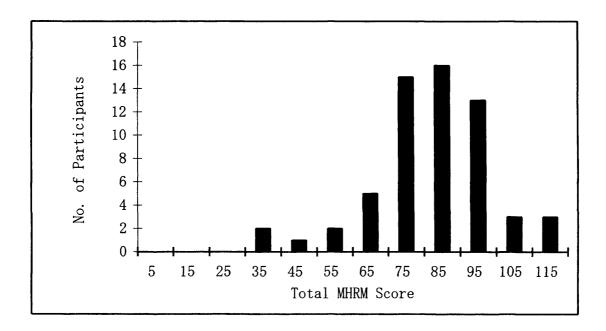


Figure 1. Total MHRM score.

# Correlations

A series of Spearman's rho bivariate correlations were conducted to assess which variables related to scores on the MHRM. These are shown in table 3.

**Table 3.** Spearman's rho correlation matrix

	Age	Time	Del	Hal	+ve	-ve	Anx	Dep	Gen
Rec	010	.058	.090	.054	.074	124	280*	383**	099
Age	-	019	208	094	125	.004	.052	024	113
Time		-	.153	058	.112	081	370**	391**	083
Del			-	.673**	.849**	.323*	.224	.099	.597**
Hal				-	.722**	.120	.355**	.098	.416**
+ve					-	.407**	.322*	.101	.708**
-ve						-	.044	.031	.527**
Anx							-	.567**	.454**
Dep								-	.401**

<sup>\*</sup>*p* < .05; \*\* *p*< .01

Notes: Rec = MHRM total; Del = PANSS delusion item; Hal = PANSS hallucination item; +ve = PANSS positive symptoms subscale; -ve = PANSS negative symptoms subscale; Anx = PANSS anxiety item; Dep = PANSS depression item; Gen = PANSS general psychopathology subscale.

Subjective recovery (MHRM) - This was negatively associated with PANSS anxiety scores (rho = -.28, N = 60, p < 0.05, two-tailed), and PANSS depression scores (rho = -.383, N = 60, p < 0.01, two-tailed). This suggests that participants who felt greater levels of subjective recovery were also more likely to be experiencing lower levels of anxiety and depression. No other variables were found to be associated with subjective recovery.

Length of time in service – This was negatively associated with both anxiety (rho = -370, N = 60, p < 0.01, two-tailed), and depression (rho = -391, N = 60, p < 0.01, two-tailed). This suggests that participants who had been in the service longer were more likely to have lower levels of anxiety and depression. Length of time in service was not itself significantly associated with subjective recovery.

## Regression analyses

To examine the relationship between anxiety, depression and subjective recovery, a series of linear regressions were conducted using the enter method. The MHRM total score was the criterion variable and different combinations of PANSS anxiety and depression scores were used as predictor variables. Standardised residuals were normally distributed, and the outcome variable was normally distributed suggesting that despite poor distributions for some predictors the regression was performed satisfactorily.

## Model 1

Predictor variable	Beta	p
PANSS anxiety	052	p = 0.732
PANSS depression	326	p = 0.036

Using the enter method, a significant model emerged (F  $_{2,57}$ =4.229, p = 0.019) Adjusted R square = 0.099.

In Model 1, using both anxiety and depression the overall model was significant (F  $_{2,57} = 4.229$ , p = 0.019), with an adjusted R square = 0.099, accounting for 9.9% of the variance in MHRM scores. However, anxiety was not significant (p = 0.732), once the effect of depression was controlled for, and has a relatively small standardized beta value (-.052) suggesting that anxiety makes only a small contribution to the model. From the correlation matrix, it was shown that anxiety and depression were strongly inter-correlated, (rho = .567, N = 60, p < 0.01, two-tailed).

A second regression analysis (model 2), was conducted with depression as the sole predictor variable.

Model 2

Predictor variable	Beta	p
PANSS depression	357	p = 0.005

Using the enter method, a significant model emerged (F  $_{1,58}$  =8.468, p = 0.005) Adjusted R square = 0.112.

The second model produced a better overall model, that accounted for a greater proportion of the variance in MHRM scores (11.2%), while also increasing the statistical significance of the model.

## **DISCUSSION**

The current study aimed to identify predictors of subjective recovery in a first-episode psychosis sample. It was hypothesised that lower levels of the general psychopathology symptoms of anxiety and depression would predict subjective recovery, and that the positive psychotic symptoms of hallucinations and delusions would not. It was also hypothesised that engagement in paid employment or education would predict subjective recovery. The results of statistical analyses demonstrated that lower levels of depression and anxiety were found to be associated with increased subjective recovery. The positive symptoms of psychosis were not found to be associated with subjective recovery. Engagement in paid employment and/or education was not, however, found to be associated with subjective recovery.

From a selection of demographic and psychopathology factors, the only variables shown to be significantly associated with subjective recovery were lower levels of anxiety and depression. Anxiety and depression were found to be strongly and significantly inter-correlated, and in the subsequent regression analyses it was shown that the majority of the variance in subjective recovery accounted for by anxiety, was also accounted for by depression. A second regression analysis demonstrated that depression alone provided a better model in predicting the variance in subjective recovery, and that this model was also more significant than if anxiety were included. In the final single-predictor variable regression model depression accounted for 11.2% of the variance in subjective recovery.

# The predictive factors of subjective recovery in FEP

The current study is the first to investigate the relationship between demographic factors, clinical outcome factors, and subjective recovery in a first-episode group. The results demonstrated that depression is an important factor in predicting subjective recovery in a first-episode psychosis group. The results of the current study provide support for the main finding of Resnick, Rosenheck and Lehman (2004), who found the strongest overall relationships they observed were between lower severity of depressive symptoms and each of their four domains of a recovery orientation. The current study's findings showed a negative predictive association between depression and subjective recovery (Beta = -.357). This value suggests a stronger relationship than that of the four values reported by (Resnick et al., 2004), where Beta values for each of their four domains were as follows: satisfaction with life = -.22, hope = -.26, knowledge = -.14, and empowerment = -.2. However, the current study used a single dedicated subjective recovery measure rather than separate related domains. Resnick et al., (2004) did not report anxiety as significantly associated, although it is unclear as to whether the influence of this variable was investigated. However, as the current study's regression analyses suggests, depression alone appears to provide a better predictive model of the variance in subjective recovery, accounting for much of the variance predicted by anxiety. The current study has supported the main findings of Resnick et al., (2004), but with a sample coming to terms with the early stages of recovery from psychosis. This suggests that depression is an important factor in predicting a sense of subjective recovery in both the early and later stages of recovery from a psychotic illness.

Associations between objective, and subjective, recovery factors in FEP

The current study also had as an explicit aim, to explore whether there was an association between objective and subjective recovery factors. Resnick et al., (2004) had identified that levels of psychotic symptoms were found to be negatively associated with one of their four domains, life satisfaction (Beta = -.14). The current study, however, did not support this finding, as none of the measures assessing positive psychotic symptoms were found to be significantly associated with subjective recovery. This finding suggests that subjective recovery may be independent of the presence of positive symptoms following a first episode. Given the relatively small sample of the current study, it would be important to verify this finding in further research.

