Thesis submitted in part fulfilment of the degree of Doctorate in Clinical Psychology, University of East Anglia

# Investigating the Relationship between Negative Symptoms, Autobiographical Memory and Concept of Self in People Recovering from First Episode Psychosis

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#### Abstract

This study brings together findings from both post-traumatic stress disorder (PTSD) and first episode psychosis (FEP) research, attempting to identify similarities in cognitive processes across the two disorders. In light of the evidence that a significant proportion of people who experience FEP display symptoms indicative of PTSD, it seems plausible that current theories derived from PTSD research may be useful in explaining some of the mechanisms involved in FEP. The study initially explored the idea that negative symptoms of psychosis are a reaction to the potentially traumatic experience of a psychotic episode. Previous research has shown that possible traumagenic elements of psychosis might include the distressing nature of the psychotic symptoms or the treatment a person receives. In addition, the study investigated whether a particular finding in PTSD, the association between a discrepant self-concept and a tendency to recall more trauma-related memories, is also seen in psychosis, and whether this is related to the level of negative symptoms a person experiences. The study recruited 51 individuals from across East Anglia, England, who had experienced FEP and were considered to be in recovery from psychosis. Although participants in the study were in remission from their positive symptoms, high levels of depression, anxiety, and psychosis-related trauma symptoms were found. The findings of the study provide support for the application of a model of post-traumatic stress disorder (PTSD), involving self-discrepancy and autobiographical memory, to individuals with FEP since there was a significant association between self-concept discrepancy and the tendency to recall memories related to psychosis for a subset of individuals who experienced their first episode of psychosis as particularly traumatic. The theoretical and clinical applications of this finding are discussed along with suggestion for future research in the area.

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#### 1. Introduction

#### 1.1 Overview

First episode psychosis (FEP) typically affects individuals at an age at which they are developing their sense of self and identity, forming relationships with others, and orienting themselves to the world. Early intervention and effective treatment of psychotic symptoms is therefore important to ensure positive long term outcomes for people experiencing their first episode of psychosis.

Although the positive symptoms of psychosis, such as hallucinations and delusions, often remit with pharmacological or psychological intervention, the negative symptoms, such as affective flattening, alogia, avolition, apathy, anhedonia, and asociality, often persist and are associated with poor long term outcomes. This study aims to extend the current psychological knowledge of the negative symptoms of psychosis by investigating a theory that negative symptoms may be a trauma response to the potentially traumatic experience of psychosis. The application of a model of post-traumatic stress disorder (PTSD), involving self-discrepancy and autobiographical memory (Sutherland & Bryant, 2008), to individuals in recovery from their first episode of psychosis will be tested.

As a background, the introduction provides an overview of the nature of psychotic illness. It examines the concept of negative symptoms and provides a rationale for research into psychological models of negative symptoms. As the introduction develops, the focus will turn to the potential link between negative symptoms and avoidance as a trauma response in psychosis. In relation to this link, the potential traumatic nature of first episode psychosis will be discussed along with the phenomenological overlap between the two disorders.

The application of models of PTSD (Ehlers & Clark, 2000; Sutherland & Bryant, 2008) to a FEP population will be then considered. There will be a particular focus on the work of Sutherland and Bryant (2008) which considers the impact of trauma on self-concept and autobiographical memory recall. The rationale for applying this model to FEP will be outlined, with particular reference to the impact of first episode psychosis on an individual's sense of self. The introduction concludes with a statement of the study aims and the research questions that this study will attempt to answer.

#### **1.2 Introduction to psychosis**

#### 1.2.1 Defining psychosis.

Psychosis was first recognised and defined in the late nineteenth and early twentieth centuries. Emil Kraepelin (1893) was the first to differentiate different types of psychosis by identifying two patterns he described as manic depressive psychosis and dementia praecox (dementia of the young). Eugen Bleuler first used the term and diagnosis schizophrenia in a 1908 lecture in Berlin. He later described schizophrenia as the result of a "splitting [and dissociation] of the mind", particularly between emotional and intellectual functions of the brain (Bleuler, 1911).

The first Diagnostic and Statistical Manual of Mental Disorders (APA, 1952) described a condition called "Schizophrenia Reactions" under "Disorders of Psychogenic Origin". Nine subtypes of this disorder were listed including simple, hebephrenic, catatonic, paranoid, acute undifferentiated, chronic differentiated, schizo-affective, childhood, and residual. This range of subtypes perhaps reflects the complexity and heterogeneity of psychosis as we understand it today.

The current understanding of psychosis is characterised by changes to the way an individual thinks, feels and understands their world (British Psychological Society, 2000). The term "psychotic experiences" is often used as an umbrella term for unusual perceptions (e.g., hearing voices or seeing visions), or unusual beliefs.

#### **1.2.2** Consideration of diagnostic criteria for psychosis.

The most widely used diagnostic criteria are those found in the International Classification of Diseases, Injuries and causes of Death, 10<sup>th</sup> edition (ICD-10; World Health Organisation, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; American Psychiatric Association, 2013). There are several types of psychosis listed in the diagnostic criteria. For example, in the ICD-10

criteria, schizophrenia, schizoptypal disorder, delusional disorder, brief psychotic disorder, shared psychotic disorder, schizoaffective disorder, other psychotic disorder not due to a substance or known physiological condition, and unspecified psychosis are all listed. Although the advent of these modern diagnostic criteria has meant that the identification and understanding of individuals presenting with a functional psychotic illness has become more reliable, the extent to which these diagnostic constructs accurately reflect the underlying disease processes is the subject of debate (Boyle, 1990). Recent years have seen a growing debate on the merits of using a symptom-based approach to psychosis instead of the traditional diagnostic categories (Bentall, 2003; van Os, Verdoux, Bijl, & Ravelli, 1999). This symptom-based approach conceptualises psychosis as a continuum rather than as a dichotomous entity.

#### **1.2.3** First episode psychosis and early intervention.

First-episode psychosis (FEP) is defined as the first treated episode experienced by an individual in their lifetime (National Early Psychosis Project Clinical Guidelines Working Party, 1998). The overall incidence rate of FEP in the UK, estimated over a 60 year period from 1950-2009, was 31.7 per 100,000 personyears (95% CI: 24.6–40.9) (Kirkbride, Errazuriz, Croudace, Morgan, Jackson et al., 2012). Within East Anglia, the study area considered in this research, incidence over a three year period from 2009 to 2012 has been estimated at 45.1 per 100 000 personyears (95% CI: 40.8–49.9) (Kirkbride, Stubbins, & Jones, 2012). These incidence rates are far greater than the anticipated incidence rates of 12 to 15 per 100 000 person-years on which Early Intervention Psychosis services, which treat individuals with FEP, were first commissioned in 2002 (Department of Health, 2001).

FEP typically has a higher incidence in males than females (Kirkbride et al., 2006; Kirkbride et al., 2012) and has elevated incidence in migrant and minority ethnic populations (Kirkbride et al., 2006). The first onset of psychosis typically occurs when individuals are in their late teens or early twenties, with typically a later age of onset for women compared to men (see Eranti, MacCabe, Bundy & Murray, 2013, for a meta-analysis). Therefore, onset typically occurs at a critical developmental life stage in terms of personality, social role, educational and vocational achievement. The onset of a first episode of psychosis is frequently associated with a pronounced decline in education and employment (Goulding, Chien, & Compton, 2010; Harris et al., 2005; Jones et al., 1993; Kessler et al., 1995; Mueser, Salyers, & Mueser, 2001; Turnbull, George, Landerman, Swartz, & Blazer, 1990). By the time people present to mental health services, close to half are already unemployed (Marwaha & Johnson, 2004; Reininghaus et al., 2008; Turner et al., 2009). Kirkbride et al. (2012) found that for an Early Intervention sample in East Anglia from 2009 to 2012, 50% of people referred to the service were unemployed. This rate is much higher than that found in the general population, which was around 8% for the same time period (Office of National Statistics, 2011).

Estimates for rates of recovery in first episode psychosis samples have varied between 10 and 25%, dependent on diagnosis and length of follow-up period (Bertelsen et al., 2009; Wunderink et al., 2009). In these studies recovery was defined as making both a symptomatic and a functional recovery. Research has suggested that intervening early can help to improve long term outcomes for people who experience their first episode of psychosis. Studies into predictors of recovery in first episode psychosis have consistently found that a shorter duration of untreated psychosis (DUP) is associated with higher rates of recovery (Chang et al., 2012; Jeppesen et al.,

2008; Verma et al., 2012; Wunderink et al., 2009). Additionally, Boonstra et al. (2012) found that shorter DUP was associated with less severe negative symptoms at short term and long term follow up.

In order to provide specialist support for individuals experiencing a first episode of psychosis, Early Intervention Services (EIS) were introduced in England in 2002. These services typically work with young people who are aged between 14 and 35 years and provide a comprehensive community-based package of care (Department of Health, 2001). One of the theoretical drivers behind EIS is the association between longer duration of untreated psychosis and poorer functional outcome (Marshall et al., 2005). There is evidence that EIS may improve outcomes for young people with psychosis in terms of fewer relapses, readmissions and symptoms (Craig et al., 2004; Grawe et al., 2006). However, a longer term follow-up study found that gains achieved through contact with EIS were not maintained at five years post-onset (Bertelsen et al., 2008). Additionally, a Cochrane review on the benefits of EIS concluded that there was insufficient evidence from randomised control trials to draw definitive conclusions about the effectiveness of these services (Marshall & Rathbone, 2008).

The impact of psychosis on young people in these formative years, relatively low recovery rates, and the possibility that any gains made early on may not be maintained in the long term, provides a strong rationale for developing our understanding of the processes involved in both symptomatic and functional recovery with the aim to develop effective interventions to enable this recovery. In light of this, the introduction will now turn to a discussion of one of the most dominant current conceptualisations of psychotic symptoms – the syndrome approach.

#### **1.2.4** The syndrome approach to psychosis.

In an attempt to understand the complexity and heterogeneity seen in psychosis, researchers and clinicians have proposed different subtypes of the illness. The symptoms of psychosis are typically divided into positive symptoms, including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), negative symptoms (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect), and disorganised symptoms (such as inappropriate affect, poverty of content of speech, and disturbances of the form of thought).

Much of the early research in this area focused on a two-syndrome approach known as the positive-negative dichotomy. Kraepelin (1919) was the first to propose a dichotomy within the symptoms of schizophrenia. Although he did not use the specific terms "positive" and "negative", he did recognise two broad classes of symptoms which closely fit with our current understanding of positive and negative symptoms. The two classes of symptoms Kraepelin (1919) described were those that were more florid and those that were marked by losses or deficits.

Crow (1980) proposed that schizophrenia could be divided into two major syndromes. He referred to these syndromes as type 1 and type 2, and suggested that these syndromes reflected two dimensions of pathology. Type 1 schizophrenia was characterised by prominent positive symptoms, normal brain structure, relatively good response to treatment, and an underlying neurochemical mechanism that was probably related to the dopaminergic system. Type 2 was characterised by prominent negative symptoms, structural brain abnormalities, impaired cognitive function and poor response to treatment and outcomes.

The validity of the distinction between positive and negative syndromes within schizophrenia has been extensively considered by researchers (e.g., Crow, 1985; Thiemann, Csernansky, & Berger, 1987; Walker & Lewine, 1988). At a rudimentary level, the distinction has been justified on the basis of the content of symptoms. The negative symptoms represent a deficit of functions, for example a general withdrawal from social or cognitive functioning (Thiemann et al., 1987), whereas the positive symptoms represent an excess of functions, for example an increase in odd perceptions or formal thought disorder.

Internal consistency between the symptoms that have been classified within the syndrome clusters has also been used as support for a two syndrome approach. Most scales of negative symptoms demonstrate at least a moderate amount of internal consistency (Thiemann et al, 1987). Correlations between measures of positive and negative symptoms are near zero, which suggests that the dimensions of positive and negative symptoms are likely to be independent (Crow, 1985; Walker & Lewine, 1988).

The relationships between the positive and negative syndromes of schizophrenia and other variables have also been considered. For example, some medications have been shown to be more effective in treating positive symptoms than negative symptoms (Johnstone et al., 1983; Kane & Mayerhoff, 1989) suggesting a distinct pathology for the two sets of symptoms. Prognosis shows the same pattern, with good prognosis being related to positive symptoms and poorer prognosis and outcome related to negative symptoms (Johnstone, MacMillan, & Crow, 1987; Lindenmayer, Kay, & Friedman, 1986; Pfohl & Winokur, 1982; Pogue-Geile, 1989).

More recent factor analytic studies have found that the two syndrome approach may be inadequate in describing the full range of symptomatology found in

psychosis and instead a three factor model may be preferable. For example, in a meta-analysis of negative and positive symptom rating scales, Grube, Bilder, and Goldman (1998) found that data across 10 empirical studies fit a three-factor model involving positive, negative, and conceptual disorganisation factors. The idea of a third discrete cluster of disorganised symptoms observed in individuals experiencing schizophrenia was originally proposed by Liddle (1987). Disorganised symptoms include inappropriate affect, poverty of content of speech, and disturbances of the form of thought.

Each person will have a unique combination of symptoms and experiences. However, this study will specifically focus on the negative symptoms of psychosis and the rationale for doing so will now be discussed.

#### 1.3 Negative symptoms of psychosis

#### **1.3.1 Defining negative symptoms.**

Negative symptoms are defined as the absence or reduction in behaviours that are normally present in the general population (Buchanan, 2007). The five major subdomains of negative symptoms are blunted affect (including affective flattening and blunted expression), alogia (poverty of speech), amotivation (loss of volition), anhedonia (reduced ability to experience or anticipate pleasure), and asociality (social withdrawal) (Kirkpatrick, Fenton, Carpenter, & Marder, 2006). While most prevalent in schizophrenia spectrum disorders, negative symptoms are also frequently present in other FEP diagnoses, perhaps with the exceptions of bipolar disorder and brief psychotic disorder (Lyne et al., 2012). Using the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1989) to assess 330 individuals presenting with FEP, Lyne et al. (2012) found that the prevalence of negative symptoms (defined

as scoring three or more on at least one item of the SANS) was high in both the schizophrenia spectrum diagnoses group (87%) and in the "all other psychotic diagnoses" group (51%). Therefore, it can be assumed that negative symptoms are a significant feature of first episode psychosis.

#### **1.3.2** Overlap between depression and negative symptoms.

Clinically significant depressive symptoms are common in individuals experiencing FEP (Addington, McCleary, & Munroe-Blum, 1998; Koreen et al., 1993; Siris, 2000). Depressive symptoms usually appear either in the prodromal period (Häfner, Löffler, Maurer, Hambrecht, & Heiden, 1999; Koreen et al., 1993; Schultze-Lutter, Klosterkötter, Picker, Steinmeyer, & Ruhrmann, 2007) or during the first psychotic episode (Birchwood, Iqbal, Chadwick, & Trower, 2000). Although depressive symptoms may be present throughout all phases of a psychotic episode, the highest rates of depression have been found during the acute phase (Koreen et al., 1993). In a recent study of individuals with first episode psychosis, Upthegrove et al. (2010) found that 80% of individuals were experiencing at least moderate levels of depression.

Depression and negative symptoms show a large degree of phenomenological overlap, with symptoms such as diminished interest, pleasure, energy, and motivation being common to both disorders. However, there are also some distinguishing features, such as cognitive concepts of guilt and suicidal thoughts, which are common features of depression but are not typically seen in individuals with negative symptoms (Siris, 2000).

Despite the high rates of co-occurrence and apparent phenomenological overlap between depression and negative symptoms, recent evidence has provided support for the validity of the independence of a depressive dimension in the structure

of psychosis. For example, there is strong evidence that depression precedes the onset of FEP for most individuals (Cunningham Owens, & Johnstone, 2006; Yung et al., 2003). Additionally, there is evidence to suggest that the severity of depression is not significantly correlated with the severity of negative symptoms (Upthegrove et al., 2010) providing further support for the argument that depression and negative symptoms may be distinct symptom constructs.

However, the relationship between depression and negative symptoms is somewhat inconclusive and the area requires further research. In this study depression and negative symptoms were conceptualised as independent constructs, but the potential overlap between the two constructs was taken into consideration.

#### **1.3.3** Negative symptoms as a barrier to recovery.

The NIMH Measurement and Treatment Research to Improve Cognition in Schizophrenia (MATRICS; Kirkpatrick et al., 2006) consensus statement on negative symptoms states that negative symptoms represent an unmet therapeutic need.

Antipsychotic medications have been very effective in the treatment of the positive symptoms of psychosis and have been associated with rapid improvement of positive symptoms in the majority of FEP patients (Álvarez-Jiménez, Parker, Hetrick, McGorry, & Gleeson, 2011). Previous research has indicated that up to 96% of FEP patients reach clinical remission in terms of positive symptoms within 12 months of treatment commencement (Robinson, Woerner, Delman, & Kane, 2005; Rummel, Hamann, Kissling, & Leucht, 2003). However, evidence suggests that this clinical benefit has not translated into substantial gains in functional recovery (Robinson, Woerner, McMenimon, Mendelowitz, & Bilder, 2004; Schooler, 2006). Cognitive and negative symptoms of psychosis have been implicated in playing a substantial role in this regard (Bowie, Reichenberg, Patterson, Heaton, & Harvey, 2006; Milev,

Ho, Arndt, & Andreasen, 2005). In many studies, neither cognitive nor negative symptoms have been found to improve significantly with antipsychotic treatment (Ho, Nopoulus, Flaum, Arndt, & Andreasen, 1998; Perlick, Rosenheck, Kaczynski, Bingham, & Collins, 2008; Schooler, 2006).

In a recent review, Arango, Garibaldi, and Marder (2013) evaluated published trials of pharmacological treatments for negative symptoms in schizophrenia from 1995 to 2012. They found some potential support for the effectiveness of the antipsychotic amisulpride over a placebo in reducing negative symptoms. However, the authors noted that many of these studies had methodological limitations. For example, many of the studies evaluating antipsychotic monotherapy treatment did not consider positive symptoms, mood symptoms or anti-psychotic motor effects. Therefore, it is possible that any effects of antipsychotic medication on negative symptoms may have been mediated through alleviation of these other symptoms. Studies evaluating the effect of medications administered as an adjunct to antipsychotics also had their limitations. These include the fact that the studies included very heterogeneous patient populations and used different criteria for persistent negative symptoms. Arango et al. (2013) concluded that although some antidepressants have shown an effect on negative symptoms, it is unclear whether this is a direct effect on negative symptoms or if it is mediated through an improvement in mood symptoms.