The current study was also unable to identify an association between occupational functioning and subjective recovery, such that being in education or paid employment was not predictive of subjective recovery. While no known previous research studies had identified an association between these factors, it had been suggested in the theoretical literature that such a relationship between these factors was plausible (Liberman & Kopelowicz, 2005). This finding suggests that subjective recovery in an FEP group is independent of functioning in terms of employment and studying. A possible explanation for this lack of a relationship is that the measures of functioning used in this study were limited. The analysis was based on a binary variable of whether the participant was either engaged in paid employment/education or not. This did not take account of a broader definition of functioning including areas such as social networks and connecting with others. Definitions of functioning

such as these may be more congruent with the subjective goals of this age group. Of the 42 participants who were not employed/studying it was not clear how many viewed this as an area they felt was lacking in their lives, and therefore considered this dissatisfaction in their appraisal of their own recovery. Additionally, no baseline measures were available to provide information on pre-morbid levels of functioning, which would probably have confounded measures of post-morbid functioning. When predicting working following a period of psychotic illness, the most consistent and strongest relationship is with pre-morbid social and occupational history (Marwaha & Johnson, 2004). If many of the sample had not been working or studying prior their first episode, then it may be that expectations of a return to these roles was less prevalent.

#### Rates of subjective recovery in the sample

The mean score on the MHRM (82.5, SD = 15.44), was found to be similar to the norms for the measure reported by the authors (mean = 80, SD = 20) (personal communication, W.A. Bullock). The minimum MHRM score of any individual was 33, and the maximum was 112, and a good spread of scores was demonstrated. Some individuals appear to have felt relatively un-recovered, while others felt they were close to 100% recovered based on the MHRM. Interestingly, there was no significant correlation observed between length of time in service and MHRM scores. It was not possible to compare the rates of subjective recovery found in this FEP sample with those reported in a similar FEP sample using the Psychosis Recovery Inventory (PRI) (Chen et al., 2005), as the MHRM does not provide percentile standards. However, a similar distribution was noted.

#### Other associations noted

Although not initially hypothesised, it was noted that length of time in service significantly negatively correlated with both anxiety and depression. A possible explanation is that this improvement over time may reflect an adjustment to the experience of a first episode or an increase in coping skills and symptom management. Despite this relationship between length of time in service and anxiety/depression and the similar relationship between subjective recovery and anxiety/depression, an association between length of time in service and subjective recovery was not found.

#### Depression in first-episode psychosis

The results suggest that participants who were depressed were less likely to subjectively feel they had recovered. In many ways this is an unsurprising result as *hopelessness* is a specific dimension of depression (Whisman & Pinto, 1997), and *hopefulness* is a common factor in subjective recovery literature, and a focus of the measures designed to capture its presence (Campbell-Orde, Chamberlin, Carpenter & Leff, 2005). Therefore it is not surprising that those who are depressed, feel less hopeful, and score lower on a measure such as the MHRM, which utilises hopefulness ('new potentials' subscale on the MHRM), within its structure. Additionally, it is worth considering that recovery has been conceptualised as a personalised shift from a negative focus on a troubling event towards an empowered, hopeful viewpoint, (Department of Health, 2005).

Research into "post-psychotic depression" suggests several explanations for this phenomenon, including co-morbid affect disorders, a reaction to the psychosis, and a dysphoric response to neuroleptic medication. The current study did not control for medication or reported side effects. Chen, Hui & Chiu, (2005) also report that a common reason for FEP individuals not feeling adequately subjectively recovered, is the need to continue with neuroleptic medication. Both medication use and beliefs about medication could usefully be explored in further research into subjective recovery in early psychosis.

While depression in the acute psychotic phase has been associated with favourable outcomes, there remains some debate as to the consequences of depression in the post-psychotic phase on clinical outcomes. Persistent depression in the post-psychotic phase has been shown to be associated with poorer outcome in terms of symptoms (Oosthuizen, Emsley, Niehaus, Koen & Chiliza, 2006). However, the development of a depressive illness following an acute psychotic phase has also been regarded as a sign of "acceptance" of the psychosis and is regarded in some quarters as a favourable prognostic sign (Roth, 1970, cited Birchwood, Fowler & Jackson, 2000).

In the current study, it is not clear as to the role of 'insight' or recovery style in reaching a judgement on subjective recovery from FEP. It has been demonstrated that first episode patients are often less aware of having an illness than multiple episode patients (Thompson, McGorry & Harrigan, 2001). Acceptance of an 'illness' can lead to pessimism, loss of self-efficacy and absorption of the pejorative

stereotypes of mental illness (Birchwood, Todd & Jackson, 1998), whereas a sealing-over coping style actually had better short-term outcomes with regard to depression (Jackson, McGorry, Edwards, Hulbert & Henry et al., 1998). It is possible that those who felt 'recovered' also possessed less insight into their situation, and may therefore have felt less depressed as a consequence.

#### Clinical implications

The findings of the current study add to the debate on the interaction between objective and subjective factors of recovery. The findings of the current study do not suggest any relationship between improvements in the positive symptoms of psychosis, functional improvement and subjective recovery. Rather, at this early stage of adjustment to having experienced an initial psychotic episode, the only factors shown to be significantly related to a sense of subjective recovery were the general psychopathology symptoms of depression and anxiety. Many writers of the 'survivor' movement, have described recovery as possible despite the presence of psychotic symptoms such as delusions and hallucinations (Jacobson & Greenly, 2001; Reeves, 2000). The findings of this study support these views, and suggest that subjective recovery remains an alternative to the bio-medical model of recovery, at least during the early stages of recovery.

The finding of depression being associated with a sense of subjective recovery is clinically important, as depression in psychosis is amenable to psychological intervention (Fowler, Garety & Kuipers, 1995). The variety in scores on the MHRM suggests subjective recovery from FEP is possible, common, but certainly not the

rule. The findings of the current study suggest that it if attempting to promote subjective recovery in a first-episode group, then a statistically and clinically significant factor is depression. The current study suggests that despite improvements in objective factors such as symptom remission or functioning, subjective recovery should not be expected to be in evidence, or vice versa. As depression accounted for only 11.2% of the variance this suggests that many other factors are involved. The pattern of factors may be complex, personally varied, and not attributable to a few objective factors. Despite the complexity of factors implicated, depression remains the strongest significant relationship observed.

#### Limitations of the current study

The current study was of a correlational design, therefore it is not possible to unambiguously determine the causal direction of the relationships observed. It may be that if an individual feels they are less recovered then they feel depressed, or that when evaluating their own recovery, they give consideration to their affect in reaching this judgement. It is suggested that this relationship is likely to be reciprocal in nature.

In the current study, depression only accounts for 11.2% of the variance in subjective recovery. This leave the majority unaccounted for. However, the findings of Resnick et al., (2004) utilised a much larger sample (N=825), and hence greater power to investigate the relationships of 27 demographic and clinical variables on their four domains of subjective recovery. Despite this sample size, and the wider range of predictors, they still only identified depression as consistently related to all four of

their recovery domains, and demonstrated smaller beta values. A significant comment regarding their findings, was that aside from depression, each of their four domains was associated with a somewhat different constellation of factors, which they felt reinforces the complexity of the recovery orientation.

The current study and those of Resnick et al., (2004) and Chen et al., (2005) all used different measures of subjective recovery, so comparisons between studies should be considered with caution. The relatively small sample size in the current was only able to detect large effect sizes, and also did not allow for a more complex, multifactoral model to be constructed. Despite the lack of observable relationships between many of the predictor variables and subjective recovery, it not possible to claim that these factors are unrelated to subjective recovery, due to research design limitations and the small sample size. It may be that these relationships will be identified in future studies.

Finally, the current study has been unable to account for the experiences and views of those individuals who were either too unwell to participate, refused to participate, or who were disengaged with the service and could not be traced. Of the 99 from the stand-alone team eligible to participate, 46 (45.5%) did not do so. For the majority, it is uncertain as to the reasons why these individuals did not wish to take part, however it is possible to suggest several explanations. This could be because of mistrust of the service, psychotic illness, or feeling fully recovered and possibly wishing to avoid contact they viewed as stigmatising. These people may have recovered exceptionally well, or have gone on to become unwell again. By being

unable to include these individuals in the study it may have excluded data that could have significantly altered the associations observed.

#### Methodological limitations

During data collection it was noted that the MHRM appeared to be well accepted by participants as easy to comprehend, and acceptable in content. However, one noted difficulty was with the two spirituality items. Many participants felt that they would not define themselves as religious or spiritual, and therefore did not feel that their recovery was influenced by these factors. This often resulted in them providing lower scores (disagreement) for these items, and therefore lower overall MHRM scores.

#### Future developments & ideas for future research

There were several variables that would have been interesting to have controlled for in the regression analysis. However, for various reasons it was not possible to obtain this data. No data was available for duration of untreated psychosis (DUP) for this sample. Many studies have demonstrated a link between longer DUP and clinical outcomes including risk of relapse (Johnstone et al., 1986, cited Birchwood, Fowler & Jackson, 2000), and both time to remission and degree of remission (Loebel et al., cited Birchwood, Fowler & Jackson, 2000), therefore it is hypothesised DUP might also affect subjective recovery as an outcome. Another possible association may be between subjective and/or objective cognitive deficits and subjective recovery, since subjective cognitive deficits have been reported as one of the main reasons for not feeling recovered (Chen, Hui & Chiu, 2005). Additionally, subjective experiences of deficits in chronic schizophrenia, in areas such as thinking, feeling and perception,

have been shown to be associated with a vulnerability to depression (Barnes, Curson, Liddle & Patel, 1989). However, this is perhaps less of a feature of FEP, and so less likely to be a significant predictor early in the illness trajectory.

The measures used for measuring depression and anxiety were the individual items of the PANSS, and these are relatively simple scales. It is therefore suggested that future research use more specialised tools such as the Beck depression and anxiety inventories. Future studies could replicate the current study with the suggested inclusion of the additional measures. It would be valuable to control for a measure of insight, to investigate its relationship to subjective recovery. If someone lacks insight into the impact of their psychosis on their life, can they make an 'informed' judgement as to how well they've recovered? The current study's focus on an FEP group, acknowledges the likely changing nature of recovery as time progresses. Therefore, it would be valuable to track the course and development of subjective recovery in parallel with objective recovery factors over time. This could then identify if subjective recovery increases over time, and in relation to increases or decreases in which factors. This could be achieved using a longitudinal follow-up of the same sample. Significant patterns could then be considered in implementing interventions to enhance subjective recovery.

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# PART 3 CRITICAL APPRAISAL

#### **CRITICAL APPRAISAL**

This review will discuss the process of conducting the study described in the first and second parts of this thesis. I will begin by discussing important factors involved in the selection of the research topic, and then look at theoretical, methodological and ethical issues that arose during the research process. Finally, I will consider how both the findings of the research and the research process itself have contributed to my learning and the evidence base.

#### Selecting a research area

I had two criteria in selecting a research project. The first was that it should be a topic of interest to me. The second was that the project should show good indications that it would run as smoothly as possible, and therefore likely be a manageable process.

#### *Interest in the topic*

Prior to training I had worked in both a clinical and research capacity with psychosis, and it had maintained my interest throughout training. I had also been curious for some time in working in the area of early intervention services (EIS), and was at that time hoping to obtain an elective placement in an EIS setting in the final year of my training. My interest in EIS was based on a rather limited amount of knowledge and experience of EIS models and practices. Rather my interest had developed in reaction to having worked with chronic rehabilitation clients, who had remained

institutionalised in psychiatric services for some 20-30 years. Many of these individuals appeared to have been ascribed a patient role that was then very hard for them to escape from. Through the somewhat aversive aspects of this experience, the philosophy of EIS models appealed to me as a more hopeful, preventative approach that might counter the development of the 'chronic' prognosis. The particular topic of subjective recovery was suggested by my supervisor. Although I knew little about this area, it immediately appealed to me. I saw it as a topic that offered an alternative to conventional medical views of psychosis, which was refreshing and again offered 'hope' in contrast to my experience of working with chronic psychosis. In addition, subjective recovery was also a 'current' topic, that appeared to have relatively little empirical research, particularly within an FEP population, and this groundbreaking rather than well-trodden aspect also appealed. Reflecting on this aspect of choice makes me aware of how research is usually approached with some degree of an agenda or a vested interest. Although I had no particularly strong feelings about how the results 'should' turn out, I was not completely unbiased. The hypotheticodeductive approach attempts to address researcher bias, however these methods are not foolproof, and the presentation or exclusion of data can either stress or downplay findings that are in conflict with the attitudes and opinions of the researcher.

#### Manageable process

Although it is impossible to predict precisely how smoothly the research process would run, it was important that I had a fair degree of confidence in the project I eventually chose. An important factor was that my supervisor had previous research experience. Another factor was that the data was to be collected in a service setting

where resources were orientated towards research. The service had been set up as a pilot service to evaluate the effectiveness of different models of EIS service delivery. Research duties were explicitly written into all staff's job description. Additionally, two full-time research assistants were already involved in gathering data, and a fellow trainee was also due to collect data at the same site. This all suggested a setting amenable to research and one that was not likely to view a trainee approaching them as an alien idea or a hassle to be avoided. Research in clinical settings is virtually impossible without the co-operation of the local staff.

#### Joint Working

#### Shared project responsibilities

Data collection was a shared responsibility between myself, a fellow trainee and two research assistants. The obvious advantage of this arrangement was that it reduced the workload, and increased the final sample size. However, while each research interview would take approximately one hour, only around 15 minutes of this hour was devoted to data relevant to my project. The remaining data was relevant to several other projects being conducted at the EIS. This meant that in effect, at least in terms of hours spent collecting data, team working did not reduce my individual workload significantly.

Collecting data for several different purposes meant that to some degree we were dependent upon each other. This added extra pressure as others were relying on my efforts to keep their own work on schedule, yet this factor was reciprocated, and this meant that things progressed steadily, especially in the early stages where ethics needed to be submitted and interview packs need to be finalised. Having other researchers who were aware of the complications involved was good for support, good to sound out ideas and helpful in piloting issues. A disadvantage was that the data collection and interview procedure was less under my control. Having more researchers present within the service may have raised the profile of research as a worthy aim, or it may have increased 'research fatigue' amongst the clinical staff. This must be an issue common in collaborative research, or studies that aim for large sample.

#### **Theoretical Issues**

#### Abstract quality of subjective recovery

A difficult issue running throughout this research was the abstract quality of 'subjective recovery'. Subjective recovery is a relatively new concept, and throughout the literature there is limited agreement in terms of definitions. These often consist of lengthy descriptions that whilst illuminating are also expansive, rather than reductive and simplifying. This was also complicated by the fact that the term 'recovery' is often used in reference to the newer concept of subjective recovery, while in other papers could be referring to more traditional clinical models of recovery such as symptom remission. This confusion was particularly apparent when trying to understand papers that straddled the traditional and newer definitions, or papers that were trying to reconcile the medical and 'recovery' models. This meant it

was easy to become lost amongst such vague terms, particularly in the early stages of planning the research.

As subjective recovery is relatively a new concept there is little published research on the topic, particularly quantitative research investigating the factors related to subjective recovery. This had both advantages and disadvantages. The advantages were that I could be more explorative in my study, and that I felt I was doing something new, and therefore possibly more interesting. The disadvantages were that there was less research to guide hypotheses, and tenuous links feel less satisfying. Throughout the research procedure, I was periodically struck by a sense of doubt as to the identity of the topic under investigation. This may be a debate for many researchers – the balance between a novel, interesting topic and a more concrete, established area.