Austin et al. (2013) conducted a 10 year follow up of patients who had experienced first episode psychosis and found that lower severity of negative symptoms predicted better rates of recovery at 10 years. Negative symptoms have been found to be more predictive of concurrent and future poor functioning in the community than the positive symptoms of psychosis (Milev et al., 2005). Negative

symptoms are major contributors to lost productivity, poor quality of life, social deficits, poor occupational attainment, and disability (Buchanan, 2007; Kirkpatrick et al., 2006; Kurtz, Moberg, Ragland, Gur, & Gur, 2005). Decreasing negative symptoms and improving functional outcomes is therefore a significant health priority (Buchanan, 2007; Kirkpatrick et al., 2006).

This thesis therefore aims to explore the nature of negative symptoms in psychosis, with the aim of understanding more about the cognitive mechanisms which underlie these symptoms. It is hoped that a greater understanding of the nature of negative symptoms will help to guide the direction for future effective interventions in order to improve outcomes for individuals experiencing negative symptoms of psychosis.

#### **1.3.4** Current models of negative symptoms.

Biological, neuropsychological and psychological theories have been proposed as underlying negative symptoms. These theories will each be briefly reviewed in turn.

#### 1.3.4.1 Biological.

Traditionally, explanatory models of negative symptoms focused on deficits and described negative symptoms in terms of degenerative neurobiology. Crow (1985) proposed that negative symptoms (termed Type II schizophrenia by Crow) were related to structural brain abnormalities and reflected a more degenerative condition or developmental impairment. Many studies have used structural brain imaging techniques such as computerised tomography (CT) and magnetic resonance imaging (MRI) in an attempt to identify possible neural mechanisms that may underlie negative symptoms. However, the results have been somewhat inconsistent. Some studies have found enlarged cerebral ventricles in patients with prominent

negative symptoms (e.g., Andreasen, Olsen, Dennert, & Smith, 1982). Marks and Luchins (1990) reviewed 28 studies that examined whether negative symptoms are associated with structural brain abnormalities (enlarged ventricles). They found that 18 studies provided support for an association between negative symptoms and structural brain abnormalities. However, it is important not to infer causality in these studies since it has been proposed that long-term antipsychotic use might result in a progressive decrease in brain volume (Ho, Andreasen, Ziebell, Pierson, & Magnotta, 2011).

More recently, research into neuroanatomical models underlying negative symptoms has focused on functional neuroimaging. Using frontal lobe patients as an analogy, it has been suggested that negative symptoms may represent a dysfunction in the prefrontal cortex, sometimes described as hypofrontality (i.e., decreased metabolism or blood flow). Pathology in the frontal lobes is thought to produce reduced activation levels which in turn result in loss of motivation, reduced emotionality, and minimal wilful behaviour. Andreasen et al. (1992) conducted a large study in order to examine hypofrontality in relation to negative symptoms. The authors compared patients with schizophrenia who had not taken neuroleptics in three weeks, patients with schizophrenia who had never received antipsychotic medications, and healthy volunteers. They measured cerebral blood flow using Xenon-133 single-photon emission computed tomography (SPECT) whilst participants completed Shallice's (1982) Tower of London frontal activation task. Andreasen et al. (1992) found that decreased activation (relative to healthy controls) was present only in patients with high levels of negative symptoms. The finding of hypofrontality in patients with schizophrenia was supported by a meta-analysis which

included studies where patients were assessed both at rest and during cognitive task performance (Hill et al., 2004).

However, these early findings in patients with chronic schizophrenia have not been consistently replicated in individuals with first episode psychosis. For example, Guerrero-Pedraza et al. (2012) found that there were no brain regions where first episode patients showed significantly less activation than controls on the n-back working memory task.

In summary, biological models of negative symptoms have provided some evidence that there may be an association between structural brain abnormalities, particularly in the prefrontal cortex in chronic schizophrenia samples. However, causality is yet to be established, results have been inconsistent, and biological models have failed to account for negative symptoms in first episode psychosis samples.

#### 1.3.4.2 Neuropsychological.

An alternative theory attributes the cause of negative symptoms to cognitive impairments (e.g., deficits in memory, attention and executive function).

Eight separable domains of cognitive impairment have been identified for schizophrenia according to the NIMH-Measurement and Treatment Research to Improve Cognition in Schizophrenia (MATRICS; Kirkpatrick et al., 2006). Seven of these (processing speed, attention/vigilance, working memory, verbal learning and memory, visual learning and memory, reasoning and problem solving, and verbal comprehension) belong to the domain of neurocognitive functioning. Social cognition (the mental operations underlying social behaviour, such as the interpretation of another person's intentions and emotions) was identified as an additional domain. Cross-sectional studies have frequently shown that negative symptoms correlate with various measures of neuropsychological performance (see

Addington, 2000, for a review). However, Addington (2000) suggested that negative symptoms account for only approximately 10% of the variance in cognitive performance. Evidence from longitudinal studies is increasingly providing support for the idea that cognitive impairment and negative symptoms are distinct constructs. One longitudinal study found that there was no relationship between change in negative symptoms and neurocognitive function (Bell & Mishara, 2006) suggesting that they represent separate disease processes. Harvey, Koren, Reichenberg, and Bowie (2006) attempted to explore the relationship between negative symptoms and cognitive impairment further by testing four proposed models for the relationship. By reviewing available evidence, including path analysis studies, they found that negative and cognitive symptoms appear to be related but potentially separable domains.

Although studies have frequently found that negative symptoms and cognitive impairment co-occur in individuals with psychosis, there is now increasing evidence from longitudinal studies that suggests that they are more likely to be distinct constructs. Cognitive impairments are not thought to directly cause negative symptoms or vice versa, and they do not seem to change in parallel over time (Bell & Mishara, 2006).

#### 1.3.4.3 Psychological.

Since biological and neuropsychological approaches have failed to provide convincing explanatory models of negative symptoms, psychological models have become more prominent in recent years. Psychological models provide an alternative perspective to traditional deficit models, proposing that the negative symptoms of psychosis may be functional.

Bleuler (1911) was the first to suggest that negative symptoms may have psychological underpinnings. Bleuler viewed negative symptoms as a defensive

position in relation to intolerable distress. Almost a century later, Rector, Beck, and Stolar (2005) revisited this idea and proposed a cognitive model of negative symptoms. This model is based on the premise that the negative symptoms of psychosis are expressed along a continuum. Primary negative symptoms are thought to persist throughout the illness (independent of other symptoms), whereas secondary negative symptoms are thought to appear only in response to either the positive symptoms of psychosis, stressful events, or to medication side effects (DSM-IV; American Psychiatric Association, 1994). Rector et al. (2005) focus on these secondary negative symptoms in their cognitive model. The model proposes that certain individuals are more susceptible to developing negative symptoms. These individuals are thought to show schizoid personality traits prior to the onset of psychosis, including social distancing (Kendler, Thacker, & Walsh, 1996) and negative thoughts about self-performance and self-evaluation (Barrowclough et al., 2003). Rector et al. (2005) suggest that upon the onset of the positive symptoms of psychosis, premorbid negative beliefs become activated and individuals resort to a familiar strategy of buffering themselves from external threat and painful symptoms. For example, to mitigate social threats, individuals experiencing paranoia may engage in interpersonal avoidance and other active safety behaviours. These behavioural avoidance strategies manifest as secondary negative symptoms with attenuated verbal behaviour being viewed as alogia, diminished emotional drive being perceived as amotivation, limited facial expressions as affective flattening, and hopelessness as apathy. Rector et al. (2005) use clinical examples to illustrate this theory. They describe one individual with a paranoid delusion who spent the entire day in bed to alleviate his fears of being monitored by government officials outside his home. Another patient, hearing voices attesting to her "worthlessness", quit her part-time job

and continuing education course and withdrew from family and friends because she feared making mistakes, which would trigger a voice stating "you're worthless".

In a similar vein to Rector et al. (2005), Stampfer (1990) has proposed that the negative symptoms of psychosis might be a reaction to the psychologically overwhelming trauma of experiencing a psychotic illness. Fundamental to Stampfer's (1990) theory is the marked similarity between positive and negative symptoms of psychosis and PTSD. For example, Stampfer suggested that the negative symptoms of amotivation and social withdrawal that are seen in psychosis resemble the avoidance phenomena typically seen in patients experiencing PTSD. However, currently there is little empirical evidence to support this theory. Although McGorry (1991) has suggested that trauma due to either "losing one's mind" or being hospitalised may be responsible for a proportion of the variance in negative symptoms and the avoidance symptoms of PTSD (as measured by the Impact of Events Scale). Priebe, Bröker, and Gunkel (1998) also found that there was no correlation between negative symptoms and the level of traumatic symptoms.

Harrison and Fowler (2004) tested Stampfer's theory by focusing on avoidance of traumatic reactions to psychosis. In a study of individuals with a diagnosis of schizophrenia, they found that participants who avoided traumatic memories of psychotic symptoms and hospitalisation had more negative symptoms, and that those with more negative symptoms retrieved fewer specific autobiographical memories. They also found that the avoidance of traumatic memories relating to psychosis and specificity of autobiographical recall were significant predictors of negative symptoms. Therefore, it appears that avoidance may mediate the link between negative symptoms and traumatic reactions to psychosis.

Research on the relationship between negative symptoms of psychosis and psychosis related PTSD is somewhat inconclusive. Meyer, Taiminen, Vuori, Aijala, and Helenius (1999) and White and Gumley (2009) both found a positive correlation between the number of negative symptoms and psychosis-related PTSD. However, McGorry et al. (1991) and Tarrier, Khan, Cater, and Picken (2007) found no significant relationship between negative symptoms and PTSD symptoms in first episode samples. One possible explanation for these null findings is that both of these studies had a small sample size and therefore may have been underpowered. It is also possible that because these studies assessed first episode samples, it may have been too early in the course of the participants' psychoses for many negative symptoms to have developed. It is anticipated that this could also be a potential issue in the present study where a first episode psychosis sample was also considered. Finally, it may be the case that individuals with negative symptoms may have more chronic psychosis generally and therefore may have a greater likelihood of hospitalisation and hence a greater likelihood of developing PTSD.

The present study will attempt to expand on current psychological theories of negative symptoms and explore the idea that negative symptoms may represent a reaction to the potentially traumatic impact of a first episode of psychosis. Evidence for psychosis being a potentially traumatic event will first be explored followed by models of PTSD that may be applicable to first episode psychosis.

#### 1.4 Links between psychosis and trauma

Traditionally, psychosis and PTSD have been conceptualised as distinct disorders. Morrison, Frame, and Larkin (2003) reviewed the research and theoretical literature on potential links between trauma and psychosis. They considered whether psychosis can cause PTSD, whether trauma can cause psychosis, and whether psychosis and PTSD could both be part of a spectrum of responses to a traumatic event.

There is increasing evidence that psychosis itself might be a traumatic event and this might have a negative impact on recovery from first episode psychosis. Additionally, people with psychosis may be more vulnerable to experiencing PTSD like symptoms because of the way they process information and difficulties with contextual integration (Steel, Fowler, & Holmes, 2005). Therefore, the experience of having psychosis may be traumatic and the experience may be processed in a way that is more likely to lead to PTSD.

#### **1.4.1** Psychosis as a traumatic event.

Much has been written about the role of adverse life events in precipitating the onset of psychosis (e.g., Nuechterlein & Dawson, 1984). However, only in recent years has research begun to focus on the traumatic impact of the psychotic illness itself. The impact of a psychotic illness on a patient's life has been of long standing interest to both clinicians and researchers. The majority of research within this area has focused on post-psychotic depression (McGlashan & Carpenter, 1976) and post-psychotic collapse (Mino & Ushijima, 1989). However, more recently the focus of research has shifted onto PTSD type reactions following an episode of psychosis (e.g., McGorry et al., 1991).

There is now a growing body of evidence to support the idea that the experience of acute psychosis and/or the experience of psychiatric hospitalisation as a result of psychotic symptoms may be sufficiently traumatic to precipitate the development of PTSD (Lundy, 1992; McGorry et al., 1991; Shaner & Eth, 1989; Shaw, McFarlane, & Bookless, 1997; Williams-Keeler, Milliken, & Jones, 1994).

In support of the idea of psychosis as a potentially traumatic event, some authors have proposed that hallucinatory and delusional disturbances can shatter a person's experience of themselves, the world and others (e.g., Bayley, 1996) in a similar way to non-psychotic trauma (Janoff-Bulman, 1979).

A number of empirical studies have shown that patients recovering from psychotic illness experience posttraumatic symptoms as a consequence of both having psychotic symptoms and being hospitalised (Meyer et al., 1999). Rates of trauma symptoms following a first episode of psychosis range between 11% and 67% (Frame & Morrison, 2001; McGorry et al., 1991; Meyer et al., 1999). The large variation in the rates of PTSD found in individuals recovering from psychosis may be at least partly explained by the fact that the studies have used a variety of methodologies and measures, and some measures of PTSD may be more sensitive to symptoms than others. These studies have also measured symptoms at varying time points in the course of psychosis and have assessed different diagnostic groups (e.g., some studies have excluded affective diagnoses whereas other studies have included these patients).

McGorry et al. (1991) conducted the first incidence study of PTSD in people with psychosis. They used the Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979) to assess 36 patients at three time points; as psychiatric inpatients, four months after discharge from hospital, and then again at 11 months after discharge

from hospital. Rates of PTSD were 46% at the four month follow up and 35% at the 11 month follow up. PTSD symptoms seemed to be particularly linked to the experience of hospitalisation as a consequence of experiencing psychosis, and less so to the psychotic experiences per se.

Shaw et al. (1997) interviewed 42 patients who were recovering after hospitalisation for a psychotic episode. They found a high prevalence of symptoms of acute distress reactions in patients recovering from a psychotic illness. Intrusive and distressing recollections of the experience of psychosis and a range of associated avoidance phenomena were commonly reported. They found that particularly distressing elements of a psychotic episode included enforced treatment, isolation from family, taking medication, and a loss of control in relation to suicidal and aggressive thoughts. In this study the prevalence of PTSD following psychosis, as assessed using the Clinician-Administered PTSD Scale (CAPS; Blake et al., 1995) was high at 49%. Even individuals who did not meet full diagnostic criteria for PTSD still had many symptoms typically seen in PTSD, especially intrusion and increased arousal. The authors note that the figure for PTSD prevalence for their sample might be an underestimate of the degree of PTSD symptomatology in the overall population of those recovering from psychosis. This is because the more "disturbed", and therefore potentially more traumatised patients, were not include in the study due to the fact that they could not give informed consent. This is an important consideration in all of the previously mentioned studies.

Bernard, Jackson, and Jones (2006) assessed individuals with first episode psychosis who were in the recovery phase of their illness (i.e., not currently acutely psychotic or suicidal) and found that 57% met the diagnostic cut-off level of 33 on the IES-R (Creamer, Bell, & Failla, 2003) for PTSD related to their episode of psychosis.

Meyer et al. (1999) found lower rates of PTSD in people recovering from psychosis of 11%. In this study the researchers were particularly strict with their criteria for diagnosing PTSD and they paid particular attention to differentiating between psychotic and trauma symptoms. Meyer et al. (1999) also attribute their low rates of PTSD to the fact that they excluded people with affective diagnoses and highlight that people with depressive symptoms may be more prone to developing PTSD. Meyer et al. (1999) also assessed the severity and quality of psychotic symptoms using the Positive and Negative Syndrome Scale (PANSS; Kay, Opler, & Fiszbein, 1987), and found that this was associated with PTSD symptomatology, assessed using the Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997), nine weeks after admission to an inpatient ward. They proposed two possible explanations for this finding. Firstly, ongoing positive symptoms may be more traumatic than quickly resolving ones, or alternatively the presence of PTSD symptoms may delay recovery from psychosis. More recently, Mueser, Lu, Rosenberg, and Wolfe (2010) have found that 39% of people who had experienced psychosis also met the full diagnostic criteria for PTSD.

Dunkley, Bates, and Findlay (2013) used interpretive phenomenological analysis (IPA) to explore how people understand the experience of first episode psychosis and its negative impact. Themes that emerged from this analysis included perceived enforced treatment, disintegration (i.e., feeling disconnected from one's identity, others and the world), estrangement, and a sense of loss and deficit. The authors concluded that the traumagenic distress of FEP goes beyond the acute episode of psychosis since most of the themes that were identified related to the aftermath of this experience.

In common with studies of PTSD following physical events (e.g., Breslau, Davis, Andreski, & Peterson, 1991), the occurrence of a psychotic episode does not inevitably produce a PTSD response. Chisholm, Freeman, and Cooke (2006) explored potential predictors of traumatic reactions to a psychotic episode. They found that lower quality of social support, previous experiences of traumatic events, and a greater number of previous psychotic episodes were associated with higher levels of PTSD symptoms. They also found that patients who reported being more helpless and less in control during their episode were more likely to develop a traumatic stress reaction.

Therefore, this research suggests that good social support, low levels of previous trauma, and feeling in control during a first episode of psychosis may all be protective factors against the development of PTSD following an episode of psychosis.

Research has also suggested that there may be elements of post-traumatic growth (PTG, Tedeschi & Calhoun, 1996) in the recovery from psychosis (Dunkley, Bates, Foulds, & Fitzgerald, 2007). Post-traumatic growth is a term used to describe the positive changes that some people can experience following traumatic life events, including psychosis. This literature may be useful in informing interventions for people who do experience an episode of psychosis as traumatic.

#### **1.4.2** Traumagenic elements of a psychotic episode.

Possible traumagenic elements of a psychotic episode might include the distressing nature of the psychotic symptoms (e.g., the hallucinations or delusions, or fear of losing one's mind), or the treatment a person receives (e.g., involuntary hospitalisation or being forced to take medication). The evidence for each of these potentially traumatic experiences will now be discussed.

#### 1.4.2.1 Psychotic symptoms as traumagenic.

Studies have investigated how much of the PTSD symptomatology seen in people recovering from psychosis is attributable to psychotic symptoms rather than other experiences of psychosis such as hospitalisation and other traumas. Meyer et al. (1999) found that psychotic symptoms caused post-traumatic symptoms in 69% of cases. Further evidence for psychotic symptoms being the predominant cause of PTSD symptoms was provided by Frame and Morrison (2001). Using multiple regression analysis, they found that psychotic symptoms explained 52% of the variance in PTSD symptoms, more than both hospitalisation and other traumas. However, it is possible that psychotic symptoms could be linked to previous traumas (Hardy et al., 2005) which could potentially complicate this finding. For example, for some people who experience auditory hallucinations, the voice they hear may be that of an abuser from a previous traumatic experience. Therefore, this result should be considered with caution and further investigation may be needed in order to tease apart the relative contributions of the actual experience of having a psychotic experience and any past traumatic experiences which may have played a role in the formation of the psychotic experience.

Given that psychotic symptoms may be a significant cause of PTSD symptoms in people recovering from psychosis, researchers have attempted to identify which psychotic symptoms are most likely to result in PTSD symptoms. Persecutory delusions, passivity phenomena, and visual hallucinations were found to be the most distressing symptoms in a study which measured the distress and intrusion caused by specific psychotic symptoms (Shaw et al., 1997). In 2002, Shaw, McFarlane, Bookless, & Air used data from a previous study (Shaw et al., 1997) to investigate which psychotic symptoms were associated with PTSD. They found that people who

experienced being controlled, visual hallucinations, being followed, believing others were hearing their thoughts, and having their mind read, were all associated with postpsychotic PTSD.

A recent review by Berry, Ford, Jellicoe-Jones, and Haddock (2013) analysed results of 28 studies. They found that the psychotic symptoms that were frequently reported as the most distressing were paranoid delusions or delusions of being controlled (e.g., Mueser et al., 2010), threatening, commanding or critical voices (Beattie, Shannon, Kavanagh, & Mulholland, 2009) or losing touch with reality more generally (Dunkley et al., 2007; Koivisto, Janhonen, & Vaisanen, 2003; Mueser et al., 2010; Shaw et al., 2002). In their review, Berry and colleagues also found that patients frequently rated thoughts of or attempts to harm the self or others as particularly distressing (Centofanti, Smith, & Altieri, 2005; Lu et al., 2011; Mueser et al., 2010; Shaw et al., 1997).

#### 1.4.2.2 Hospitalisation as traumagenic.

Contrary to the findings that PTSD symptomatology is mainly attributable to the positive symptoms of psychosis, particularly persecutory delusions, passivity phenomena, visual hallucinations, and unusual thought content, McGorry et al. (1991) suggested that the experience of hospitalisation is the most traumagenic element of a psychotic episode. After analysing qualitative information about people's experiences, they concluded that symptoms "seemed to be linked especially to the experience of hospitalisation and less so to the psychotic experience per se, for example, recurrent nightmares involving forced sedation or seclusion". Meyer et al. (1999) found that 25% of post-traumatic symptoms were related to the hospitalisation experience.
Berry et al. (2013) reviewed evidence from 28 studies in order to determine the most distressing elements of hospitalisation. They found that the hospitalisation experiences that were most frequently rated as distressing were aspects of treatment, such as restraint, seclusion, sedation, being forced to take medication, and medication side effects (Bonner, Lowe, Rawcliffe, & Wellman, 2002; Centofanti et al., 2005; Cusack, Frueh, Hiers, Suffoletta-Maierle, & Bennet, 2003; Mueser et al., 2010; Shaw et al., 1997; Swartz, Swanson, & Hannon, 2003; Tarrier et al., 2007; Wood & Pistrang, 2004). Studies also found distress associated with threats or actual acts of physical and sexual assault by both other patients and staff, involuntary admissions, police involvement, isolation from family members, lack of choice and not understanding the reasons for admission (e.g., Centofanti et al., 2005). Other studies found that some patients found a lack of fairness, respect, empathy, and support from staff distressing (Bonner et al., 2002; Cusack et al., 2003; Priebe et al., 1998). There were also aspects of the physical environment that were reported as causing distress. These included the noise levels (Priebe et al., 1998), locked doors (Dunkley et al., 2007), and inadequate privacy (Frueh et al., 2005).

Using the Hospital Experiences Questionnaire (HECS), which they designed for their study, Shaw et al. (2007) found that the most distressing aspects of hospitalisation were being secluded, being physically abused, being on a closed ward, and being detained.

The majority of evidence indicates that hospitalisation contributes less to the development of post-psychotic PTSD than do the psychotic symptoms themselves (Frame and Morrison, 2001; Meyer et al., 1999). However, there is evidence to suggest that the experience of hospitalisation can be traumatic for some individuals (McGorry et al., 1991).

### 1.4.2.3 First person accounts of the traumagenic elements of psychosis.

Individual accounts and clinical case studies of those who have experienced a first episode of psychosis (e.g., Herrig, 1995; Jordan, 1995) have provided evidence in support of the experience of first episode psychosis conforming to the current conceptualisations of PTSD (Ehlers & Clark, 2000). These accounts depict the terror of psychosis and also describe the re-experiencing of the psychotic episode, and the widespread avoidance of cognitive, affective, and situational reminders of the experience (Shaner & Eth, 1989). As part of an analysis of posttraumatic stress disorder in response to acute psychosis, Bendall, McGorry, and Krstev (2006) reviewed several personal accounts which attested to the traumatic nature of psychotic experiences and events. In relation to the psychotic experiences themselves, they found that a common psychotic experience was one of being controlled and punished:

I had one particular friend. I called him the "Controller". He was my secret friend. He took on all of my bad feelings and my paranoia. I could see him and hear him, but no one else could.

The problems were compounded when I went off to college. Suddenly, the Controller started demanding all of my time and energy. He would punish me if I did something he wouldn't like. He spent a lot of time yelling at me and making me feel wicked. I didn't know how to stop him from screaming at me and ruining my existence. It got to the point where I couldn't decipher reality from what the Controller was screaming. So I withdrew from society and reality. I couldn't tell anyone what was happening because I was so afraid of being labelled "crazy". I didn't understand what was going on in my head. I really thought that other "normal" people had Controllers too. (Jordan, 1995, pp. 501-502)

Bendall et al. (2006) also found that fears of being annihilated were also some of the shared experiences of people experiencing psychosis.

Going to work was pure hell. I continued to hear voices. One day while sitting at my desk I saw a fly I had never seen. It could not have been real, not in February. One of my duties was to read information intended for military personnel. I remember reading about Hellfire missiles. I imagined the manmade hellfire killing people. I became convinced that I was reading top secret information and that someone would try to have me killed so that I couldn't talk. (Herrig, 1995, pp. 340)

They also describe first person accounts of the traumatic nature of hospitalisation for some individuals. For example, Christina, a young person experiencing her first episode of psychosis described her experience of hospitalisation as follows:

As I run my hands along the smooth surface around me I feel the small wooden pricks of the surface which I touch. It is a wooden box which surrounds me and I feel trapped, I have nowhere to move, my body aches with pain from this cramped position...

I am my own prisoner, entrapped both in body and mind, locked in this tiny box. There is no way to control the situation and I am physically unable to be freed from the corners surrounding me, crying out, sobbing like a newborn baby; oh why, oh why did I place myself here!

It's a delusion and I don't know what reality is any more. The only reality I have is my nightmare, which is real as hell. Will I never, ever be allowed to see my family again? (Early Psychosis Prevention and Intervention Centre (EPPIC), 2000, pp. 13)

One of the main criticisms of first-person accounts is that the authors are often self-selected and are likely to be atypical of the general patient population in terms of demographic characteristics, personal qualities, and their degree of recovery and insight (Stanton & David, 2000). However, despite these limitations, Chadwick (1997) argues for the value of service users' accounts and suggests that both 'insider and outsider-based information' should be combined in order to enrich psychopathology research and treatment.

In addition to the evidence suggesting that individuals who experience psychosis may have a traumatic reaction to their experiences, further evidence for a relationship between psychosis and PTSD has come from observations of the apparent phenomenological overlap between psychosis and PTSD.

# **1.4.3** Phenomenological overlap between psychotic and PTSD symptoms.

It had been suggested that just as the symptoms of psychosis can be categorised into positive and negative clusters, so can those of PTSD (McGorry, 1991).

# 1.4.3.1 Positive symptoms.

It can be difficult to differentiate between the delusions and hallucinations a person might experience during a psychotic episode and intrusive memories or flashbacks a person might experience as a consequence of a trauma. An intrusive thought of a delusion or hallucination may be phenomenologically very similar to the actual experience of a delusion or hallucination. Researchers have pointed out the difficulty in separating these phenomena in research studies (e.g., Meyer et al., 1999). It may also be difficult for patients to differentiate between what might be an intrusive memory of their psychotic episode and what might be a relapse of their symptoms. "Flashbacks" often appear to take the form of auditory, visual, tactile, and/or olfactory hallucinations and are often accompanied by paranoia (Allen, Coyne, & Console, 1997; Butler, Meuser, Sprock, & Braff, 1996). Another identified similarity between PTSD and the positive symptoms of psychosis is the increased levels of arousal and hypervigilance seen in both disorders (Stampfer, 1990).

## 1.4.3.2 Negative symptoms.

It has been suggested that the negative symptoms of psychosis have many similarities to the avoidance and numbing symptoms of PTSD (Lundy, 1992; McGorry et al., 1991; Stampfer, 1990). Stampfer (1990) suggested that there are many phenomenological similarities between the negative symptoms of psychosis and PTSD symptoms including flattened affect, social withdrawal, feeling disconnected from others, and diminished interest in life.

In light of the evidence that experiences of psychosis can be traumatic for some individuals and that there is significant phenomenological overlap between PTSD symptoms and symptoms of psychosis, the diagnostic criteria for PTSD will now be reviewed in order to establish if traumatic reactions following an episode of psychosis might meet these criteria.

# **1.4.4** Considering diagnostic criteria for PTSD following psychosis.

PTSD as a definable disorder was included in the Diagnostic and Statistical Manual (DSM) for the first time in the Third Edition (DSM-III; American Psychiatric Association, 1980).

Prior to 2013, DSM-IV (American Psychiatric Association, 1994) was widely used to classify and diagnose PTSD. DSM-IV (American Psychiatric Association, 1994) states that there are six criteria that must be met in order for someone to be diagnosed as having PTSD. These criteria are listed below:

- Criterion A requires that a person has been exposed to a traumatic event in which there was actual or threatened death or serious injury, or a threat to the physical integrity of the self or others. It also requires that the person's response to the traumatic event involved intense fear, helplessness, or horror.
- Criterion B requires that the traumatic event is persistently re-experienced (for example, in the form of flashbacks or distressing dreams).
- Criterion C focuses on the persistent avoidance of stimuli associated with the trauma and a numbing of general responsiveness.
- Criterion D requires that a person experiences persistent symptoms of increased arousal that were not present prior to the trauma. This includes difficulty falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hypervigilance to threat, or an exaggerated startle response.
- Criterion E requires that the symptoms stated in Criteria B, C, and D must have been present for more than one month.
- Criterion F requires that these symptoms must have caused clinically significant distress or impairment in social, occupational, or other important areas of functioning.

There has been some debate over the eligibility of psychotic experiences for meeting Criterion A of the DSM-IV diagnostic criteria. Of particular contention is whether people with psychosis have experienced an event that involves actual or threatened death, injury, or a threat to the physical integrity of the self or others. Some researchers have argued that a person's subjective experience should be considered and what is important is a person's perception of threat rather than whether the underlying trigger is a hallucination or delusion, or a real world event (Lundy, 1992; Morrison et al., 2003; Shaner & Eth, 1989). In support of this, there is evidence from studies into PTSD resulting from experiences other than psychosis that the subjective experience of threat is a better predictor of distress than the objective experience (Alvarez-Conrad, Zoellner, & Foa, 2001; Bernat, Ronfeldt, Calhoun, & Arias, 1998).

Some studies have compared the rates of PTSD in people recovering from psychosis when full diagnostic criteria or just symptom criteria (criteria B, C and D) are met. When just the symptom criteria are applied much higher rates of distress are recorded. For example, a recent onset study found that 66% of participants met symptom criteria for PTSD (Mueser et al., 2010), and a study of patients who had experienced multiple psychotic episodes found that 69% met symptom criteria (Lu et al., 2011).

In an attempt to resolve this debate, Shaw et al. (1997) suggested that the diagnostic criterion for a traumatic event should be expanded to include threat to psychological integrity as well as the currently stated threat to physical integrity. However, this suggestion is yet to be incorporated into the DSM.

It has been proposed that although the aetiological events that lead to PTSD reactions are important, and feature heavily in diagnostic criteria for PTSD, it is the impact of the event or events and how they influence a person's view of himself, the world or others which appears to be crucial (Power & Dalgleish, 2007). It is questionable whether a focus on the diagnostic criteria of PTSD is the most useful approach in understanding the traumatic impact of psychosis. Considering post

traumatic stress symptoms, rather than a dichotomous conceptualisation of PTSD as a diagnosis, may be a more useful approach to apply when exploring traumatic reactions to psychosis.

In summary, research has suggested that the experiences of psychosis, including the actual psychotic symptoms and the consequences of a psychotic episode, can be traumatic for some individuals. Although diagnostic criteria may have limited utility in classifying traumatic reactions to psychosis, considering PTSD symptoms and psychological models of PTSD may be applicable. In light of this, current theories of PTSD will now be reviewed.

### **1.5 Post-traumatic stress disorder (PTSD)**

The psychopathology of trauma is currently conceptualised clinically in terms of post-traumatic stress disorder (PTSD). PTSD develops following a stressful event or situation of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone (NICE, 2005). Between 50-60% of people will experience a serious trauma – as a result of combat, sexual assault, major accidents, or other real life horrors – at some point in their lives. However, only 5-10% of people are estimated to develop symptoms qualifying them for a diagnosis of PTSD (Aupperle, Melrose, Stein, & Paulus, 2012).

PTSD is characterised by re-experiencing symptoms, for example, in the form of flashbacks where the person acts or feels as if the event is recurring; nightmares; and repetitive and distressing intrusive images or other sensory impressions from the event. Reminders of the traumatic event can arouse intense distress and physiological reactions. Other core symptoms of PTSD include an avoidance of reminders of the trauma; hyperarousal, including hypervigilance for threat; exaggerated startle responses; irritability and sleep problems. Emotional numbing is also common and typically includes a lack of ability to experience feelings, feeling detached from other people, giving up previously significant activities, and amnesia for significant parts of the event.

#### 1.5.1 Models of PTSD.

Since the inception of PTSD in 1980, a host of theoretical models of the disorder have been proposed. All the major models of psychology are represented: the biological (e.g., van der Kolk, Greenberg, Boyd, & Krystal, 1985); the psychodynamic (e.g., Freud, 1919); the behavioural (e.g., Keane, Zimmering, & Cadell, 1985); the cognitive (e.g., Ehlers & Clark, 2000); and the social-cognitive

(e.g., Janoff-Bulman, 1992). Below some of the most influential theories of PTSD from the last 20 years are discussed.

Horowitz (1986) proposed a theory involving the motivational process of assimilation and integration of information (thoughts, ideas, images) related to a traumatic event. Horowitz suggested that personal schemata relating to the world and ourselves are used to interpret incoming data and when traumatic events occur they present us with information that is incongruous with our existing schema or models. Horowitz conceptualises the response to such traumatic events as a stress response requiring reappraisal and revision of our existing models, and suggests that PTSD is an indication of incomplete processing.

In 1992, Janoff-Bulman proposed a theory of "shattered assumptions" to explain PTSD. This theory focusses on an individual's pre-trauma appraisals and assumptions about the self and the world, and argues that these can become shattered by the impact of a traumatic event. Janoff-Bulman suggests that people hold three types of pre-existing assumptions: the assumption of personal invulnerability; the perception of the world as meaningful or comprehensible; and the view of the self as worthy and good. The shattering of these assumptions about the self and the world are seen as the basis of PTSD as an individual attempts to rebuild his personal models of the world and himself. Symptoms such as intrusions, avoidance, anxiety and depression are seen as by-products of this rebuilding process.

Modern information processing theories of PTSD propose that the disorder is a result of dysfunctional cognitive processing of traumatic events, including disrupted encoding, storage and retrieval of traumatic memories, unconscious attentional biases and maladaptive beliefs (Reinecke, 2010). Brewin, Dalgleish, and Joseph (1996) proposed a model to explain the alternation between re-experiencing (e.g., flashbacks)

and avoiding trauma-related memories. Their model, known as the dual representation model of PTSD, suggests that there is a dual representation of traumatic experiences in a person's memory.

Ehlers and Clark (2000) have proposed a cognitive model of PTSD. They suggest that due to factors occurring around the time of the traumatic event, such as dissociation, emotional numbing, and overwhelmed cognitive resources, trauma memories may be recorded without coherent elaboration or adequate contextual information. This can lead to difficulties retrieving complete accounts of traumatic events and difficulty placing traumatic images in time and place. The model also suggests a role of negative appraisals in PTSD including negative thoughts about the self, the future and other people.

Lancaster, Rodriguez, and Weston (2011) proposed that there are two cognitive constructs that play crucial roles in the maintenance of PTSD symptoms – event centrality and post-traumatic cognitions. Event centrality refers to the extent an individual construes a traumatic event as a central part of their identity (Berntsen & Rubin, 2006). Post-traumatic cognitions refer to the negative thoughts and beliefs that occur after a traumatic experience. Barton, Boals, and Knowles (2013) replicated this finding that event centrality and post-traumatic cognitions predict PTSD symptoms.