#### Definitions of subjective recovery are a work in progress

Working on the literature review particularly helped me to think more about how recovery from psychosis is currently conceptualised and assessed. This highlighted the inadequacy of these definitions and measures, and how a well-crafted definition might still not apply universally. This has significant implications for services, as their overall aim is to aid people in their recovery, yet definitions of recovery are neither clear nor agreed. This has led me to believe that recovery is varied, not well established, and remains a work in progress. This 'work in progress' quality is particularly true of the newer concept of subjective recovery. With subjective recovery the various definitions consist of different constellations of elements such

as insight, compliance, finance, etc. The inclusion or exclusion of one or more of these can radically alter the construct you are measuring. Yet presently they are all spoken of as 'subjective recovery'. Attempts to make definitions more inclusive cause as many problems as they solve. If it becomes too broad and all encompassing then the definition can appear more vague and unmanageable and its utility decreases. The complexity and abstract nature of subjective recovery also presented problems when writing sections of the thesis. For example, subjective recovery can be seen as an alternative to an 'illness' model, however, it is hard to talk about recovering without reference to an event from which to recover. To some degree this inherently implies 'illness'. Definitions of recovery from psychosis appear to have changed over time in line with other social and political changes (Anthony, 1993). Subjective recovery is very much a model that fits our society at this current time. This gives the phenomena under investigation something of a transient and possibly temporary character.

#### Methodological Issues

Participant refusal and its effect on the measurement of subjective recovery

All potential participants were to be approached initially via their designated care coordinator. However, if these potential participants were deemed as being 'too unwell' to participate then they could not be approached. While ethically this was unavoidable, it did feel contradictory to the phenomena under investigation. If you are trying to assess how much a group feels subjectively recovered, yet you cannot include those who are too unwell or have disengaged, then this seems to risk missing out on data that might be at either extreme of the recovery spectrum. Those individuals less recovered in the conventional sense are automatically excluded due to being deemed unwell, as are those who refuse to have contact with the service for whatever unknown reason. The reasons for refusing contact may range from refusing to acknowledge they had difficulties, to possibly feeling so well recovered that they felt contact with the service was a waste of time or stigmatising. This raised the pragmatic issue of a need to conduct research as systematically as possible to maintain scientific integrity, yet the reality of having to conduct this in a chaotic clinical setting, with all the uncontrollable factors that go with it.

Initially, this apparent contradiction in assessing recovery felt most unsatisfactory. Prior to this I had been working towards something of a convenience sample. Later, through supervision, we decided it would be more rigorous (and still manageable at that stage), to work to a timeframe of two-years of the EIS caseload intake, and approach all potential participants. This two year period was a pragmatic decision based upon the number of participants available to us, the sample we predicted we would need for statistical power, and the need to have as homogenous a sample as possible in terms of duration since first episode. It was decided that we must be able to show that we have made every effort to contact potential participants so that their views could be recorded, whilst expecting a proportion to not participate. It was then clearer to me that I would be presenting the data from a controlled time frame, whilst acknowledging the distortions caused by people being non-contactable, or refusing to participate, and interpreting the results in the light of this. Once these decisions were made the design felt more satisfactory. This I felt to be a pragmatic solution that managed to maintain a satisfactory degree of scientific rigor. In research this

compromise must be a common issue. Just because it is a difficult area to investigate, and the design may be flawed, should it not be investigated? Doing research in services is ideal for ecological validity, however difficult to maintain tight control.

#### Measurement issues

The eventual dependent variable (DV) measure was chosen from a compendium of subjective recovery measures (The Evaluation Centre HSRI, 2005). Within this there were nine measures of individual recovery to choose from. My decision was partly influenced by practical constraints and the quality of the measure. For example, the measures presented had varying degrees of validation and reliability checks, and this was an important factor. However, some measures were copyrighted and required permission or even payment before using. Another important factor was that it needed to be short, and to take only a maximum of 15 minutes to complete. This was an important factor due to the aforementioned time constraints on including measures in the interview. However, the most influential factor in my eventual decision was the face validity of the measures' items. I was hoping to measure something different from the clinician centred measurements that are typically employed in psychiatric services. The Mental Health Recovery Measure (MHRM), (Young & Bullock, 2003) had used consumer involvement in its development, and attempted to assess recovery independent of symptoms and symptom management. I felt this was important, as the items appeared, more than most measures, to be an alternative to the established medical model of recovery.

In use the MHRM worked well as a measure. It was quick to complete, easy to understand, and its empowering, positive items were well received by participants. This became what I considered to be the 'nice' part of the interview compared with, for example, the PANSS interview. However, I noticed that the MHRM had a slight problem when used with my intended sample. Particularly, the two spirituality items were often noticeably disagreeable to many participants. The measure had been developed on a U.S. population where spirituality might be considered more widespread in influencing recovery. My experience was that this was not the case in an EIS London sample. Ideally it would have been preferable to develop a measure specifically for use with the intended sample. However, time and work constraints meant this was not possible. Therefore it was necessary to compromise by using a tool that may have been developed on a slightly different sample, thus having a degree of cultural specificity, yet was ready to use with established validity and reliability.

#### **Ethical Issues**

Participants being 'too unwell' to participate

For the needs of the regression analysis, a spread of recovery scores was required, whereby some participants feel recovered, and others feel less recovered. The extreme confounder in achieving this was that clients who were too unwell were not approached. However, it was possible to be interviewing a participant who was displaying an increase in their psychotic symptoms, and according to their medical records/care co-ordinator, was becoming unwell. This raised an ethical issue

regarding putting people through the interview procedure and asking potentially upsetting questions related to illness, stigma etc. This ethical dilemma also came into conflict with the empowerment aspect of subjective recovery, whereby if the individual feels they are well enough to be interviewed, then I should respect this rather than, as an 'expert' clinician, tell them otherwise. While the MHRM did not appear particularly upsetting for most individuals, the PANSS did occasionally appear to raise uncomfortable and distressing issues. This demonstrated the requirement for a sensitive balance in the need to achieve research aims whilst being mindful of ethical considerations.

#### Payment for participants

This ethical issue was compounded by the fact that participants were paid for completing the interview. This may have 'encouraged' participants to take part, when otherwise they would have declined. However, without the cash incentive I believe that recruitment would have been significantly compromised as there would have been less of an incentive. Despite a possible clouding of participants' judgement, it was the choice of the participants, and no explicit pressure was applied. Despite one or two people becoming upset during the interview, everyone appeared very pleased to receive payment, with some even asking if they could participate in any further interviews.

Pressures from service and clinical responsibilities

From the beginning of the project, recruitment numbers were predicted to be hopeful based on previous research conducted at the EIS. While eventual numbers weren't quite as high as were hoped for initially, the minimum sample size we had planned for was achieved, and on reflection this was a considerable achievement based on a considerable amount of work. During the latter half of recruitment, the service became under-staffed, meaning that care co-ordinators were over-worked and had less time and patience. While research was never their number one priority, this became far more apparent at this stage. While I sympathised with their difficult situation, I was unable to postpone my study, and the need to maintain pressure to recruit and interview continued. This was compounded with the abstract quality of 'subjective recovery, which meant that speaking to care co-ordinators about the research felt as though I was selling an abstract and irrelevant topic. It may have appeared to them as an interesting, yet largely intellectual luxury that would have little clinical significance to their work. Ideally, at this time it would have been beneficial to have presented a follow-up session of the aims of the research. Perhaps this would have increased understanding and appreciation, and thus increased cooperation. However, it is inescapable that when resources are thin research is often not viewed as a priority.