In recent years, attention has turned to the role of autobiographical memory in PTSD. Research has suggested that people with PTSD are more likely to report memories of their traumatic experience than those who have a traumatic experience but do not go on to develop PTSD (Kangas, Henry, & Bryant, 2005; McNally, Lasko, Macklin, & Pitman, 1995). Of particular interest has been the relationship between self-image and autobiographical memory in PTSD. By investigating the link between self-discrepancy and trauma-related autobiographical memory recall, Sutherland and

Bryant (2008) proposed that perceiving that oneself is missing desired outcomes is linked to focusing on a previous trauma experience.

Several of these models may be useful in helping to explain the apparent symptomatic overlap between the positive symptoms of psychosis and symptoms of PTSD (e.g., hallucinations and flashbacks). For example, auditory hallucinations where the voice is the perpetrator of previous abuse could be considered flashbacks that occur due to incomplete processing that occurred at the time of the trauma, in line with Ehlers and Clark's (2000) model. However, of all the PTSD theories discussed, Sutherland and Bryant's (2008) model may be particularly relevant in helping to explain the traumatic impact of psychosis and a possible link to negative symptoms because it considers the role that self-discrepancies, which are commonly seen in those recovering from a first episode of psychosis, may play in traumatic reactions to psychosis. Therefore this study will attempt to explore Sutherland and Bryant's model further in relation to traumatic reactions to first episode psychosis. Sutherland and Bryant's model and its application to traumatic reactions following first episode psychosis will now be explored in more detail.

### 1.6 The Sutherland and Bryant model of PTSD and its application to FEP

The rationale for exploring the link between autobiographical memory recall and self-concept developed following studies of PTSD. In a study of veterans of the Vietnam War, McNally et al. (1995) found that veterans who still wore their military insignia were more likely to have difficulty retrieving specific positive autobiographical memories and were more likely to retrieve memories of Vietnam than those who did not still wear military insignia. In their research with cancer patients, Kangas et al. (2005) also found that retrieval of distressing memories was guided by a person's current self-image and their attitude towards their future. Patients recalled more negative memories as they became more hopeless about their condition.

Autobiographical memory (ABM) models have been used to attempt to explain these findings. ABM relates to an individual's capacity to recollect personal events and facts from their life (Riutort, Cuervo, Danion, Peretti, & Salame, 2003). In their model of autobiographical memory, Conway and Pleydell-Pearce (2000) suggest that autobiographical memory for specific events is reconstructed from representations in the autobiographical knowledge base. According to this model, when we retrieve memories we select those that are consistent with our "working self", which comprises our self-image and associated goals (see Figure 1). For example, individuals with PTSD who perceive themselves as vulnerable to future harm may selectively recall memories involving harmful experiences.

## Figure 1. The Self Memory System



*Fi*gure 1. An illustration of the Self Memory System (Conway & Pleydell-Pearce, 2000)

Conway and Pleydell-Pearce's (2000) model of the Self Memory System proposes that autobiographical memories are the transitory mental constructions of a complex goal-driven set of control processes collectively referred to as the working self. Goals are viewed as processes and are thought to contain a standard or ideal, some mechanism for assessing the discrepancy between the standard and current state of the world, and plans for reducing the discrepancy. Conway and Pleydell-Pearce (2000) further suggest that within the Self Memory System, the retrieval of specific autobiographical information is directly influenced by one's self representations and goals. The goal structure of the working self makes highly available those aspects of the autobiographical knowledge base that relate most directly to current goals.

Higgins (1987) proposed that our goals emerge from discrepancies between the different domains of self (actual, ideal and ought), and these drive autobiographical remembering. Over the years, many different facets of the self or self-images have been suggested. For example, Rogers (1961) distinguished between what others believe a person should or ought to be (i.e., the normative standard) and a person's own belief about what he or she would ideally like to be and Cooley (1964) described a social "ideal self" built up by imagining how a "better I" would appear in

the minds of the people we look up to. Based on these and other ideas about the self, Higgins (1987) proposed that there are three basic domains; the actual self, which is a person's representation of the attributes that someone (yourself or another) believes you actually possess, the ideal self, which is a person's representation of the attributes that someone (yourself or another) would like you ideally to possess (i.e., a representation of hopes, aspirations, or wishes), and the ought self, which is a person's representation of the attributes that someone (yourself or another) believes you should or ought to possess (i.e., a representation of a sense of duty, obligations, or responsibilities). Higgins described the actual-ideal self-discrepancy as the extent to which an individual perceives their current self to be different from the self they would ideally like to be. This discrepancy is typically associated with depressive disorders. The actual-ought self-discrepancy refers to the extent to which an individual perceives their current self to be different from the self they believe they should attain to. This discrepancy is typically associated with the development of anxiety disorders (Higgins, 1996). Discrepancies in self-concept are common in PTSD (Sutherland & Bryant, 2008) and are thought to drive autobiographical remembering (Higgins, 1987).

Sutherland and Bryant (2008) further investigated the link between perceptions of self and retrieval of autobiographical memories in PTSD. They found that the retrieval of trauma focused memories in response to positive cues was strongly associated with perceptions that one's actual self was discrepant from one's ideal self. This finding was restricted to memories recalled in response to positive, but not negative cue words. This led them to suggest that perceiving that one is missing desired outcomes after trauma is linked to focusing on the trauma experience. They also found partial support for an association between trauma related retrieval to

positive cues and an actual-ought self-discrepancy. This model suggests that the experience of trauma impacts upon a person's sense of self.

The impact of experiencing a first episode of psychosis may have a significant impact on a person's sense of self. Authors have suggested that following an episode of psychosis a reconstruction of the self occurs. Where individuals fall short of their preferred or aspired to be self, this can result in a sense of entrapment and loss (Birchwood & Iqbal, 1998). Birchwood, Iqbal, Chadwick, and Trower (2000) observed a discrepancy between the "like to be" and "probable/future" self in individuals with FEP and found that this conflict was associated with post-psychotic depression. Furthermore, Fowler et al. (2006) found that individuals with first episode psychosis tend to hold very negative beliefs about the self.

Therefore, Sutherland and Bryant's (2008) model of PTSD, which focuses on self-discrepancy following traumatic events and its relationship to autobiographical memory, may be useful in helping to explain the mechanisms which may be involved in potential traumatic reactions to FEP. Figure 2 illustrates the theories underlying Sutherland and Bryant's (2000) model of self-discrepancy and autobiographical memory following traumatic events. Reference has been made to the ideas of Higgins (1987) and Conway and Pleydell-Pearce (2000).





*Fi*gure 2. An illustration of Sutherland and Bryant's (2000) model of self-discrepancy and autobiographical memory following traumatic events.

## 1.7 Summary

This literature review highlights the need for increased knowledge of the psychological mechanisms that might underlie barriers to recovery following first episode psychosis. With increasing financial pressure on mental health services, patients often face potential discharge from services once the positive symptoms of psychosis have remitted. There is a need for effective interventions to help support individuals who experience a traumatic reaction to their psychotic episode.

There is evidence that prevention of secondary morbidity, including PTSD type reactions, can influence the prognosis of individuals who experience an episode

of psychosis (Birchwood & MacMillan, 1993; McGorry, 1993). For example, studies investigating associations between psychosis related PTSD and suicide have found that those who meet criteria for PTSD are significantly more likely to experience suicidal thoughts (Shaw et al., 2002) and suicidal behaviour is also more common in those identified as having psychosis related PTSD (Tarrier et al., 2007), although this last association was not significant. There is therefore a strong clinical case for implementing strategies and interventions to prevent and manage psychosis related PTSD. In order to develop these strategies and interventions, an understanding of the nature of the processes involved in psychosis related PTSD is required.

This study will investigate whether similar cognitive processes that are seen in people who have experienced PTSD are also observed in FEP. Firstly, the study will attempt to expand on research by Harrison and Fowler (2004) that has suggested that negative symptoms are part of a traumatic avoidance reaction to the experience of psychosis. Secondly, Sutherland and Bryant's (2008) model of PTSD will be explored in order to examine its utility in explaining traumatic reactions to FEP. Finally, the study will attempt to bring together these two areas to investigate if the variables implicated in Sutherland and Bryant's (2008) model, namely selfdiscrepancy and psychosis-related memory recall, are associated with levels of negative symptomatology in individuals with first episode psychosis.

# **1.8 Research Questions**

The study will set out to answer the following research questions:

- 1) Is the avoidance of trauma-related memories associated with increased negative symptoms in people recovering from first episode psychosis?
- Is increased retrieval of psychosis-related memories associated with a more discrepant self-concept (ought-ideal self-discrepancy and actual-ideal selfdiscrepancy) in people recovering from psychosis?
- 3) Are discrepancies in self-concept and the tendency to retrieve psychosisrelated memories predictive of increased negative symptoms of psychosis?

## 2. Method

# 2.1 Study design

A within-groups, correlational design was adopted. The study was crosssectional with information being collected from participants at only one time point, via the use of questionnaires and semi-structured interviews. The analysis was twotailed and central research questions were examined using parametric and nonparametric correlations and an exploratory multiple regression. The design also meant that covariates (or control variables) could be included in the statistical analysis to help to rule out the possibility that the results might be caused by factors other than those being investigated.

# 2.2 Participants

## 2.2.1 Recruitment.

Participants were recruited through Early Intervention in Psychosis Services in Norfolk, Essex, Bedfordshire, and Community Mental Health Teams in Suffolk. Early Intervention in Psychosis Services are multidisciplinary specialist services that work with people aged between 14 and 35 who are experiencing their first episode of psychosis. Following a recent service redesign in Suffolk, individuals with first episode psychosis who were previously seen within the Suffolk Early Intervention Psychosis Service (SEIPS) are now seen within Community Mental Health Teams known locally as Integrated Delivery Teams (IDTs) across Suffolk. Therefore, participants in Suffolk were recruited through these IDTs.

## 2.2.1.1 Inclusion criteria.

Referrals were requested for anyone experiencing their first episode of psychosis who was aged 18 to 65 years in the recovery stage of their illness. This was defined as having received treatment for first episode psychosis from an Early Intervention Service or an Integrated Delivery Team for at least 12 months and having no significant positive psychotic symptoms (as judged by the clinician currently responsible for their care) at the time of recruitment and assessment. An additional inclusion criterion was that a participant's clinical presentation was stable, indicated by no hospital admissions or medication changes in the past month.

# 2.2.1.2 Exclusion criteria.

Due to the nature of the assessments being used, participants were not invited to take part in the research if they were illiterate or unable to speak English. Further exclusion criteria included being diagnosed with a comorbid depressive disorder, having a primary diagnosis of organic disorder or substance abuse, or having had a brain injury. The purpose of having these final exclusion criteria was to increase the chances that any potential effects on autobiographical memory recall, which might be suggested by the results of this study, are due to the impact of a person's psychosis and no other confounding variables.

# 2.2.1.3 Number of participants.

The sample size required in order to maximise the chance of detecting an effect was calculated using the G\*Power programme (Faul, Erdfelder, Lang, & Buchner, 2007). For the correlational analysis, assuming a medium effect size (r = 0.3), a one-tailed significance level of 0.05 and a power of 0.8, the suggested sample

size was 68. This calculation was also supported by effect sizes found in studies by Sutherland and Bryant (2008) and Harrison and Fowler (2004) which indicated that a minimum sample size of 49 would be sufficient. Therefore, the aim was to recruit 68 individuals with first episode psychosis from Early Intervention Services (EIS) in Norfolk, Essex and Bedfordshire, and the Integrated Delivery Teams (IDTS) in Suffolk.

Recruitment to the study took place between September 2013 and May 2014. During this time, a total of 51 participants were recruited to the study. A descriptive analysis of the demographic characteristics of the study participants is described in detail in the results section. Figure 3 depicts the recruitment of participants during the study.





Figure 3. Consort diagram depicting the recruitment of participants during the study.

### 2.3 Measures

## 2.3.1 Demographic Information.

Basic demographic information was collected from participants including age, gender, ethnicity, educational level, and employment status. The length of time that a participant had been treated for first episode psychosis within an EIS or IDT and how much time had passed since their most recent psychotic episode was also recorded. Participants' medical notes were examined in order to obtain information about diagnosis, if applicable, the type and dosage of any current medication, and information about whether the participant had received psychological therapy as part of their treatment with the EIS or IDT.

The rationale for collecting basic demographic and treatment-related information was to establish if the sample of participants recruited to the study were representative of what might be expected from an Early Intervention sample, based on previous research.

This information was collected by the researcher asking each participant a series of demographic and treatment related questions using a questionnaire that was developed by the researcher. This questionnaire took approximately five minutes to complete.

### **2.3.2** The Scale for the Assessment of Negative Symptoms.

The Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1989) was used to assess the level of negative symptomatology. The SANS is a semi-structured interview in which ratings are made on a five-point likert scale ranging from zero (symptom not present) to five (severe) for 25 negative symptom

behaviours making up five subscales – affective flattening, alogia, avolition/apathy, anhedonia/asociality, and attentional impairment.

Before selecting the SANS as a measure of negative symptoms, its merit relative to other measures of negative symptoms was considered. The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987) is frequently used in studies which measure psychosis symptomatology, including negative symptoms. However, the NIMH-MATRICS consensus statement (Kirkpatrick et al., 2006) argues that the SANS is a preferable measure of negative symptoms since several negative constructs are obtained, with multiple items related to each construct, which improves the psychometric properties of the scale. The PANSS is also not designed to rate negative symptoms exclusively and instead it is a comprehensive scale for the assessment of psychopathology. Since the MATRICS consensus statement was produced in 2006, two new measures of negative symptoms have been developed in line with the MATRICS consensus criteria (Kirkpatrick et al., 2006). These measures are the Brief Negative Symptom Scale (BNSS; Kirkpatrick et al., 2011) and the Clinical Assessment Interview for Negative Symptoms (CAINS; Blanchard, Kring, Horan, & Gur, 2010). However, since these measures are relatively new, they are not yet widely used in studies of negative symptoms. Therefore, this makes comparisons to other research difficult. Marder and Kirkpatrick (2014) suggest that the relative strengths and limitations of the BNSS and the CAINS will be revealed as they are included in large multicentre trials.

The SANS is the most comprehensive measure of negative symptoms and is widely used and well validated. Previous research reports subscale intra-class correlations from r = .95 to .98 (Avery, Startup, & Calabria, 2009) indicating high

inter-rater reliability, and good internal consistency with Cronbach's α typically ranging from .63 to .84 (Ishak, Burt, & Sederer, 2002).

It was important to choose a measure that had good face validity in measuring the negative symptoms of psychosis. The NIMH-MATRICS consensus statement (Kirkpatrick et al., 2006) was used to guide the decision about which assessment of negative symptoms to use. Kirkpatrick et al., 2006 characterised the domains of negative symptoms as blunted affect, alogia, asociality, anhedonia, and avolition, and suggested that measures of negative symptoms should include items relating to each of these domains. They also highlight the importance of not including items that are in a psychopathological domain other than negative symptoms. There is general consensus that the attention subscale of the SANS should not be included when calculating an overall total score for negative symptomatology. This subscale is regularly excluded in studies which use the SANS as a measure of negative symptoms (e.g., Rabany, Weiser, Werbeloff, & Levkovitz, 2011). The rationale behind excluding the attention subscale is that attention deficits are thought to belong to the domain of cognitive deficits rather than to the domain of negative symptoms (Milev et al., 2005), and it has also been demonstrated that the exclusion of the attention subscale improves the internal consistency of the SANS (Peralta, Cuesta, & de Leon, 1992). Item eight ("inappropriate affect") was also excluded since this item has frequently been found to load onto a disorganisation factor in factor analytic studies and is therefore not thought to be part of the negative symptom construct (Liddle, 1987; Peralta et al., 1992).

Therefore, total scores on the SANS were calculated by excluding the attention subscale and item eight ("inappropriate affect"). Global ratings for the

affective flattening, alogia, avolition-apathy, and anhedonia-asociality subscales were then summed to give an overall total score for negative symptoms.

The inter-rater reliability of the SANS in the current study was excellent with an intra-class correlation coefficient of .97 (95% CI: .80 to .99). In the present study, ratings for the SANS were made immediately after the research session using information gained through the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987) and general observations during the session. The SANS therefore took no extra time to complete and took the researcher approximately 15-20 minutes to rate following the session.

# 2.3.3 The Autobiographical Memory Test.

The Autobiographical Memory Test (AMT; Williams & Broadbent, 1986) was used to assess personal event memory. In particular, the study was interested in whether participants retrieved autobiographical memories that were related to their episode of psychosis.

Ten cue cords were printed on cards and presented in turn to participants. Five cards were printed with positive words (happy, surprised, interested, successful, and safe) and five were printed with negative words (clumsy, angry, sorry, hurt, and lonely). The words were presented in a fixed order, with positive and negative words alternating. Visual presentation of the words was used to reduce the likelihood of valency bias that has been shown to arise if the words are read aloud by the researcher (Kuyken & Dalgleish, 1995).

Prior to being shown the words the participants were given the following instructions by the researcher:

I am interested in your memory for events that have happened in your life. I am going to show you some words. For each word, I want you to think of an event that happened to you which the word reminds you of. The event could have happened recently or a long time ago. It might be a trivial event or an important event. I also want you to make sure that the memory is for a specific event, so something that happened on a particular day at a particular time. For example, if the word was "good" it would not be ok to say "I always enjoy a good party" because that does not mention a specific event. It would be OK to say "I had a good time at Jane's party" because that is a specific event.

Before starting the task, the researcher was careful to ensure that the participant had fully understood the instructions of the task and the experimental session did not begin until specific personal memories had been retrieved to three practice cue words (enjoy, friendly, and bold). The procedure and participants' responses were all recorded on audiotape.

Participants were given 60 seconds to respond to each cue word. If the participant had not recalled a memory in the time, the response was recorded as an omission and the researcher proceeded to the next word. The time to respond to each cue word (i.e., the response latency) was recorded by the researcher. Participants who did not give a specific memory as a first response were given a prompt ("Can you think of a particular time – one particular event?"). This instruction was repeated if responses remained inappropriately general. Once responses had been collected for each of the 10 cue words, each participant was asked how long ago each specific memory occurred. This was recorded by the researcher.

Following the research session, each of the memories recalled was rated by the researcher according to whether or not the content related to the participant's psychotic episode (i.e., "psychosis-related" or "not psychosis-related"). A memory was rated as psychosis-related when it involved the psychotic experiences themselves or the immediate consequences of them.

The AMT is typically used to categorise memories according to their specificity. However, Sutherland and Bryant (2008) adapted the way in which this measure was scored in order to assess whether memories recalled were psychosisrelated or not. This was how the AMT was used in a study by Sutherland and Bryant (2008) in their study of individuals who had experienced trauma. Other than Sutherland and Bryant's study, no other studies have used the AMT in this way and so the reliability and validity of using the measure in this way is unknown, particularly in a psychosis sample. The AMT took approximately 10 minutes to complete.

## 2.3.4 Higgins' Selves Questionnaire.

Self-discrepancy was measured using the Higgins' Selves Questionnaire (Higgins, 1987). This task asks people to provide qualities they would ideally like to have (ideal-self), qualities they believe they should have (ought-self), and qualities they believe they do have (actual-self). Each quality is then rated on a 4-point Likert scale. In this task, the adjectives that are generated are coded according to whether the attribute is a synonym, antonym or non-relational according to Roget's Online Thesaurus (Online, n.d.). For example, where a participant had noted the word "kind" when describing their actual-self and the word "loving" when describing their idealself, these words were classed as synonyms or matches. Conversely, where a participant had noted the word "fat" when describing their actual-self and "skinny"

when describing their ideal-self, these words were classed as antonyms or mismatches. For each word a participant generated for the actual self, the Roget's Online Thesaurus (Online, n.d.) was used to note the number of synonyms and antonyms amongst the words generated for the ideal self. This procedure was then repeated for the number of synonyms and antonyms between the actual self and the ought self word lists that were generated by participants. Self-discrepancy scores were then derived by subtracting the total number of actual-ideal synonyms from the total number of actual-ideal antonyms. The same calculation was used for the actualought self-discrepancy score. The Higgins' Selves Questionnaire has adequate testretest reliability for calculating discrepancy scores ranging from r = .39, p < .05 to r =.53, p < .01 (Moretti & Higgins, 1990). As with the AMT, the Higgins' Selves Questionnaire was used in order to replicate the methodology used by Sutherland and Bryant (2008) in their study with a PTSD sample. Therefore, this measure has not been widely used in a psychosis sample and the psychometric properties of the measure in a FEP sample are not known. The questionnaire took approximately 10 minutes to complete.

#### 2.3.5 Depression Anxiety Stress Scales.

Levels of depression and anxiety in the sample were measured using subscales of the Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995). Considering the level of depression and anxiety was important in order to control for any effect anxiety or depression might have on the other study variables. The DASS was administered as a self-report questionnaire. Both the depression and anxiety subscales consist of 14 items which are rated on a three-point scale (0 = did not apply to me at all, 3 = applied to me very much). Brown, Chorpita, Korotitsch, and Barlow (1997) have assessed the psychometric properties of the DASS in a clinical

population. They found that the anxiety and depression subscales show good construct validity, with good correlation with the Beck Anxiety (BAI) and Beck Depression (BDI) Inventories (r = .83 and r = .75 respectively). In the same study the authors also found the scales to have good temporal stability with test-retest correlations ranging from r = .71 to r = .81. Although the DASS has previously been used in psychosis sample (Fowler et al., 2006), there is limited psychometric data available for this group. However, Huppert, Smith, and Apfeldorf (2002) have provided evidence that the DASS has good psychometric properties when used to measure anxiety and depression in individuals with schizophrenia and schizoaffective disorder. Huppert et al. (2002) found the internal consistency of each of the three subscales of the DASS to be high with Cronbach's  $\alpha$  values of .93, .91, and .93 for the depression, anxiety and stress subscales respectively. The test-retest reliability of the DASS was also found to be good with test-retest correlations of r = .76 for the depression subscale, r = .77 for the anxiety subscale, and r = .72 for the stress subscale. The DASS is also freely available and relatively brief compared to other measures of depression and anxiety, taking participants approximately 10 minutes to complete.

## 2.3.6 Positive and Negative Syndrome Scale.

Positive psychotic symptoms were assessed using the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987). PANSS scores were obtained in order to assess the level of psychosis symptomatology within the sample and also to identify whether or not participants were considered in recovery (i.e. no significant positive psychotic symptoms). The PANSS is the most widely used measure of positive psychotic symptoms. The PANSS is a semi-structured interview designed to assess positive and negative symptoms of psychosis, as well as general psychopathology. These three scales each have seven items and these items are rated on a seven-point scale, where one represents the absence of the symptom and seven represents an "extreme" symptom. Only the positive subscale was used within this study. This subscale includes items which assess the presence and severity of delusions, conceptual disorganisation, hallucinatory behaviour, excitement, grandiosity, suspiciousness/persecution, and hostility.

Kay et al. (1987) have provided a manual with guidance for rating and anchoring points within the seven point scale. This manual was used to rate the items on the positive subscale of the PANSS within this study. When assigning ratings the authors advise that the rater first considers whether an item is present or not by using the definitions they provide. If an item is absent it is rated as one, whereas if an item is judged to be present the severity is then rated. The highest applicable rating is always assigned, even if the participant meets criteria for lower ratings as well. In judging the severity of each item, Kay et al. (1987) advise the rater to utilise a holistic perspective and consider the impact the item has on a participant's functioning. The rating points of two to seven correspond to incremental levels of symptom severity. A rating of two (minimal) denotes questionable, subtle or suspected pathology, or it also may allude to the extreme end of the normal range. A rating of three (mild) is indicative of a symptom whose presence is clearly established but not pronounced and interferes little in day-to-day functioning. A rating of four (moderate) characterises a symptom which, though representing a serious problem, either occurs only occasionally or intrudes on daily life only to a moderate extent. A rating of five (moderate severe) indicates marked manifestations that distinctly impact on one's

functioning but are not all-consuming and usually can be contained at will. A rating of six (severe) represents gross pathology that is present very frequently, proves highly disruptive to one's life, and often calls for direct supervision. A rating of seven (extreme) refers to the most serious level of psychopathology, whereby the manifestations drastically interfere in most or all major life functions, typically necessitating close supervision and assistance in many areas.

All ratings were performed in consultation with these guidelines. The total subscale score on the positive scale was interpreted in terms of a percentile rank using the PANSS manual (Kay et al., 1987) and these percentile ranks were categorised as either very low (0-5%), low (6-25%), average (26-74%), high (75-94%), or very high (95+%). Any participants who scored in the high or very high categories for positive symptoms were excluded from the main analyses so that positive symptoms would not have a confounding effect on the study's results.

The positive subscale of the PANSS has high internal consistency, with an  $\alpha$  coefficient of .73 for the positive scale, and a high test-retest reliability coefficient of .80 for the positive scale (Kay et al., 1987). Kay, Opler, and Lindenmayer (1988) have also shown good inter-rater reliability on individual items ranging from .69 to .94 and concurrent validity for both the positive and negative scales of .77.

The researcher received training in the administration of the PANSS from assistant psychologists from an Early Intervention Psychosis Service who were experienced in administering the PANSS. Initial concordance was established by watching training videos of the assessment. Inter-rater reliability within the current study was assessed by a second individual rating ten randomly selected recordings of PANSS assessments. Inter-rater reliability for the Positive Scale of the PANSS in the current study was found to be excellent with an intra-class correlation coefficient of

.98 (95% CI: .94 - 1.00). The PANSS took between 20 minutes and one hour to complete.

#### **2.3.7 Impact of Event Scale – Revised.**

The Impact of Event Scale – Revised (IES-R; Weiss & Marmar, 1997) is a 22item self-report measure of current subjective distress and posttraumatic symptoms in relation to a specific traumatic event. It can be anchored to any serious life event.

The IES-R is a revised edition of the original 15-item Impact of Event Scale (IES; Horowitz et al., 1979). In addition to the eight items assessing avoidance and eight items assessing intrusion from the original IES, the IES-R also contains seven additional items related to the hyperarousal symptoms of PTSD. The items in the IES-R correspond directly to 14 of the 17 DSM-IV symptoms of PTSD. The intrusion subscale measures the extent to which memories of the traumatic event continue to impinge on the mind (e.g., "Any reminder brought back feelings about it") and the avoidance subscale measures the extent to which the individual tries to exclude unpleasant memories from consciousness that are associated with the trauma (e.g., "I tried not to talk about it"). The hyperarousal subscale measures symptoms of increased psychophysiological arousal due to the trauma (e.g., "I felt watchful or on guard").

Each item within the IES-R is rated on a five-point scale ranging from 0 ("not at all") to 4 ("extremely"). Total scores range from 0-88 with higher scores representing greater severity. The measure takes approximately five minutes to complete and the measure was administered as a self-report questionnaire.

In this study the IES-R was used specifically to assess the traumatic impact of an individual's episode of psychosis. Consistent with Jackson, Knott, Skeate and Birchwood (2004), participant's psychotic experiences were cued in memory by

asking them to think back to their "illness" or "psychosis" (depending on their own frame of reference).

Weiss and Marmar (1997) assessed the psychometric properties of the IES-R and found that the questionnaire has good test-retest reliability with reliability coefficients ranging from .51 to .94. They also found high internal consistency for all subscales with  $\alpha$  coefficients ranging between .87 and .92 for the intrusion subscale, .84 and .86 for the avoidance subscale, and .79 and .90 for the hyperarousal subscale. In the present study the internal consistencies for all three subscales of the IES-R were acceptable with  $\alpha$  coefficients of .87 for the avoidance subscale, .89 for the intrusion subscale, and .86 for the hyperarousal subscale. The internal consistency for the total scale was high with an  $\alpha$  coefficient of .95.

In general, the IES-R is not used as a diagnostic tool for PTSD. However, several studies have suggested cut-off scores for a preliminary diagnosis of PTSD. Creamer et al. (2003) proposed a cut-off score of 33 as indicative of the probable presence of PTSD. This cut-off score of 33 was used in this study.

The IES-R has been previously used to assess trauma symptoms related to a first episode of psychosis (e.g., Jackson et al., 2004). The measure demonstrates adequate internal consistency and subscale validity and has been widely used in psychosis research (Weiss & Marmar, 1997). The measure takes approximately five minutes to complete.

## 2.3.8 Life Events Checklist.

The Life Events Checklist (LEC; Blake et al., 1995) is a 17-item self-report questionnaire measure which is designed to screen for potentially traumatic events that may have occurred in a participant's lifetime. The measure assesses exposure to 16 events that are known to potentially result in PTSD or stress. It also includes one further item which asks if any other potentially traumatic event has occurred in order to capture any events not already captured within the first 16 items. This measure was chosen to assess the level of previous traumas, other than a person's psychotic episode, in order to establish if this may have had a confounding effect on the study's findings.

The LEC forms part of the Clinician Administered PTSD Scale (CAPS; Blake et al., 1995) and is used to index the number of traumatic life events that have happened for a person. In non-psychosis samples, when the LEC has been used as an independent checklist it has been shown to have good psychometric properties (Gray, Litz, Hsu, & Lombardo, 2004). The LEC has demonstrated high test-retest reliability (r = .82, p < .001) and reasonable correlations with other measures of trauma exposure such as the Traumatic Life Events Questionnaire (TLEQ; Kubany et al., 2000).

However, the psychometric properties of the LEC alone have not been considered in a psychosis sample. The full CAPS has been used widely in psychosis research, particularly in studies investigating the relationship between trauma and psychosis (e.g., Meyer et al., 1999; Tarrier et al., 2007). The full CAPS could not be administered in this study because it would have meant the assessment burden would have been too great on participants.

The life events approach to assessing the experience of stressful life events has been broadly criticised because it fails to explain differences between individuals in their reactions to stressful life events (Phillips, Francey, Edwards, & McMurray, 2007). Phillips et al. (2007) argue that simply assessing the frequency of stressful life events is not sufficient to fully understand the relationship of stressful life events with the course of a psychotic disorder. To overcome this difficulty in the present study, the original version of the questionnaire was adapted to include two additional
questions ("Did you feel as though there was a risk of death or serious injury to yourself or someone else as a result of the event?" and "Did you experience intense fear, helplessness or horror as a result of this event?"). These questions were included in order to establish whether any events that had occurred were of sufficient severity to meet DSM-IV criteria for a traumatic exposure (Criterion A1 in DSM-IV; American Psychiatric Association, 1994). The LEC took approximately five minutes for participants to complete.

## 2.3.9 Cognitive assessments.

In order to control for the influence of cognitive functioning on autobiographical memory recall, cognitive abilities were assessed. The lack of consideration of cognitive functioning has been a criticism of previous studies of trauma and psychosis (e.g., Harrison & Fowler, 2004). The FAS task (Benton, Hamsher, & Sivan, 1994) was included as a measure of verbal fluency and the digit span task from the Wechsler Memory Scale – Third Edition (WMS-III; Wechsler, 1997) was included as a measure of working memory.

## 2.3.9.1 FAS task.

The FAS task (Benton et al., 1994) was included as a measure of phonological verbal fluency. This was included in order to control for the impact that verbal fluency might have on the production of words in the Higgins' Selves Questionnaire (Higgins, 1987) and the ability of participants to articulate memories on the AMT (Williams & Broadbent, 1986) and

Verbal fluency tests have been found to measure processing speed (Nuechterlein, et al., 2008) and executive function (Velligan, et al., 2004) in people with psychosis. In the COWAT, the participant is required to name as many words as they can starting with a specified letter (the letters F, A, and S) within 60 seconds

each. The COWAT has been found to possess good internal consistency ( $\alpha$  = .83) and test-retest reliability (r > .70), and has previously been used with individuals with psychosis (Strauss, Sherman, & Spreen, 2006). There is some evidence to suggest that people with psychosis show deficits in verbal fluency (Crawford, Obonsawin, & Bremner, 1993; Kolb & Whishaw, 1983), therefore this is an important area of cognitive functioning to control for in this research. It is well reported that individuals with psychosis show deficits in verbal fluency (Crawford, Obonsawin, & Bremner, 1993; Kolb & Wishaw, 1983).

Badcock, Dragovic, Garrett, and Jablensky (2011) assessed verbal fluency using the FAS in both individuals with an ICD-10 diagnosis of schizophrenia or schizophrenia spectrum disorder, and healthy controls. They found that individuals in the schizophrenia group generated significantly fewer words in the FAS test than healthy controls. The mean total number of words recalled in the schizophrenia group (N = 53) was 27.4 words (SD = 10.4), whereas in the healthy control group (N = 69)the mean was 42.5 words (SD = 11.7).

A smaller, but still significant difference was found by Groom et al. (2008). In this study the authors assessed verbal fluency using the FAS and compared performance by individuals with adolescent-onset schizophrenia spectrum disorders and healthy controls. They found that the mean total number of words recalled on the FAS task by individuals with schizophrenia spectrum disorders (N = 30) was 31.1 words (SD = 9.0), compared to 36.3 words (SD = 9.3) in a healthy control group.

The FAS is a brief and straightforward measure of verbal fluency to administer taking approximately five minutes.

# 2.3.9.2 Digit Span task.

Digit Span is a working memory task from the Wechsler Memory Scale – Third Edition (WMS-III; Wechsler, 1997), wherein the participant listens to sequences of numbers of increasing lengths, and repeats them back to the examiner either as originally stated or in reverse order. As with verbal fluency, deficits in working memory in individuals with psychosis are well documented (Lee & Park, 2005), so it was important to control for the influence of working memory difficulties on outcome variables. The Wechsler tests are widely used and possess good psychometric properties across a range of clinical groups (Lezak, Howieson, & Loring, 2004; Strauss et al., 2006). The digit span task took approximately 5-10 minutes to complete.

### **2.4 Procedure**

## 2.4.1 Recruitment procedure.

Managers from Early Intervention Services and IDTs were initially contacted by telephone or email to inform them of the research. The researcher then arranged to meet with team managers in person to describe the study in detail and gain agreement for participation. Of the 17 clinical services that were approached to take part in the study, all agreed to be involved. Once team leaders had agreed to participate, arrangements were made for the study to be introduced to the rest of the clinical team. A presentation was given to participating teams, as well as copies of the participant information sheets and the inclusion and exclusion criteria in a care coordinator leaflet. Participating clinics were asked to identify eligible individuals for the study, and for care coordinators or other appropriate clinicians to pass on an information sheet to these individuals. The clinician was asked to gain verbal consent for the researcher to phone the service user and explain the study further.

Recruitment was undertaken collaboratively with another Trainee Clinical Psychologist, who was also conducting research with this population. The same individuals were asked to participate in both studies, but could chose to participate in just one of the two studies if they preferred. Appendix 6 summarises the process of shared recruitment and data collection.

### **2.5 Ethical considerations**

#### **2.5.1 Ethical approval.**

Prior to the recruitment of participants, ethical approval was obtained from the Local Research Ethics Committee and NHS Trust Research and Development departments.

## 2.5.2 Informed consent.

Service users were approached in the first instance via their care coordinator, who introduced the study and gave participants a copy of the information sheet (see Appendix 3). Direct contact with service users only took place once the service user had consented to this. Informed consent was gained in writing from all participants before data collection commenced using the consent form included in Appendix 5. Participants were given at least four days, and as much time as they needed, to view the information sheet and ask questions before being contacted by a researcher. Written consent included consent for the researcher to examine medical notes to gain information regarding diagnoses and medication, and to audiotape the interview. Participants were made aware that consent was voluntary and they were free to withdraw at any time if they changed their mind. They were also advised that a decision to withdraw from the study would not affect the care they received from their clinical team in any way. Inclusion criteria for the study (that the individual was in the recovery stage of their psychotic episode and not acutely unwell) ensured that individuals had the capacity to make decisions regarding consent. This decision regarding the stage of recovery and capacity to consent was made by the clinician responsible for the service user's care at the point of referring an individual to the study. The researcher was also alert to any potential capacity concerns when meeting

the participants. If there was any doubt over the capacity to make the decision to be in the study, the individual was not invited to participate.

#### 2.5.3 Confidentiality.

Once consent was obtained, participants were assigned an identification number, to be used in place of names on all response sheets in order to record data anonymously. Names and identification numbers were stored in a separate, password-protected database which only the researcher had access to. It was necessary to keep some record of matched names and identification numbers should any information need to be passed on to the clinic.