#### Researcher/clinician hat dilemma

The above dilemma was further complicated as during the data collection period I was also on a clinical placement at the service. This dual role was helpful for access to participants as they tended to present in a chaotic unpredictable pattern, and an opportunistic approach paid dividends. Being on placement also better enabled me to

soak up the character of the service my participants were involved in, and the issues FEP clients commonly face. Another benefit was that I was able to keep research at the top of people's minds, whereas otherwise it might have been more easily forgotten. However, this led to a conflict between clinical and research roles. Staff often expected me to provide clinical information following a research interview, despite confidentiality having been made explicit during consent. Sensitive handling of this issue was important, as I was reliant on care co-ordinators' future cooperation for further recruitment. Conversely, during the interview, participants sometimes wanted expect clinical advice, when I was actually constrained by my researcher role. This created ethical dilemmas that psychological researchers need to face in their practice. This may be especially apparent, as clinical psychologists are encouraged to work as scientist practitioners and promote research in their roles.

#### Strengths and weaknesses of the research

The findings of this research are a good starting point for investigating the factors related to subjective recovery in a first-episode psychosis group. However, a clear weakness is that the participants who declined may well have some of the most valuable data, and it has not been possible to include this in the analysis. The analysis only found depression to be significantly associated with subjective recovery, and this association is one that may have been expected. The model only accounts for a small amount of variance in subjective recovery, so these findings may not be that useful in informing clinical interventions. Perhaps its greatest strength is that it creates debate through what it looked for but did not find. If reductions in psychotic symptoms are not related to a greater sense of subjective recovery, and neither is

having a job or being in education, this raises questions for services working towards. The National Institute for Mental Health in England's guiding statement on recovery (Department of Health, 2005), which, 'puts respect for the values of individual users at the centre of policy and practice, and recognises there are many diverse routes to recovery.'

Towards the end of the research procedure I wished I had considered drug-induced psychosis as a separate group. This is because it seems to me that those who have a one-off drug-induced episode would likely face a different set of issues from the group who are left with residual symptoms, maintenance medication, and a relapsing illness. Both are worthy of investigation, however it would have been interesting to be able to distinguish between the two groups. The service intake guidelines intend to screen out individuals who had a one-off psychotic episode that was clearly related to substance use, however this distinction was often blurred in practice.

#### Reflections on the research process

The process of conducting research teaches you many things that you were unaware of the need to consider before embarking on the project. I feel, as a researcher, you may learn more from engaging in the research process, than from the findings of the study itself. Once you've finished you 'almost' wish you could start again, but do it better. Therefore, it would be good to continue with researching a specialised area as your experience could begin to overcome some of the hurdles that are so time-consuming, stressful and possibly damaging to the validity of the research otherwise.

#### **Conclusions**

I have gained a lot from this study, both in terms of knowledge of the topic of investigation and about the research procedure. Recovery from psychosis and subjective recovery appears to be an evolving paradigm. It is currently a fashionable topic, and fashions change. I wonder if it will still be commonplace or considered relevant in the near future.

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08/00511/40



#### Camden & Islington Community Local Research Ethics Committee

25 July 2006

Mr Stephen Pilling
Consultant Clinical Psychologist and Director of CORE
University College London
CORE

Dear Mr Pilling

Full title of study:

An evaluation of outcomes from two models of early intervention service provision and exploration of factors

explaining these outcomes

#### REC reference number:

Thank you for your e-mail of 07 July 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 18 July 2008. A list of the members who were present at the meeting is attached.

#### Confirmation of ethical opinion

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

#### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

06/Q0511/40

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Dacane	Versions	Date:
Participant Information Sheet: With changes illustrated	2	20 June 2006
Participant Information Sheet: Original document	1	04 May 2006
Participant Information Sheet: Revised document	2	20 June 2006

#### Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0511/40	Please quote this number on all correspondence
With the Committ	ee's best wishes for the success of this project
Yours sincerely	
Chair	
Email:	
Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	Standard approval conditions
	•

Copy to:

Key Collaborator:

R&D Department for NHS care organisation at lead site

06/Q0611/40

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## Camden & Islington Community Local Research Ethics Committee Attendance at Sub-Committee of the REC meeting on 18 July 2006

#### Committee Members:

Neme	Proféssion .
	Former Civil Servant
	Consultant Psychiatrist

### Camden and Islington **MIS**

3	
Mental Health and Social Care Trust	
Client EIS Number:	
Date:	

#### CLIENT INFORMATION SHEET

The Early Intervention Service: Finding out about client's views and experiences since being in contact with the service

#### Version 2 20.06.06

You are being invited to take part in a research study. Before you decide, it is important for you to 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.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### PART 1

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

We would like to find out more about our clients' beliefs and experiences since being in contact with the Early Intervention Service. We are interested in looking at people's symptoms, their views about their illness, how they think others view their illness, how they feel about their life in general and the recovery they have made, and their satisfaction with mental health services. The information we obtain will be used in several ways.

#### Why have I been asked to take part?

You have been asked to take part because you are in contact with the Early Intervention Service We are inviting people to take part in the study if they have been in contact with our service for between 1 and 3 years.

#### Do I have to take part?

It is up to you to decide whether or not you would like to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and 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 now or in the future.

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

You will be invited to meet with a researcher who will ask you some questions that will take approx 1 hour – 1hr 30 mins. Areas covered will include questions about your symptoms and your views about your mental health problems and about how others view them. We will also ask you about your social circumstances and ask you how content you are with your life in general and how far you feel you have recovered from your mental health problems. Finally, we would like to know how satisfied you are with the mental health services you have received.

The researchers would also like to have access to information that clinical staff regularly record about you to monitor your progress and to monitor how well the service as a whole is performing.

You may stop the interview at any time and the interview would be arranged at a time and place that is convenient for you.

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

The information gained from the study may be used to inform development of our service, hopefully improving the services offered to patients in the future. Participants will also be given £15 for their completion of the interview as a small token of our gratitude.

#### What are the possible disadvantages of taking part?

Many people feel it is helpful to talk about their experiences, however some people may find discussing some aspects of their personal experience distressing. If you find any topic upsetting and you wish to stop the interview at any point you are free to do so.

#### What if there is a problem?

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, their contact details are below. You can also talk to your Care Coordinator about the study.

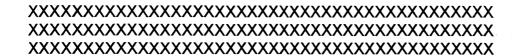
If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure or you can contact the Independent Complaints Advocacy Service on .

#### Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information that is kept about you will have your name and address removed so that you cannot be recognised from it. When we report on the research, it will not be in any way possible to identify you from the report.

Clinical staff responsible for your care will not be told anything about the answers you give, nor will we pass the information on to any other agency. The only situation in which the researcher would pass any information on to clinical staff is if they have reason to be concerned about your or someone else's immediate safety following the interview (for example, if you tell them you are about to harm yourself).

#### **Contact details**



#### PART 2

#### What happens to the results of the study?

The information collected will be anonymised and written up in a report. The report will not contain any personal information from which you could be identified. The results are also likely to be published in a journal read by people planning and researching mental health services. Some of the analyses of the data will be used by two doctoral clinical psychology students to write the theses that will help them qualify as clinical psychologists.

#### Who is organising and supporting the research?

The research is being organised by staff working in the Departments of Clinical Health Psychology and Mental Health Sciences, at University College London and in Camden and Islington Mental Health and Social Care Trust. Camden and Islington Mental Health and Social Care Trust support the project.

#### Who has reviewed this study?

The study has been reviewed by Camden and Islington Community Local Research Ethics Committee.