All electronic data were stored in an encrypted database and on an encrypted USB memory stick. All questionnaire booklets were kept securely by the researcher during the data collection and analysis phases of the research. Following the completion of the study, they were kept in a locked drawer at the University of East Anglia and were stored for five years, in line with current policy. Recordings were destroyed after the completion of the study. All data were stored in accordance with the Data Protection Act (1998).

Information from the research assessments was kept anonymous and confidential unless a participant disclosed something which posed a risk to themselves or others. In this case the researcher had a duty of care to pass the information on to the participant's care coordinator. This was detailed within the participant information sheet and consent form.

It was possible that data obtained from the study could helpfully inform clinical care, and participants were asked if they agreed to the researcher passing on clinically relevant information to their care coordinator. Participants were also asked

if they wanted to be informed of the general findings of the study, and if so they were sent a leaflet summarising the overall study findings.

### 2.5.4 Potential risks for participants and researcher.

There were no perceived risks for participants taking part in this study. All the measures used had been previously used in similar populations, and were used as part of standard clinical care in some clinics. Participants were reminded at the end of the session that they could seek their care coordinator's support if, for any reason, they became distressed following the session. Before beginning the assessments, participants were informed that information may be shared with their care team if the researcher thought it would be harmful (to the participant or to others) not to do so.

To minimise any potential risks associated with completing the assessments in participants homes, lone working policies (e.g., Norfolk and Suffolk NHS Foundation Trust Policy Q17/RM08: Lone Working, 2012) were followed. A "buddy system" with another researcher was also implemented to ensure personal safety.

### 2.6 Assessment procedure

At the beginning of the appointment, the information sheet was reviewed and the participant was given the opportunity to ask the researcher questions about the research. Where the participant was happy to proceed, the consent form was signed and data collection commenced. The demographic questionnaire was administered first, followed by the tests of cognitive functioning (to avoid any effects of fatigue), the Autobiographical Memory Test (to avoid any priming about memories of their psychotic episode by questions included in the subsequent measures), the interviewbased measures (the SANS and PANSS), and then the self-report questionnaires. In total the assessment session took approximately 90 minutes to two hours. For some participants, who took longer to complete the measures or became fatigued, the

assessment session was split over two visits. As a thank you for their time, participants were entered into a raffle to win a £50 Amazon voucher.

Following the interview, patient notes were reviewed for confirmation of the individual's diagnosis (if applicable) and for medication and dosage information.

### **2.7 Dissemination of Findings**

Following the completion of the study, a summary of the findings was disseminated to the clinical teams who had taken part. This was done either by sending a report or, where requested, by giving a presentation of the findings and their clinical implications to the team. Participants were also asked if they wanted to be informed of the general findings of the study and where this preference was indicated they were sent a leaflet summarising the findings. All participant details were anonymised for the dissemination process so that individuals could not be identified.

### 2.8 Analysis Plan

### 2.8.1 Data management.

Data were entered into databases created by the researcher using the Statistical Package for Social Sciences (SPSS Inc., Chicago, Illinois, USA) for Windows (Version 21). Data were checked and cleaned by the researcher by visual inspection following the data entry phase. Questionnaires had been carefully checked with individuals during the assessment sessions to ensure that rates of missing data were as low as possible. For two participants where partial data was collected due to disengagement from the research process, the data that had been collected was analysed in relevant analyses (for example, the analysis of demographic data, which was available for all individuals). However, where a particular measure had not been completed and relevant data was not available, these individuals were excluded from

the corresponding analysis. Prior to conducting the analyses, the data was also checked to ensure assumptions for each statistical test, such as being normally distributed, were met.

## 2.8.2 Participant characteristics.

Participant characteristics were analysed and reported, including the demographic characteristics of the sample and means, SDs, median values and ranges for all of the measures used. Psychosis symptomatology was reported using the results of the Positive Scale of the PANSS and the SANS, as well as comorbid levels of trauma symptoms, depression, and anxiety.

The analysis plan for each of the three study hypotheses will now be described in turn.

2.8.3 Is the avoidance of psychosis-related memories associated with increased negative symptoms in people recovering from first episode psychosis? (Research Question One).

To determine if there was an association between the avoidance of traumarelated memories and the level of negative symptoms experienced, correlational analyses were performed using scores obtained on the Avoidance subscale of the IES-R and total scores on the SANS. Since the data for these two measures were normally distributed and met parametric assumptions, Pearson's Product Moment Correlation coefficients were calculated. The effect of depression was considered using the total score on the depression subscale of the DASS in order to investigate if this was a confounding variable. A partial Pearson's correlation was performed using

bootstrapping since the DASS subscale could not be transformed to meet parametric assumptions.

2.8.4 Is increased retrieval of psychosis-related memories (particularly in response to positive cue words) associated with a more discrepant self-concept (ought-ideal self-discrepancy and actual-ideal self-discrepancy) in people recovering from psychosis? (Research Question Two).

In order to investigate if increased retrieval of psychosis-related memories on the Autobiographical Memory Test (AMT; Williams & Broadbent, 1986) was associated with a more discrepant self-concept, as assessed by the Higgins' Selves Questionnaire (Higgins, 1987), correlations between these variables were calculated. Non-parametric Kendall's tau tests were performed since the data for the AMT were not normally distributed, could not be transformed to meet parametric assumptions, and there were a large number of tied ranks.

2.8.5 Are discrepancies in self-concept and the tendency to retrieve psychosis-related memories predictive of increased negative symptoms of psychosis? (Research Question Three).

To establish if discrepancies in self-concept and the tendency to retrieve psychosis-related memories are predictive of increased negative symptoms of psychosis, an exploratory multiple regression analysis was carried out with negative symptoms, as assessed by the SANS, being the criterion variable. This enabled the relative contributions of the main study variables (self-concept discrepancy and number of psychosis-related memories recalled) to be assessed as well as other potential independent variables that may be important (e.g., levels of depression, and avoidance of trauma related to psychosis).

### 3. Results

### 3.1 Data analysis overview

Analysis of the data was carried out using the Statistical Package for Social Sciences (SPSS Inc., Chicago, Illinois, USA) for Windows (Version 21).

Descriptive data for the study variables were generated first to ensure that the data met parametric assumptions. Each research question was then explored in turn.

## **3.2 Descriptive data analysis**

## 3.2.1 A description of the research sample.

Fifty-one participants consented to take part in the study. Two participants disengaged from the research process after an initial assessment session, but did not officially withdraw from the study. Therefore, the partial data that had been obtained from these participants was included in the analysis. Table 1 summarises the demographic characteristics of the 51 participants who were recruited to the study.

Demographic variable	N	%	М	SD	Range
Gender					
Male	32	62.7			
Female	19	37.3			
Ethnicity (self-ascribed)					
White British	47	92.2			
Black/African/Caribbean/Black British	2	3.9			
Mixed/Multiple ethnic group	1	2.0			
Other ethnic group – Bangladeshi	1	2.0			
Age (years)			26.9	5.6	18-40
Educational Level					
None	2	3.9			
GCSEs (or equivalent)	33	64.7			
A levels (or equivalent)	9	17.6			
Degree or higher	7	13.7			
Employment status					
Unemployed	32	62.7			
Voluntary	9	17.6			
Part-time paid	3	5.9			
Full-time paid	7	13.7			

# Table 1. Summary data for the demographic variables

Of the 51 individuals who participated in the study, 32 (62.7%) were male and 19 (37.3%) were female. The higher number of men in this study is consistent with incidences reported in other studies of first episode psychosis (Kirkbride et al., 2006; McGrath, Saha, Chant, & Welham, 2008). The gender split in this study is very similar to that observed in a study by Kirkbride et al. (2012) where 66.2% of individuals accepted into Early Intervention Services across East Anglia over a three year period were male and 34.8% were female.

The range of ages of participants recruited to this study was 18 to 40 years, with the mean age of the sample being 26.9 years (SD = 5.6 years). Since most of the participants who took part in the study were previously or currently under the care of Early Intervention Services, this age range is what would be expected given that Early Intervention Services are commissioned to work with individuals who are experiencing their first episode of psychosis between the ages of 14 and 35 (Department of Health, 2001).

The mean age of the 32 men who took part in the research was 25.9 years (SD = 5.2 years) and the mean age of the 19 women who took part was 28.6 years (SD = 5.8 years). However, this difference was not significant at the 5% significance level (t = 1.73, df = 49, ns, two-tailed). This finding is consistent with previous research which has suggested that women typically have a later onset of first episode psychosis than men (see Eranti et al., 2013, for a meta-analysis).

The sample was predominantly White British in terms of self-ascribed ethnicity (92.2%). Four participants (7.9%) were from Black or Minority Ethnic (BME) groups. Therefore, the sample of people recruited to the study was not very ethnically diverse. This lack of ethnic diversity in the participants recruited to the study is consistent with the ethnicity statistics for the general population in the East

Anglian region from which individuals were recruited (Corke & Wood, 2009). However, this sample was not representative of the national prevalence of first episode psychosis in relation to ethnicity where typically BME groups have been found to have a greater relative risk of psychosis (Kirkbride et al., 2006).

In relation to education, the majority of participants had completed secondary education (GCSEs or equivalent) but had not pursued education beyond this (64.7%).

In terms of employment, 62.7% of the participants were unemployed at the time of the research assessment. For the remainder of the participants, 17.6% of were engaged in voluntary work, 5.9% were in part-time paid work and 13.7% of participants were in full-time paid work. In concordance with other studies of first episode psychosis (e.g., Kirkbride et al., 2012), levels of unemployment were significantly higher than rates of unemployment in the general population (Office of National Statistics, 2011).

Overall, the sample of participants recruited to the study was representative of an early intervention first episode psychosis sample in the East Anglian region, but not necessarily in the wider UK, due to the lack of ethnic diversity.

# **3.2.2** A description of treatment related information.

Treatment related variable	N	%	Μ	SD	Range
Early Intervention Team attended					
Central Norfolk	21	41.1			
Great Yarmouth	5	9.8			
Kings Lynn	1	2.0			
Coastal Suffolk	1	2.0			
Central Suffolk	1	2.0			
Ipswich, Suffolk	5	9.8			
Bury, Suffolk	4	7.8			
Bedford	1	2.0			
South Essex	12	23.5			
Length of time with services for psychosis (months)			20.7	20.2	10.150
Length of time with service for psychosis when			30.7	20.2	12-152
outlier is excluded (months)			28.2	10.5	12-52
Time since last episode of psychosis (months)			10.1	12.4	0-42
Primary Diagnosis					
F19.5: Psychotic disorder due to multiple drug use and	2	3.9			
use of other psychoactive substances					
F20.0: Paranoid schizophrenia	15	29.4			
F20.9: Schizophrenia, unspecified	3	5.9			
F21: Schizotypal disorder	1	2.0			

# Table 2. Summary data for treatment related variables

F23: Acute and transient psychotic disorder	7	13.7
F28: Other nonorganic psychotic disorder	5	9.8
F29: Unspecified nonorganic psychosis/Psychosis	13	25.5
NOS		
F30.2: Mania with psychotic symptoms	1	2.0
F31.9: Bipolar affective disorder, unspecified	1	2.0
F33.3: Recurrent depressive disorder, current episode	1	2.0
severe with psychotic symptoms		
F53.1: Puerperal psychosis NOS	1	2.0
No diagnosis	1	2.0
Medication		
Antipsychotic	40	78.4
Antidepressant	17	33.3
Anxiolytic	3	5.9
Hypnotics	4	7.8
Anti-parkinsonian	2	3.9
Mood stabiliser	1	2.0
Antipsychotic medication dose <sup>a</sup>		
None	11	21.6
Low	12	23.5
Medium	23	45.1
High	5	9.8

### Previous counselling or psychological therapy

Yes - prior to experiencing psychosis	3	5.9
Yes - since experiencing psychosis	33	64.7
No	15	29.4

<sup>a</sup> Medication categories established by comparing participant doses to maximum doses in the BNF.

Participants were recruited from Early Intervention Services (EIS) and Integrated Delivery Teams (IDTs) in four counties of East Anglia – Norfolk, Suffolk, Essex and Bedfordshire. The greatest number of participants was recruited from the Central Norfolk EIS in Norwich (41.1%). Lower recruitment rates were seen in Suffolk, where a recent service redesign had occurred and a new service delivery model was in place, and in teams that were approached to take part later on in the study (e.g., Bedfordshire).

The mean length of time that individuals had been with mental health services for treatment for psychosis was 30.7 months (SD = 20.2 months). There was a large degree of heterogeneity in the length of time that participants had been with a service for treatment for psychosis. This ranged from 12 months (the minimum amount of time required in order for participants to meet the inclusion criteria for the study and to be considered in recovery from psychosis) to 152 months. The participant who had been with services for psychosis for 152 months was an outlier in the sample. This participant was from one of the newly formed IDTs in Suffolk. It was not anticipated that participants recruited through EIS would have been with services for this long since EIS are typically commissioned to work with individuals for up to three years from their initial onset of psychosis (Department of Health, 2001). When this person was excluded from the analysis, the length of time that participants had been with

services ranged from 12 to 52 months, the mean length of time was 28.2 months (SD = 10.5 months) and the sample was normally distributed.

The mean length of time since the most recent episode of psychosis, as reported by participants, was 10.1 months (SD = 12.4 months). Eleven participants (21.6%) reported that they were still experiencing symptoms of psychosis (i.e., their psychotic episode was ongoing) and therefore were rated as it having been zero months since their most recent psychotic episode.

Information about diagnosis was obtained by interviewing participants and reviewing their clinical notes. This revealed that the sample was very heterogeneous in relation to diagnosis with a total of 11 different diagnoses being recorded. This is perhaps reflective of the diagnostic uncertainty and instability which is often seen throughout the course of a psychotic episode. In fact, embracing diagnostic uncertainty is frequently stated as one of the principles of best-practice management of first-episode psychosis (Spencer, Birchwood, & McGovern, 2001). The most common diagnoses in the present study were paranoid schizophrenia (29.4% of the sample) and psychosis not otherwise specified (25.5% of the sample). One participant did not have a diagnosis recorded in their clinical notes and during the assessment session was not aware of having been given a diagnosis during their time with the service.

Medication information was reviewed in participants' clinical notes and by asking participants about medication they were taking at the time of the assessment. This revealed that the majority of participants were taking antipsychotic medication at the time of the research assessment (78.4%).

The participants in this study represented a heterogeneous sample in relation to diagnosis, length of time since onset, and length of time since their most recent

episode of psychosis. There was also variability in the presence or absence of psychological therapy, as well as the presence or absence, type, and dosage of any medication being taken by participants. Therefore, the participants in this study reflect the variability in demographics and treatment received within a first episode psychosis early intervention sample within East Anglia.

## **3.2.3** A description of the study measures.

Measure	М	Median	SD	Skewness	SE of Skewness	Kurtosis	SE of Kurtosis	Range
Positive Scale ( <i>N</i> =50)	11.44	11.00	3.78	.93**	.34	.20	.66	7-22
Negative Scale ( <i>N</i> =50)	12.46	12.00	4.67	.83*	.34	.00	.66	7-24
SANS total ( <i>N</i> =50)	5.70	6.00	3.19	02	.34	-1.02	.66	0-11
IES-R Avoidance Subscale ( <i>N</i> =50)	11.66	10.00	7.60	.43	.34	50	.66	0-29
IES-R Intrusion subscale ( <i>N</i> =50)	11.64	11.50	7.76	.08	.34	-1.13	.66	0-25
IES-R Hyperarousal subscale ( <i>N</i> =50)	8.62	9.00	6.40	.28	.34	-1.06	.66	0-22
IES-R Overall total ( <i>N</i> =50)	31.92	35.50	19.93	.17	.34	79	.66	0-70

## Table 3. Summary data for the study measures

Measure	М	Median	SD	Skewness	SE of Skewness	Kurtosis	SE of Kurtosis	Range
LEC Number of past traumas ( <i>N</i> =50)	5.76	5.00	3.64	.21	.34	-1.10	.66	0-12
DASS Depression subscale ( <i>N</i> =50)	14.74	14.00	11.66	.69*	.34	20	.66	0-42
DASS Anxiety subscale ( <i>N</i> =50)	11.78	8.50	11.24	.85*	.34	41	.66	0-38
DASS Stress subscale ( <i>N</i> =50)	14.20	11.50	11.86	.81*	.34	17	.66	0-42
DASS Overall total ( <i>N</i> =50)	40.72	36.00	32.88	.87**	.34	10	.66	0-121
FAS total summed score ( <i>N</i> =50)	27.38	27.50	10.26	.48	.34	.18	.66	6-53
Digit span (scaled score) ( <i>N</i> =50)	8.62	8.00	2.27	.35	.34	.17	.66	4-14
Actual-ideal synonyms ( <i>N</i> =48)	2.33	1.00	2.95	1.58***	.34	2.56***	.67	0-13
Actual-ideal antonyms ( <i>N</i> =48)	1.25	1.00	1.88	2.71***	.34	9.57***	.67	0-10
Actual-ideal discrepancy (antonyms minus synonyms) ( <i>N</i> =48)	-1.08	.00	3.80	35	.34	1.32	.67	-12-9

Measure	М	Median	SD	Skewness	SE of Skewness	Kurtosis	SE of Kurtosis	Range
Actual-ought synonyms ( <i>N</i> =48)	2.52	2.00	2.47	0.69*	.34	73	.67	0-8
Actual-ought antonyms ( <i>N</i> =48)	1.15	.00	2.09	2.60***	.34	7.22***	.67	0-10
Actual-ought discrepancy (antonyms minus synonyms) ( <i>N</i> =48)	-1.27	-1.00	3.44	.55	.34	1.00	.67	-8-9
AMT: Number of psychosis related memories ( <i>N</i> =51)	1.69	1.00	1.48	.73*	.33	12	.66	0-6
AMT: Number of non- psychosis related memories ( <i>N</i> =51)	8.00	8.00	1.57	61	.33	23	.66	4-10
AMT: Number of omissions ( <i>№</i> =51)	.31	.00	.71	2.65***	.33	7.15***	.66	0-3

\* significantly skewed variable at p < .05 (skewness/SE skewness > 1.96)
\*\* significantly skewed variable at p < .01 (skewness/SE skewness > 2.58)
\*\*\* significantly skewed variable at p < .001 (skewness/SE skewness > 3.29)

### 3.2.3.1 Positive and negative symptomatology.

Positive and negative symptoms of psychosis were measured using the Positive and Negative Syndrome Scale (PANSS: Kay et al., 1987). Negative symptoms were also measured using the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1989).

The total scores for PANSS positive and PANSS negative subscales were not normally distributed and showed a significant positive skew, with more participants scoring at the lower end of the scale. This deviation from normality was supported by a Kolmogorov-Smirnov test (D(50) = .206, p < .001 and D(50) = .130, p < .05respectively) and visual inspection of the data. The SANS data were found to be normally distributed.

Spearman's correlations were used to determine non-parametric associations between the scales used to assess positive and negative symptoms of psychosis. Table 4 shows that the correlation between the positive and negative subscales of the PANSS was low (rho = .28, ns, two-tailed, N = 50) suggesting that they were measuring independent symptom dimensions. There was a significant correlation between the two measures of negative symptoms, the PANSS negative subscale and the SANS (rho = .85, p < .001, two-tailed, N = 50), suggesting that these two measures may have been assessing a similar negative symptom dimension.

	PANSS Positive	PANSS Negative	SANS
PANSS Positive	-	-	-
PANSS Negative	.28	-	-
SANS	.28*	.85***	-

 Table 4. Inter-correlations (Spearman's rho) between measures of psychotic symptoms

\*Correlation is significant at p < .05 level (2-tailed).

\*\*\* Correlation is significant at p < .001 level (2-tailed).

Figure 4 shows the distribution of scores on the Positive Scale of the PANSS when scores were converted into percentile ranks (obtained from the PANSS manual; Kay et al., 1987) and categorised accordingly as very low (0-5%), low (6-25%), average (26-74%), high (75-94%), or very high (95%+). Since no participants scored in the high or very high range, there was no justification for excluding any participants from the main analyses. The data for the Positive Scale of the PANSS indicate that this sample of individuals were in remission from positive symptoms.

**Figure 4. Positive Symptom Scores** 



*Figure 4*. Histogram to show Positive Scale scores on the PANSS after conversion of raw scores to percentile ranks.

Due to the enhanced psychometric properties of the SANS, in comparison with the Negative Scale of the PANSS, in assessing the negative symptoms of psychosis (see method section for a summary review), the results from the SANS were used as the measure of negative symptomatology in subsequent analyses.

Negative symptoms, as measured by the SANS, were relatively common in the sample, with 86% (N = 43) of participants scoring three or more on at least one item of the SANS. This figure is very similar to the reported prevalence in a study by Lyne et al. (2012) which found that the prevalence of negative symptoms (defined as scoring three or more on at least one item of the SANS) was high in both the schizophrenia spectrum diagnoses group (87%) and in the "all other psychotic diagnoses" group (51%). This similarity with the schizophrenia spectrum group is slightly unexpected since only around a third of this sample had a schizophrenia spectrum diagnosis.

#### 3.2.3.2 A description of trauma symptoms.

## 3.2.3.2.1 Trauma symptoms related to psychosis.

Symptoms of trauma in response to a person's psychotic episode were measured using the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997). The overall total scores and scores on the three subscales of the IES-R all met parametric assumptions and so normality was assumed.

The results of the IES-R indicated that 52% of participants in the study (N = 26) scored above the cut-off level of 33 out of 88 which is suggestive of a diagnosis of PTSD, as defined by Creamer et al. (2003). Although a formal diagnostic measure of PTSD was not used, this does indicate that PTSD symptoms related to the experience of psychosis were high in this study relative to rates observed in previous studies, which have ranged between 11% and 67% (Frame & Morrison, 2001; McGorry et al., 1991; Meyer et al., 1999). This finding is very similar to the findings of Bernard et al. (2006). They assessed individuals with first episode psychosis who were in the recovery phase of their illness (i.e., not currently acutely psychotic or suicidal) and found that 57% met the diagnostic cut-off level of 33 on the IES-R (Creamer et al., 2003) for PTSD related to their episode of psychosis.

## 3.2.3.2.2 Considering previous trauma.

Of the 50 people who completed the Life Events Checklist (LEC; Blake et al., 1995), 94% (N = 47) reported that a traumatic life event had either happened to them personally, they had witnessed it happening to someone else, or they had learnt about it happening to someone close to them. This high rate of previous traumatic life events is comparable with research by Shaw et al. (2002) which found that 100% of

people recovering from psychosis had experienced at least one traumatic event (other than their psychotic episode) that met DSM-III-R stressor criteria. They also found that 36.8% of people had experienced two such events, and 43.4% had experienced three or more. In the present study the incidence of three or more past traumatic life events was much higher at 80% (N = 40).

Furthermore, 34% (N = 17) of participants indicted that the trauma they experienced (personally, witnessed, or learned about it happening to someone close to them) met Criterion A (i.e., felt as though there was a risk of death or serious injury to them or someone else as a result of the event and experienced intense fear, helplessness or horror as a result of the event) required for a diagnosis of PTSD (DSM-IV; American Psychiatric Association, 1994). This is slightly higher than the lifetime prevalence rate of trauma that would meet diagnostic criteria for PTSD found by Neria, Bromet, Sievers, Lavelle, and Fochtmann (2002), which was 26.5%. However, in the present study only criterion A of the PTSD diagnostic criteria was applied and so it is possible that this is an overestimate.

Figure 5 shows the frequency distribution for the number of reported traumas. The modal number of reported traumas was four.

**Figure 5. Mean Number of Past Traumas** 



*Figure 5*. Graph to show the number of traumas reported by participants on the Life Events Checklist (a reported trauma is defined as happening to someone personally, witnessing it happening to someone else or learning about it happening to someone close to you).

Three individuals identified within the Life Events Questionnaire that their psychotic episode was a traumatic event. This information was gained in response to question 17 of the questionnaire, which asked participants to state "Any other very stressful event or experience". In answer to this question, one individual referred to their psychotic episode generally, one person referred to the consequences of their first symptoms of psychosis ("Police incident when I first became psychotic") and one person referred to their experiences of being in hospital.

## 3.2.3.3 Depression and anxiety symptomatology.

The Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) was used to measure the levels of depression and anxiety among participants in the study. The data for all subscales of the DASS and the overall total were significantly positively skewed with more individuals scoring at the lower end of each scale. The depression subscale of the DASS could not be transformed sufficiently to achieve normality.

The levels of depression and anxiety measured in the study sample were comparable to those seen in previous studies. For example, Huppert et al. (2002) reported a mean DASS depression score of 16.12 (SD = 12.22) and anxiety score of 14.45 (SD = 11.09) in a study of individuals with schizophrenia.

Using the severity rating categories for the DASS defined by Lovibond and Lovibond (1995), it was found that 36% of participants fell within the "normal" range for depression, 8% were in the "mild" category, 32% in the "moderate" category, 8% in the "severe" category, and 16% in the "extremely severe" category. For anxiety, 44% of participants fell within the "normal" range on the DASS, 10% were in the "mild" category, 12% obtained a score representing "moderate" anxiety, 12% were in the "severe" category and 22% were in the "extremely severe" category.

## 3.2.3.4 Cognitive ability.

Tests of cognitive ability were included in order to control for potential deficits in domains of cognitive functioning which might impact upon performance in the Autobiographical Memory Task (AMT; Williams & Broadbent, 1986). The measures that were used were the FAS task and the digit span task.

## 3.2.3.4.1 FAS verbal fluency task.

The FAS task was used in order to measure verbal fluency, since deficits in this area might influence a participant's ability to produce and articulate memories within the AMT.

Scores obtained on both the FAS verbal fluency task and the digit span task were normally distributed and met parametric assumptions. Performance on the FAS was poor when compared to normative data for 16-59 year olds (Tombaugh, Kozak, & Rees, 1999) with the mean score for the total number of words recalled of 27.38 (SD = 10.26) recorded within the 10<sup>th</sup> percentile. Comparison with normative data also revealed that, when stratified for years of education, 56% (N = 28) of participants fell below the normal range (i.e., below the 10<sup>th</sup> percentile) for performance on the FAS task.

A one-sample t-test revealed that the mean number of words generated on the FAS by participants in this study was significantly lower than what would be expected in a healthy normative sample (t(49) = 9.04, p < .001, two-tailed), when compared to the normative mean of 40.5 words found in a healthy sample of 16 to 19 year olds with between 9 and 12 years of education (Tombaugh et al., 1999).

This finding of poor performance on the FAS task is consistent with previous research which has shown that deficits in verbal fluency are frequently reported for individuals with psychosis (e.g., Badcock et al., 2011). The mean score on the FAS in this study was very similar to that reported by Badcock et al. (2011) for individuals with schizophrenia, where the mean score was 27.4 (SD = 10.4). Of note is that Badcock et al. (2011) assessed a more chronic sample with a mean length of illness 10.8 years.

## 3.2.3.4.2 Digit Span task.

The digit span task was included as a measure of working memory since deficits in this area might influence a participant's ability to recall memories on the AMT. Age-adjusted scaled scores on the digit span task were normally distributed and met parametric assumptions.

The mean age-adjusted scaled score was 8.62 (SD = 2.27). This score falls at the  $32^{nd}$  percentile when compared with normative data. Comparison with normative data also revealed that 16% (N = 8) of participants fell below the normal range (i.e., below the 10<sup>th</sup> percentile) for performance on the digit span task.

A one-sample t-test provided evidence to suggest that the mean scaled score obtained on the digit span task by participants in this study was significantly lower than what would be expected in a healthy normative sample (t(49) = 4.31, p < .001, two-tailed), when compared to the normative mean of 10 (Wechsler, 1997).

This finding of poor performance on the digit span task is consistent with previous research which has shown that deficits in working memory are frequently reported for individuals with psychosis (e.g., Lee & Park, 2005).

## 3.2.3.5 Self-concept discrepancy.

Discrepancies between participants' perceptions of their actual and ideal self and their actual and ought self were measured using the Higgins' Selves Questionnaire (Higgins, 1987). A positive score for self-discrepancy indicates that an individual's perceived actual self is different from how they would ideally like to be (actual-ideal self-discrepancy) or how they feel they ought to be (actual-ought selfdiscrepancy). The more positive the score, the greater the perceived self-discrepancy. A negative score indicates that a person's perception of themselves is consistent with how they would ideally like to be or feel they ought to be. Discrepancy scores for

both actual-ideal discrepancy and actual-ought discrepancy were not significantly skewed and therefore met parametric assumptions. There was no significant association between self-discrepancy scores and performance on the cognitive tasks (verbal fluency FAS task and digit span task).

Scores for actual-ideal self-discrepancy ranged from -12 to 9. The mean actual-ideal self-discrepancy was -1.08 (SD = 3.80). Scores for actual-ought self-discrepancy ranged from -8 to 9. The mean actual-ought self-discrepancy was -1.27 (SD = 3.44). These scores indicate that, on average, participants in this study did not show a significant ideal or ought self-discrepancy and their perceptions of self were largely consistent with how they would ideally like to be or feel they ought to be.

However, despite self-discrepancy being low in the sample on average, there was a large range in the recorded self-discrepancy scores indicating that some individuals did have very high levels of self-discrepancy. In fact, 31.3% of participants had a positive score for actual-ideal discrepancy and 22.9% of participants had a positive score for actual-ought discrepancy indicating that for these individuals their actual self was discrepant from how they feel they would ideally like to be or how they feel they ought to be.

In comparison, Sutherland and Bryant (2008) did observe an average selfdiscrepancy for both ideal and ought self in trauma-exposed individuals with PTSD. They found a mean actual-ideal self-discrepancy of 2.12 (SD = 3.37) and a mean actual-ought self-discrepancy of 1.29 (SD = 4.55). Therefore, this study's findings for self-discrepancy in individuals who have experienced first episode psychosis are not consistent with those for individuals with PTSD.

This finding is perhaps not surprising given that psychosis might not have been a traumatic experience for all participants who took part in the study, whereas in

PTSD samples (e.g., Sutherland & Bryant, 2008) all individuals will have been exposed to a traumatic event. It is possible that for some individuals their experiences and engagement with Early Intervention Services may not have been traumatic at all. For example, they may have had a short duration of untreated psychosis, hospital treatment may not have been necessary, and their psychotic symptoms may have been swiftly treated and remitted.

In light of this, and considering that there was quite a range observed in participants' self-discrepancy scores, an additional post-hoc analysis was undertaken using the self-discrepancy scores to see if there was any difference in self-discrepancy for those who scored above cut-off on the IES-R (indicating that there was a traumatic impact of their psychotic episode) compared with those who did not. Parametric assumptions were met and therefore an independent samples t-test was used. This revealed no significant difference in actual-ideal discrepancy (t(46) = .66, ns, two-tailed) or actual-ought discrepancy (t(46) = .99, ns, two-tailed) between those who had scored above and below the cut-off suggestive of PTSD on the IES-R.

### 3.2.3.6 A description of autobiographical memories.

Autobiographical memory was measured using the Autobiographical Memory Test (AMT; Williams & Broadbent, 1986). All memories generated by participants in this test were rated as either psychosis related, non-psychosis related, or omissions. The distribution of the data for the total number of psychosis related autobiographical memories recalled by participants was positively skewed (see Table 3). This significant deviation from normality was confirmed by a Kolmogorov-Smirnov test (D(51) = .248, p < .001) and visual inspection of the data. This positive skew in the data indicates that most people recalled a low number of psychosis related memories on the AMT. There was no significant association between the number of psychosis related memories recalled on the AMT and performance on the cognitive tasks (verbal fluency FAS task and digit span task)

The recall of at least one autobiographical memory relating to the experience of psychosis was relatively common in the sample with 76.5% of participants recalling at least one psychosis related autobiographical memory. The cue word that psychosis related memories were most frequently generated in response to was "sorry", closely followed by "lonely". Themes that emerged among psychosis related autobiographical memories in response to the word "sorry" generally related to the impact of a person's psychotic episode. This included being sorry for the impact their illness had on family and friends or feeling sorry for lost opportunities, such as having to leave work. Many of the psychosis related autobiographical memories generated in response to the word "lonely" included reference to the sense of social isolation participants felt during and after their episode of psychosis. "Angry" was another cue word to which psychosis related memories were frequently generated. Two participants described memories of being angry with their employers for how they reacted to their mental health difficulties. Additionally, two participants described feeling angry at the time of their admission to hospital. In terms of positive cue words, "safe" was the word that most frequently elicited psychosis related memories. One common theme relating to "safe" was feeling safe recently during the recovery phase of their illness, compared to how they felt during the more acute phase of their episode. Participants also frequently commented that they felt safe when surrounded by friends or family during the time when they were acutely unwell.

As described previously, it is likely that not all participants in the study found the experience of psychosis traumatic. To investigate if psychosis related autobiographical memory was more common for individuals who indicated that their

experiences of psychosis had a traumatic impact, a Mann-Whitney test was performed. This non-parametric test was selected because the assumptions required for a parametric independent samples t-test were not met and the data for overall psychosis related memory recall on the AMT were not normally distributed. The number of psychosis related memories recalled by participants who scored above cutoff (Mdn = 1.00) did not differ significantly from the number of psychosis related memories recalled by participants who scored below cut-off (Mdn = 1.00) on the IES-R (U = 272.5, z = -.79, ns, r = -.11).

The influence of the valency of the cue word presented to participants in this task was considered in order to establish if similar findings to those found with participants with PTSD (see Sutherland & Bryant, 2008) were also seen in this first episode psychosis sample. Table 5 shows the means for each type of memory produced according to valency.

 Table 5. Mean (SD) number of psychosis related and non-psychosis related

 memories, together with omissions, generated to positive and negative cue words

 on the AMT.

С	ue
Positive	Negative
.59 (.75)	1.10 (1.12)
4.22 (.83)	3.78 (1.17)
.20 (.49)	.12 (.38)
	Positive .59 (.75) 4.22 (.83)

A Kolmogorov-Smirnov test of normality revealed that the data for the number of psychosis related memories produced in response to both positive and negative cue words were not normally distributed (D(51) = .351, p < .001 and D(51) = .241, p < .001 respectively). Therefore matched-pair non-parametric tests were used to examine the recall of psychosis related memories in response to positive and negative cue words since the data could not be transformed to meet parametric assumptions. Wilcoxon's Signed Ranks tests revealed that there was a significant difference between the number of psychosis related memories recalled in response to positive and negative cue words (z = -2.81, p < .01, two-tailed), with more psychosis related memories being recalled in response to negative cue words. This finding is consistent with the findings of Sutherland and Bryant (2008) who found that trauma exposed individuals with and without PTSD recalled significantly more trauma related memories in response to negative cue words than they did in response to positive cue words.

Sutherland and Bryant (2008) found that trauma-exposed individuals with PTSD recalled a mean of 1.53 (SD = 1.42) trauma related memories in response to positive cue words and 2.21 (SD = 1.58) trauma related memories in response to negative cues. The trauma-exposed non-PTSD group recalled a mean of .06 (SD = .25) trauma related memories in response to positive cue words and .69 (SD = .95) trauma related memories in response to negative cue words. The mean number of psychosis related words recalled by individuals in recovery following first episode psychosis in this study (mean of .59 [SD = .75] for positive cue words and 1.10 [SD = 1.12] for negative cue words) was lower than the means reported in Sutherland and Bryant's study for individuals with PTSD, but were higher than the results for trauma-exposed individuals with PTSD.