Thank you for reading this

# Camden and Islington MIS

Mental Health and Social Care Trust  Client EIS Number:  Date:
CONSENT FORM FOR CLIENT
Interviews at 1 year looking at client's experiences and thoughts since being with the Early Intervention Service.
Version 1 04.05.06
<ul> <li>a. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.</li> </ul>
<ul> <li>b. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.</li> </ul>
<ul> <li>c. I understand that the interview records and data will be stored confidentially.</li> </ul>
d. I understand that if there are concerns about self harm or harming another the researcher may be in contact with the clinical team to ensure that support is available to me.
e. I give permission for relevant professionals in the mental health services to     be contacted and for my medical notes to be looked at for some
routinely collected social and clinical data.
f. I agree to take part in the above study.
Name of client Signature Date

Name of person taking consent (if different from researcher)	Signature	Date
Researcher	Signature	Date

1 for patient; 1 for researcher; 1 to be kept with client notes

# Camden and Islington Early Intervention Service

# **CLIENT INTERVIEWS**

# To Be Completed:

No.	Interview Measure	Tick when completed
1	Manchester Short Assessment of Quality Of Life (MANSA)	- Sampiosa
2	Mental Health Recovery Measure	
3	The Illness Perception Questionnaire	
4	Client Satisfaction Questionnaire	
5	Insight Questionnaire	
6	Perceived Devaluation Discrimination Scale	
7	Positive and Negative Symptom Scale (PANSS)	
8	Education and Employment	

Date Completed	
Researcher	
EIS Number	
Gender	
Age	
Ethnic Origin	

.....

# 1. Quality of Life Assessment

Age at leaving full time education (yrs or 99 if still in full time education)							
Number of years of ed	lucation						
Employment status	1=paid employment 2=sheltered employment 3=training/education 4=unemployed 5=retired 6=other (specify)						
work	(1=only if income is commensurate with hours worked. 4 includes tho experience or education who are receiving unemployment	<b>—</b> •					
What is your occupati	On (if employed)						
How many hours a we	ek do you work (if employed)						
Total monthly income	after tax (if shared with partner add both together and divide by two	»)					
Which (if any) state be	enefits do you receive						
How many children do	-						
Who else do you live	1=alone 2=with partner 3=with parents 4=with child/childrer 5=with child/children over 18 6=other (specify) (if live with children under and over 18 code as 4)	ı under 18					
Where do you current	1=house/flat (owner occupied) 2=house/flat (housing associated aso	hostel/group					

# \*Satisfaction Scale

1	2	3	4	5	6
7 Couldn't be Couldn't be Worse	Displeased	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased
	etter				
How satis	fied are yo	u with your life as	s a whole	today*	
How satis	fied are yo	u with your job* (	or occupation	as in employment status)	
	fied are yo	u with being uner	mployed/r	etired*	
	fied are yo	u with your financ	cial situat	ion*	
(includes fami		who you would or refers but not professio		e friend 1=yes 2=	no
-	seen a frie	nd in the last wee	k	1=yes 2=	no
	fied are yo	u with the numbe	r and qua	lity of your friendship	os*
	fied are yo	u with your leisur	e activitie	s*	
	fied are yo	u with your accor	nmodatio	n*	
-	year have	you been accus	ed of a cri	<b>me</b> 1=yes 2=r	10
•	year have	you been a victii	m of phys	ical violence 1=yes 2=r	00
	fied are yo	u with your perso	nal safety	*	
	fied are yo	u with the people	that you l	ive with*	
<i>Or</i> How satist		u with living alon	e*		

now satisfied are you with your sex life"	
How satisfied are you with your relationship with your family* (if not living them)	<b>j</b> with
How satisfied are you with your physical health*	
How satisfied are you with your mental health*	

#### 2. Mental Health Recovery Measure (Young & Bullock, 2003)

The goal of this questionnaire is to find out how you view your own current recovery process. The mental health recovery process is complex and is different for each individual. There are no right or wrong answers. Please read each statement carefully and indicate how much you agree or disagree with each item by ticking the appropriate box.

		Agree Strongly	Agree	Not sure	Disagree	Disa Stro
1	I work hard towards my mental health recovery.					
2	Even though there are hard days, things are improving for me.					
3	I ask for help when I am not feeling well.	į				
4	I take risks to move forward with my recovery.					
5	I believe in myself.					
6	I have control over my mental health problems					
7	I am in control of my life					
8	I socialize and make friends					
9	Every day is a new opportunity for learning					
10	I still grow and change in positive ways despite my mental health problems					
11	Even though I may still have problems, I value myself as a person of worth					
12	I understand myself and have a good sense of who I am					
13	I eat nutritious meals everyday					
14	I go out and participate in enjoyable activities every week					
15	I make the effort to get to know other people.					
16	I am comfortable with my use of prescribed medications					
17	I feel good about myself					

111

18	The way I think about things helps me to achieve my goals					
19	My life is pretty normal					
20	I feel at peace with myself					
		Agree Strongly	Agree	Not sure	Disagree	Disa Stro
21	I maintain a positive attitude for weeks at a time					
22	My quality of life will get better in the future					
23	Every day that I get up, I do something productive					
24	I am making progress towards my goals					
25	When I am feeling low, my religious faith or spirituality helps me feel better					
26	My religious faith or spirituality supports my recovery					
27	I advocate for the rights of myself and others with mental health problems					
28	I engage in work or other activities that enrich myself and the world around me					
29	I cope effectively with stigma associated with having a mental health problem					
30	I have enough money to spend on extra things or activities that enrich my life					

#### 3. Illness Perception

We are interested in your own personal views of how you NOW see your mental health problems. We understand that your views are likely to have changed considerably over time, but please indicate how you NOW view things.

Please indicate how much you agree or disagree with the following statements about

your mental health problems by ticking the appropriate box.

	VIEWS ABOUT YOUR MENTAL HEALTH	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP1	PROBLEMS	4.3				
IFI	My mental health problems will last a short time					
IP2	My mental health problem is a serious condition					
IP3	There are some things which I can do to control my symptoms					
IP4	There is little treatment available that can improve my mental health problems					
IP5	I get depressed when I think about my mental health problems					
IP6	I feel very puzzled by my mental health problems					
IP7	My mental health problem is likely to be permanent rather than temporary					
IP8	My mental health problem does not have much effect on my life					
IP9	To some extent what I do can determine whether my mental health problems get better or worse					
IP10	When I think about my mental health problems I get upset					
IP11	My treatment will be effective in managing my mental health problems					
IP12	I don't have any understanding of my mental health problems at all					
IP13	My mental health problems will last for a long time					
IP14	My mental health problems have financial consequences					
IP15	My mental health problems make it more difficult for me to do day to day things					
IP16	Nothing I do will affect my mental health problems at all					
IP17	My mental health problems make me feel angry					
	VIEWS ABOUT YOUR MENTAL HEALTH	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

1.4	PROBLEMS		I	singer afficial of		
IP18	The negative effects of my mental health			100 mm 10		
	problems can be prevented (avoided) by		1			
	my treatment					Take A 1
IP19			-			
11.13	I feel that I don't know anything about my					
IP20	mental health problems  My mental health problems will pass	<del> </del>	<del>                                     </del>		<del> </del>	
	quickly					
	4					
IP21	Sometimes I have more symptoms than					
	other times					
IP22	My mental health problems cause			10 SA 418		
	difficulties for those who are close to me		<u> </u>			
IP23	My actions will have no effect on the					
	outcome of my mental health problems					
IP24	My mental health problems do not worry					
	me					
IP25	My montal hoolth much laws and laws are				<del> </del>	
11.72	My mental health problems make no sense to me at all					
	to me at an					
IP26	I expect to have this mental health problem				<del> </del>	
-	for the rest of my life					
IP27	I don't get on as well with my family since	L. Maria de la companya della companya della companya de la companya de la companya della compan				
	my mental health problems					
IP28	If I tried harder I could control my					
	symptoms					
IP29	Having this mental health problem makes				1	
	me feel anxious		1			
IP30	My treatment can control my mental health					
	problems					
IP31	I have a clear picture or understanding of		<b> </b>	100 / kg 0 / 50 // 1 1 1 1 1 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2		
11.71	my mental health problems	Baran	1			
IP32	I have times when I am well and times			100 200		
	when I am not so well					
IP33	My mental health problems have messed					
	up my social life		<u> </u>			
IP34	I could do more to help myself					
IP35	My mental health problems mean that I am					
TP2 1	valued less by other people		ļ		ļ	
IP36	My mental health problems make me feel					
	afraid					
IP37	There is no treatment that can help with			7996774368		23/4/2010
11.57	my condition					
IP38	Sometimes the symptoms of my mental				<u> </u>	
	health problems are worse than other times					
IP39	My mental health problems make working	IA VII. AC				
	very difficult					
	VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP40	If I was a stronger person I would get better					
IP41	My mental health problems make me feel					
. 41 4	worthless					

IP42	Some of my symptoms will be there all the time but others will come and go		
IP43	I have lost important relationships as a result of my mental health problems		
IP44	I get very frustrated by my mental health problems.	147.5 147.1	
IP45	My mental health problems have had some positive effects on my life		
IP46	My mental health problems will improve in time		
IP47	I feel a sense of loss due to my mental health problems		

#### 3. Perception of Mental Health

We are interested in your views on how individuals with mental health problems are perceived.

Please read each statement carefully and indicate how much you agree or disagree with each item by circling the appropriate number.

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disa Stro
A	Most people would willingly accept a former mental health patient as a close friend.	1	2	3	4	5
В	Most people believe that a person who has been in a mental health hospital is just as intelligent as the average person.	1	2	3	4	5
С	Most people believe that a former mental health patient is just as trustworthy as the average citizen.	1	2	3	4	5
D	Most people would accept a fully recovered former mental health patient as a teacher of their young children in a public school.	1	2	3	4	5
Е	Most people feel that entering a mental health hospital is a sign of personal failure	1	2	3	4	5
F	Most people would not hire a former mental health patient to take care of their children, even if he or she had been well for some time.	1	2	3	4	5
G	Most people think less of a person who has been in a mental health hospital.	1	2	3	4	5
Н	Most employers will hire a former mental health patient if he or she is qualified for the job.	1	2	3	4	5
I	Most employers will pass over the application of a former mental health patient in favour of another applicant.	1	2	3	4	5
J	Most people in the community would treat a former mental health patient just as they would treat anyone.	1	2	3	4	5
K	Most young women would be reluctant to date a man who has been hospitalised for a serious mental disorder.	1	2	3	4	5
L	Once they know a person was in a mental health hospital, most people will take his opinion less seriously.	1	2	3	4	5

#### 4. Service Feedback Questionnaire

The goal of this questionnaire is to find out how satisfied you are with the service you are receiving. We are interested in your honest opinions whether they are positive or negative. Your feedback is important to us as it assists us in monitoring and improving our services. Please read each question and circle the appropriate answer.

1 1. How would you rate the quality of service you receive?

4	3	2	1
Excellent	Good	Fair	Poor
·			

2 2. Do you get the kind of service you want?

4	3	2	1
No, definitely not	No, not really	Yes, generally	Yes, definitely

3 3. To what extent has the service met your needs?

4	3	2	1
Almost all of my needs have been met	•	Only a few of my needs have been met	

4. If a friend were in need of similar help, would you recommend the service to him or her?

4	3	2	1
No, definitely not	No, not really	Yes, generally	Yes, definitely

5. How satisfied are you with the amount of help you have received?

4	3	2	1
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied

6. Have the services you received helped you to deal more effectively with your problems?

4	3	2	1
Yes, they helped a great deal	Yes, they helped somewhat	No, they really didn't help	No, they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the service you have received

overan, perioral conservan				
4	3	2	1	
Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied	
	l l	uissausticu		

#### 5. Insight Questionnaire

The next few questions are designed to gain an understanding of how you view your experience with the mental health service.

#### **Insight**

1. \	Why do	you have conta	ct with the Com	munity Mental	Health Services?
------	--------	----------------	-----------------	---------------	------------------

2. Do you feel you have a mental illness?

3. Can you tell me a little bit about the illness you have experienced?

# **PANSS Interview questions**

G2. Anxiety	
Have you been feeling	worried or nervous in the past week?
If no:	Would you say that you're usually calm and relaxed?
If yes:	What's been making you feel nervous (worried, uncalm, unrelaxed)?
•	Just how nervous (worried, etc.) have you been feeling?
	Have you been shaking at times, or has your heart been racing?
	Do you get into a state of panic?
4	Are you afraid of something? Of someone?
	Has your sleep, eating, or participation on activities been affected?
Notes	rias your sleep, earnig, or participation on activities been affected?
Notes	
D1 Dalasiana 8 CO	Thursday Abourable contours
	Unusual thought content
Have things been going	
Has anything been both	
Can you tell me someth	ing about your thoughts on life and its purpose?
Do you follow a particu	ılar philosophy?
	ey believe in the devil; what do you think?
Can you read people's i	
	How does that work?
Can others read your m	
If yes:	How can they do that?
	Is there any reason that someone would want to read your mind?
	Who controls your thoughts?
Notes	
110163	
	· · · · · · · · · · · · · · · · · · ·
P6. Suspiciousness/pe	ersecution
1	
Have do you spand you	r tima thaga daya?
How do you spend you	
Do you prefer to be alo	
Do you join in activitie	
If no:	Why not? Are you afraid of people, or do you dislike them?
If yes:	Can you explain?
•	· ·
If vee	Tell me about it.
Do you have many friend	
If no:	
li no:	Any?Why not?

	Why just a few friends? Close friends?	
Do you feel that you can	n trust most people? Why not?	
	n particular that you don't trust?  Can you tell me who they are?  Why don't you trust people (or specific	
not to trust?	If don't know/don't want to say:	
	Is there something that did to you? Perhaps might do to you now?  If yes: Can you explain this to me?	
Notes	What's the problem?	
Notes		
P6. Suspiciousness/p	ersecution cont'd	
Do you have a quick ter	mper?	
Do you get into argume	nts?	
If yes:	How do these arguments start?	
	Tell me about these arguments.	
	How often does this happen?	
Do you sometimes lose		
Do you like most people		
	Why not?	
	people who don't like you? For what reason?	
Do others talk about you		
	What do they say about you? Why?	
	n you or plot against you?	
Do you sometimes feel		
If yes:	Would you say that your life is in dange	
	Is someone thinking of harming you or	even thinking of killing you?
	Have you gone to the police for help?	
	Do you sometimes take matters into y	ou own hands or take action
	on those who might harm you?	
Notes	If yes: What have you done?	

Notes	 		_

#### G1. Somatic concern

How have you been feeling in terms of your health?

If other than 'good': What has been troubling you?

Do you consider yourself to be in good health? If 'good':

Do you have any medical illness or diseases?

Has any part of your body been troubling you? If no: How is your head? Your heart? Stomach? The rest of your body? If ves: Could you explain? Has your head or body changed in shape or size? If yes: Please explain. What is causing these changes? Notes G10. Disorientation Can you tell me what is today's date (i.e., the day, month, and year)? What is the name of the place that you are in now? If hospitalised: What ward are you on? What is the address of where you now stay? If someone had to reach you by phone, what number would that person call? What is the name of the doctor who is treating you? If hospitalised: Can you tell me who else is on the staff and what they do? Do you know who is our queen? Who is our prime minister? P5. Grandiosity If you were to compare yourself to the average person, how would you come out: A little better, maybe a little worse, or about the same? If worse: Worse in what ways? Just how do you feel about yourself? If better: Better in what ways? If about the same: Are you special in some ways? If yes: In what ways? Would you consider yourself gifted? Do you have any talents or abilities that most people don't have? If yes: Please explain. Do you have any special powers? If yes: What are these? Where do these powers come from? Do you have extrasensory perception (ESP), or can you read other people's minds? Are you very wealthy? If yes: Explain please. Can you be considered very bright? **If yes:** Why would you say so? Would you describe yourself as famous?

Would some people recognise you from tv, radio, or the newspaper?

If yes: Are you close to god?  If yes: Did god assign you some special role or purpose?  Can you be one of god's messengers or angels?  If yes: What special powers do you have as god's messenger (angel)?  Do you perhaps consider yourself to be god?  Do you have a special mission in life?  If yes: What is your mission?  Who assigned you that mission?
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Do you perhaps consider yourself to be god?  Do you have a special mission in life?  If yes: What is your mission?  Who assigned you that mission?
If yes: What is your mission? Who assigned you that mission?
Who assigned you that mission?
Notes
G. 12 Judgement and Insight
O. 12 Judgement and misight
What brought you to the hospital/clinic/service?
Are you in need of treatment? Medicine? Hospitalisation?
Was your hospitalisation a mistake? A punishment? Part of a scheme or plot?
Do you have a psychiatric disorder? Have you had one in the past?
What are/were the symptoms of your illness?
(if receiving medication) Why are you taking medicine?
Are you ready to be discharged from the hospital/Clinic etc What are your immediate plans? Your plans for the future?
Notes
<del></del>
G. 3 Guilt Feelings
Do you feel less worthwhile than the average person?
Do you consider yourself a bad person in some ways?
Do you feel guilty about something you may have done in the past?
Have you done something to deserve punishment?
Is your present situation (hospitalisation, illness etc) some kind of punishment? How do you know this?
Have you had thoughts of harming yourself as one kind of punishment? Have you ever acted on those thoughts?
Notes

Subjective Recovery in First-Episode Psychos	SIS	Appendice
	A STATE OF THE STA	
G. 6 Depression		
What is your typical mood like? Are you mostly happy? Sad? Why	v?	
How unhappy have you been feel	ing?	
When do you feel the saddest? Ho Do you sometimes cry? How ofte		
Has your mood affected your app	etite? Your sleep? Your ability to	
Have you had thoughts of harmin suicide?	g yourself or ending your life? H	lave you attempted
Notes		
N5. Difficulty in abstract thinking	3	
Next I'm going to say two wor start, for example with the do they have in common?		
	fruit": Good. Now what about	.?
"They both have	given that is concrete, tangentia e skins", "You can eat them", 'hem": OK, but they're both frui	"They're small", or
(Select 3 other items from the sim A)	nilarities list at varying levels of	difficulty from Appendix
Appendix A (mark the si	imilarities used)	
How are ball and orange alike?	Arm and leg?	Apple and
Rose and tulip?	Pencil and pen?	Uncle and cousing
5 pence piece and ten pence piece	e? The sun and the moon?	Bus and train?
Table and chair? elephant?	Painting and poem?	Tiger and

	Hilltop	and valley?	Hat and shi	irt?	Air and water?				
mean	You've probably heard the expression, 'Carrying a chip on the shoulder'. What does that really nean? There's an old saying, 'Don't judge a book by its cover'. What is the deeper meaning of this roverb? (Select 2 other proverbs from the list in Appendix B at varying levels of difficulty)								
		What does the following say	ing mean?						
		Plain as the nose on your factis good	e.		What's good for the goose				
		Carrying a chip on your shoother	ulder.		for the gander.  The grass is greener on the side of the fence.				
		Two heads are better than or one	ie.		Don't keep all your eggs in basket.				
		Too many cooks spoil the bi	oth.		One swallow does not summer.				
		Don't judge a book by it's a	cover.		A stitch in time saves nine.				
		One man's food is another moss.	nan's poison.		A rolling stone gathers no				
		All that glitters is not gold.		-	who live in glass houses n't throw stones.				

### 7. Positive and Negative Symptom Scale (PANSS)

Positive Scale	SCORE											
Item	Absent	Minim al	Light	Moderat e	Moderat e severe	Severe	Extreme					
P1: Delusions	1	2	3	4	5	6	7					
P2: Conceptual disorganisation	1	2	3	4	5	6	7					
P3: Hallucinatory behaviour	1	2	3	4	5	6	7					
P4: Excitement	1	2	3	4	5	6	7					
P5: Grandiosity	1	2	3	4	5	6	7					
P6: Suspiciousness/persecution	1	2	3	4	5	6	7					
P7: Hostility	1	2	3	4	5	6	7					

Negative Scale	SCORE											
Item	Absent	Minim al	Light	Moderat e	Moderat e severe	Severe	Extreme					
N1: Blunted affect	1	2	3	4	5	6	7					
N2: Emotional withdrawal	1	2	3	4	5	6	7					
N3: Poor rapport	1	2	3	4	5	6	7					
N4: Passive/apathetic social withdrawal	1	2	3	4	5	6	7					
N5: Difficulty in abstract thinking	1	2	3	4	5	6	7					
N6: Lack of spontaneity and flow of conversation	1	2	3	4	5	6	7					
N7: Stereotyped thinking	1	2	3	4	5	6	7					

General Psychopathology Scale				SCORE	C		
Item	Absen t	Mini mal	Light	Modera te	Modera te severe	Severe	Extrem e
G1: Somatic concern	1	2	3	4	5	6	7
G2: Anxiety	1	2	3	4	5	6	7
G3: Guilt Feelings	1	2	3	4	5	6	7
G4: Tension	1	2	3	4	5	6	7
G5: Mannerisms and Posturing	1	2	3	4	5	6	7
G6: Depression	1	2	3	4	5	6	7
G7: Motor Retardation	1	2	3	4	5	6	7
G8: Uncooperativeness	1	2	3	4	5	6	7
G9: Unusual thought content	1	2	3	4	5	6	7
G10: Disorientation	1	2	3	4	5	6	7
G11: Poor attention	1	2	3	4	5	6	7
G12: Lack of judgement and insight	1	2	3	4	5	6	7
G13: Disturbance of volition	1	2	3	4	5	6	7
G14: Poor impulse control	1	2	3	4	5	6	7
G15. Preoccupation	1	2	3	4	5	6	7
G16. Active social avoidance	1	2	3	4	5	6	7

#### 8. Education and Employment

1	Current Educational Le	evel:	Which of the	e fol	lowing	best d	lescribes t	he clie	ent's l	highest	educational	level?	,

	Some school but no qualifications.	ì
2.	GCSEs or other school leaving exam taken before 17 or equivalent NVQ etc.	ļ
3.	A-levels (or school leaving exam of high school diploma take at 17 or 18 in another	l

- 3. A-levels (or school leaving exam of high school diploma take at 17 or 18 in and country or equivalent GNVQ etc).
  4. Higher national diploma (HND) or professional qualification other than degree.
- 5. Some university but no degree obtained.
- 6. Degree.7. Post-grad training.
- 8. If other or in doubt which of these applies, please record details.

2. Current Employment Status	<ol> <li>Employed Full-time</li> <li>Employed Part-Time</li> <li>In sheltered work/employment</li> <li>Unemployed, but able to work</li> <li>Unemployed, but not able to work</li> <li>specify reason e.g. if seeking asylum etc</li> </ol>	
	<ul><li>6. Housewife/househusband</li><li>7. Student</li><li>8. Other</li><li>99. Not known</li></ul>	
3. If currently employed, what is the client's job?		
(Describe as accurately as you can)		
4. If currently studying, what is the client's course?		
(Describe as accurately as you can)		
5. If currently employed, is the client:	<ol> <li>Supporting self through paid work alone</li> <li>Receiving benefits in addition to paid work (i.e. not supporting self through paid work alone)</li> </ol>	
	99. Not known	
6. If not currently employed, has the clipast year?	ent had a job or obtained a regular income as a self-employed p	erson in the
1. Yes 2. No 99. Not known		