LF .	D D I V		C DI	н <u>6</u>		D 4 00	00 Y C			11:14	4 1 A		TIMIN	TIME
	CONIA	SANS	IES-K	IEO-K	LEC past	CCAU	CCAU	FAS	ngiru	Actual-Ideal	Actual-ought	AIM I psychosis	positive	negative
Pc	Positive		total	avoidance	traumas	depression	anxiety		span	discrepancy	discrepancy	related memories	cues	cues
PANSS Positive														
SANS	.28*			ı	ı	ı			,	ı	·		ı	ı
IES-R total .4	.46***	**44*		ı	ı	·				ı			ı	ı
IES-R avoidance	.36*	.44**	***68.	ı	ı			·	ı	ı			ı	ı
LEC past traumas	.14	.16	.24	.27	ı	·		ı	ı	ı			ı	ı
DASS depression	.29*	.61***	.80***	.70***	.16	·	ı	ı	ı	ı			ı	ı
DASS anxiety	.31*	.33	.74***	.62***	.24*	.74***	ı	ı	ı	ı			ı	ı
FAS	.16	-00	04	08	.13	17	.05	ı	ı	ı			ı	·
Digit span	.20	01	.05	11	.06	-00	05	.38**	·	·			·	
Actual-ideal discrepancy -	01	.26	.25	.13	15	.22*	.12	.07	.12	·			ı	
Actual-ought discrepancy	.19	.24	.29*	.17	-00	.16	.16	.15	.14	.77***			·	
AMT psychosis related	03	-00	.06	01	13	.01	.02	.01	.16	.05	60 <sup>.</sup>	ı		ı
tive cues	06	10	60	22	60.	04	.04	01	.13	.12	.14	.61***	ı	
AMT negative cues	02	06	.12	.13	27*	.01	00 <sup>.</sup>	00 <sup>.</sup>	.12	02	.03	***67.	.21	ı

Table 6. Correlation matrix for the study measures.
### **3.3 Hypothesis testing**

### 3.3.1 Avoidance and negative symptoms (Research Question One).

It was predicted that people who avoid traumatic memories about their experience of psychosis would have more negative symptoms. Therefore, the relationship was explored between two of the main study variables – avoidance of traumatic memories, as assessed by the IES-R avoidance subscale, and negative symptoms of psychosis, as assessed by the SANS. Correlations between these variables and depression were also examined in order highlight possible confounding effects.

Since the data for the avoidance subscale of the IES-R and the SANS were both normally distributed and met parametric assumptions, Pearson's correlations were performed for these variables. There was a significant positive correlation between avoidance relating to experiences of psychosis and negative symptoms (r = .44, p < .01, two-tailed, N = 50). However, this finding did not remain significant when the effects of depression were partialled out (r = .07, ns, two-tailed, N = 50). Bootstrapping was used when performing this partial correlation since the DASS subscale could not be transformed to meet parametric assumptions.

There was a significant correlation between depression and negative symptoms (rho = .61, p < .001, two-tailed, N = 50). Depression was also significantly correlated with avoidance (rho = .70, p < .001, two-tailed, N = 50). It is therefore difficult to conclude if there is a significant association between negative symptoms and avoidance, or whether any observed relationship is a consequence of the two variables strong association with depression.

# **3.3.2** Psychosis related autobiographical memory and self-concept discrepancy (Research Question Two)

It was predicted that increased retrieval of psychosis related memories on the AMT (Williams & Broadbent, 1986) would be associated with a more discrepant self-concept (actualideal and actual-ought self-discrepancy) as assessed by the Higgins Selves Questionnaire (Higgins, 1987).

Non-parametric tests were performed since the data for the AMT were not normally distributed and could not be transformed to meet parametric assumptions. Kendall's tau was used due to the number of tied ranks. Correlations between psychosis related memory recall and self-discrepancy are reported in Table 7.

# Table 7. Non-parametric correlations (Kendall's tau) between psychosis related memory recall and self-discrepancy (n=48).

	Total number of psychosis related memories recalled	Number of psychosis related memories recalled in response to positive cues	Number of psychosis related memories recalled in response to negative cues
Actual-ideal self- discrepancy	.05	.12	02
Actual-ought self- discrepancy	.09	.14	.03

No significant associations were found between self-discrepancy and the number of psychosis related memories recalled when the whole sample of participants was considered. However, when only those individuals who indicated that their psychotic episode had a traumatic 100 impact were considered (as indicated by scoring above 33 on the IES-R), a significant correlation was found between actual-ideal self-discrepancy and psychosis-related memory recall in response to positive cues (t = .37, p < .05, two-tailed, N = 25) and actual-ought self-discrepancy and psychosis-related memory recall in response to positive cues (t = .43, p < .05, two-tailed, N = 25).

Table 8. Non-parametric correlations (Kendall's tau) between psychosis related memory recall and self-discrepancy for participants scoring above cut-off for trauma symptoms on the IES-R (n=25).

	Total number of psychosis related memories recalled	Number of psychosis related memories recalled in response to positive cues	Number of psychosis related memories recalled in response to negative cues
Actual-ideal self- discrepancy	.15	.37*	01
Actual-ought self- discrepancy	.12	.43*	08

\*Correlation is significant at p < .05 level (2-tailed).

Therefore, this study's findings did not support the hypothesis that the recall of psychosis related memories is associated with a discrepant self-concept in the whole sample. However, when a smaller subset of only those participants for whom their episode of psychosis had a traumatic impact was considered, significant correlations were found. The findings of Sutherland and Bryant (2008) for individuals with PTSD were replicated in this first episode psychosis sample with the retrieval of trauma-focused memories in response to positive cues being strongly associated with the perception that one's actual self was discrepant from one's

ideal self. This finding was restricted to memories recalled in response to positive, but not negative cue words in both Sutherland and Bryant's and the current study supporting the idea that perceiving that one is missing desired outcomes after trauma is linked to focusing on the trauma experience. Sutherland and Bryant (2008) only found partial support for an association between the trauma-related retrieval to positive cues and an actual-ought self-discrepancy. However, this association was found to be significant in the present study.

# 3.3.3 Exploratory regression (Research Question Three).

In addition to the correlational analyses that were undertaken in order to explore hypotheses one and two, the data were further explored using multiple regression. The aim was to identify whether discrepancies in self-concept and psychosis related memory recall could be used to predict negative symptoms.

However, no significant correlation was observed between the number of psychosisrelated memories recalled on the AMT and the level of negative symptoms, as measured by the SANS (t = -.09, ns, two-tailed, N = 50).

Although there appears to be a moderate association between both actual-ideal selfdiscrepancy (r = .26, ns, two-tailed, N = 48) and actual-ought self-discrepancy (r = .24, ns, twotailed, N = 48) with negative symptoms, this was not significant at the 5% significance level. Therefore it seems unlikely that either psychosis-related memory recall or self-discrepancy will be significant predictors of negative symptoms.

In order to consider other variables that might also predict negative symptoms, a total of five independent (predictor) variables were included in the regression model. These were avoidance, depression, overall psychosis related memory recall, actual-ideal self-discrepancy and actual-ought self-discrepancy.

Since the number of cases in the sample was small (N = 48 complete data sets) in comparison to those that are recommended for multiple regression analysis (Tabacknick & Fidell, 1996), the simultaneous (enter) method was used.

Prior to executing the analysis, the data were examined to ensure that the statistical assumptions for this procedure were met. Although the dependent variable (negative symptoms) had already been shown to be normally distributed, two of the independent (predictor) variables (depression and overall psychosis related memory recall) were not and could not be transformed to achieve a normal distribution. Therefore, the bootstrapping method was used in the regression analysis. The independence of the predictor variables was also checked in order to minimise the instability of the regression model and reduce the risk that significant relationships might reflect spurious correlations between measures.

Table 9. Summary data for the multiple regression of negative symptoms using actual-ideal self-discrepancy, actual-ought self-discrepancy, psychosis related memory recall, avoidance and depression as predictor variables

Predictors	R	R <sup>2</sup>	Adjusted R <sup>2</sup>	d.f.	F
Actual-ideal self-discrepancy, actual-ought					
self-discrepancy, psychosis related memory	.59	.34	.27	5,42	4.41**
recall, avoidance and depression					

\*\*significant at p < .01 level (two-tailed)

Table 9 reveals that the regression *F* statistic for the model was significant (F [5,42] = 4.41, p < .01). This indicates that R is significantly different from zero and that there is a linear relationship between the dependent and independent variables. The analysis resulted in an

overall multiple correlation of .59 (R). Altogether, 34% (27% adjusted  $R^2$ ) of the variance in negative symptoms was explained by the predictor variables.

Table 10. Standardised bootstrapped regression coefficients (ß), T-values and semi-partial correlations of predictor variables for actual-ideal self-discrepancy, actual-ought self-discrepancy, psychosis related memory recall, avoidance and depression

Predictors	ß	SE	95% confidence interval		р
			Lower	Upper	
Actual-ideal self-discrepancy	.04	.21	35	.48	.84
Actual-ought self-discrepancy	.08	.24	50	.45	.74
Psychosis related memory recall	17	.27	73	.33	.54
Avoidance	.05	.07	07	.19	.48
Depression	.12*	.05	.01	.22	.03

\*significant at p < .05 level

Table 10 shows that depression was the only independent variable which contributed significantly to the prediction of negative symptoms. There was a strong association between depression and negative symptoms in this study, as assessed by Spearman's correlations (rho = .61, p < .001, two-tailed, N = 50). As stated in the introduction, some previous studies have suggested a conceptual overlap between negative symptoms and depression and so it is possible that at least part of this association may be attributable to the same symptoms being identified within both measures.

### 3.4 Additional analyses

As an additional analysis, correlations between self-discrepancy scores (actual-ideal and actual-ought) and anxiety and depression scores obtained on the DASS were considered. Previous research has found an actual-ideal self-discrepancy is associated with depression and an actual-ought self-discrepancy is associated with anxiety (Higgins, 1996; Higgins, Bond, Klein, & Strauman, 1986). Since the anxiety and depression scores on the DASS were not normally distributed and there were a high number of tied ranks for self-discrepancy scores, a non-parametric Kendall's tau test was used. Tied ranks occur when there are a several scores of the same value and so when the data is ranked in order to carry out non-parametric analyses such as Spearman's correlations, several data points will be attributed the same rank value.

Consistent with previous findings for participants without psychosis, a significant correlation was found between depression and actual-ideal self-discrepancy (t = .22, p < .05, two-tailed, N = 48). However, no significant correlation was found between levels of anxiety and actual-ought self-discrepancy (t = .16, ns, two-tailed, N = 48). As expected there was no significant correlation between anxiety and actual-ideal self-discrepancy (t = .12, ns, two-tailed, N = 48) or between depression and actual-ought self-discrepancy (t = .16, ns, two-tailed, N = 48) or between depression and actual-ought self-discrepancy (t = .16, ns, two-tailed, N = 48).

In order to investigate if psychological therapy or counselling received by individuals following the onset of psychosis had an impact on how they had adjusted and coped with their past experiences of psychosis, overall total scores on the IES-R were considered in relation to this variable. The assumptions required for an independent samples t-test were met. No significant difference in trauma symptomatology, as assessed using the total score on the IES-R, was found between those who had received psychological therapy or counselling following their episode of psychosis and those who had not (t(48) = -1.30, ns, two-tailed). The effect of

psychological therapy and counselling on the level of negative symptoms was also considered, but again no significant difference was found (t(48) = -.98, ns, two-tailed).

### 3.5 Summary of results

The sample of participants recruited to the study were representative of a first episode psychosis sample in recovery from their positive symptoms in terms of their demographic characteristics and scores on the PANSS positive subscale. Even though levels of positive psychotic symptomatology were low in the sample, levels of anxiety and depression were relatively high. The sample also showed high levels of trauma symptomatology in relation to the impact of their psychotic episode, with 52% of participants meeting criteria suggesting a diagnosis of PTSD on the IES-R. There was also a high level of previous trauma in the sample, with 94% of participants indicating that at least one traumatic event had been either experienced, witnessed, or they had learned about it happening to someone close to them. Furthermore, 88% of participants indicated that at least one traumatic event had happened to them personally and for 34% of people the traumatic event met criterion A (DSM-IV; American Psychiatric Association, 1994), which is required for a diagnosis of PTSD. Three participants spontaneously identified their experiences of psychosis as a traumatic event. The prevalence of negative symptoms was high in the study with 86% of individuals reporting at least one significant negative symptom. The level of negative symptomatology was comparable with previous studies which have included individuals with schizophrenia spectrum disorders.

The results provide some evidence consistent with the study hypotheses. For example, a significant positive correlation between avoidance relating to experiences of psychosis and

negative symptoms. However, this finding did not remain significant when the effects of depression were partialled out.

When the whole sample was considered, no correlation was found between selfdiscrepancy and the number of psychosis related memories that were recalled. However, when only the participants who had scored above the cut-off of 33 on the IES-R (i.e., those participants who were experiencing clinically significant trauma symptoms in relation to their experiences of psychosis) were considered, a significant correlation was detected. This correlation replicated the findings of Sutherland and Bryant (2008) in a PTSD sample in that a significant correlation was found between both actual-ideal and actual-ought self-discrepancies and psychosis related memory recall in response to positive cue words. Consistent with Sutherland and Bryant, this finding was not replicated for negative cue words. The average self-discrepancy was low indicating that participants' perceptions of their actual-self were generally consistent with how they would ideally like to be or feel they ought to be. However, there was a large range in selfdiscrepancy scores indicating that for some people they did have a discrepant self-concept.

Both self-discrepancy scores and the level of psychosis-related memory recall were not significantly associated with the level of negative symptoms. In a regression analysis considering the impact of avoidance, depression, overall psychosis related memory recall, actualideal self-discrepancy and actual-ought self-discrepancy on negative symptoms, depression was found to be the only significant predictor of negative symptoms.

#### 4. Discussion

# 4.1 Overview

This study aimed to extend psychological knowledge and understanding of negative symptoms of psychosis by assessing the applicability of a model from the PTSD literature. It aimed to investigate the idea that the experience of psychosis can be a traumatic event for some individuals, whether this relates to the psychotic symptoms themselves or the impact and treatment associated with a psychotic episode (e.g., hospitalisation, forced medication, restraint, etc.), in a first episode psychosis sample. The study aimed to repeat a finding from research in more chronic schizophrenia samples, that negative symptoms are associated with the avoidance of traumatic memories of the experience of psychosis. The study then aimed to expand on previous research by testing the applicability of a model relating to trauma-related autobiographical memory recall and self-discrepancy from the PTSD literature to a first episode psychosis sample. It was proposed that there would be an association between a tendency to recall memories relating to experiences of psychosis and a discrepancy in self-concept. Finally, the study aimed to explore whether psychosis-related memory recall and self-discrepancy could be used to predict the level of negative symptomatology seen in individuals recovering from first episode psychosis.

In the following section, the main findings of the research will be summarised in relation to the three study hypotheses and additional analyses that were conducted. The strengths and limitations of the study methodology will then be considered, including the design, sampling, measures used, and analysis. Omissions in the study will be also be highlighted throughout. The results will then be interpreted in reference to current theoretical knowledge of negative

symptoms, trauma, autobiographical memory and self-discrepancy, as outlined in the introduction to this study. Finally, a discussion of the clinical implications of the research will be provided and directions for future research will be offered.

## 4.2 Summary of the findings

Fifty-one individuals with first episode psychosis who were receiving support from Early Intervention Services and Integrated Delivery Teams across East Anglia participated in the study. The participants represented an early intervention first episode psychosis sample from four counties throughout the East Anglian region. The sample represented a heterogeneous group in terms of demographic characteristics and treatment related variables, such as diagnosis and length of time with a service for psychosis. The only exception to this was the ethnicity of the sample, which was mainly white British. Although the sample size was small, and the study was underpowered, there were several significant results which will now be discussed.

### 4.2.1 Participants' scores on the main measures.

The participants in this study represent a first episode psychosis sample in remission from positive psychotic symptoms. This was suggested by the low levels of positive symptoms reported on the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987). However, despite this recovery from positive symptoms, the sample still had relatively high levels of anxiety, depression, negative symptoms, and post-traumatic symptoms in relation to their psychotic episode. The results indicated that 52% of the participants met screening criteria for PTSD on the IES-R, in relation to their experiences of psychosis. This figure is comparable with previous estimates of PTSD in relation to the experience of psychosis, which have ranged between 11% and 67% (Frame & Morrison, 2001; McGorry et al., 1991; Meyer et al., 1999).

The result of psychosis related PTSD in this sample is strikingly similar to that found in a study by Bernard et al. (2006). This study used very similar inclusion criteria (individuals with first episode psychosis who were in the recovery phase of their illness) to the present study and found a comparable rate of psychosis related PTSD of 57%. Consistent with previous research (e.g., Shaw et al., 2002), the lifetime prevalence of other traumas was very high with 94% of participants having either experienced or witnessed a traumatic life event or learned about a traumatic event happening to someone close to them.

Self-discrepancy scores were lower than anticipated (representing less discrepancy between the actual-ideal and actual-ought selves) given that previous research has suggested that the experience of psychosis can have a significant impact upon a person's sense of self (e.g., Birchwood et al., 2000). The mean number of psychosis related memories that were recalled on the AMT was relatively low, but 76.5% of participants did recall at least one psychosis related autobiographical memory. This suggests that autobiographical memories relating to experiences of psychosis are stored and readily recalled for most participants.

The findings related to the three study hypotheses will now be discussed.

# 4.2.2 Findings related to avoidance and negative symptoms (Research Question One)

Previous research (e.g., Harrison & Fowler, 2004) predicted that there would be a significant association between avoidance and negative symptoms in individuals with psychosis. A significant association was found between avoidance relating to experiences of psychosis and negative symptoms. However, this finding did not remain significant when the effects of depression were partialled out. Rates of depression were relatively high in this study and depression was also shown to strongly correlate with negative symptoms. Some of this

association between depression and negative symptoms could be a consequence of the phenomenological overlap that has frequently been commented on by researchers (Siris, 2000) and therefore the symptoms may have been scored on both the SANS and the DASS depression subscale resulting in the two variables not being independent. Another possible explanation is that those participants who were avoiding traumatic memories of psychosis were also more depressed and that depression was leading to this avoidance. Avoidance on the IES-R and the depression subscale of the DASS were found to be highly correlated.

Despite the effects of depression in this result, the initial finding does provide tentative evidence that there may be a relationship between negative symptoms and avoidance relating to psychosis in a first episode sample. However, further research, with a larger sample, looking more closely at the potential relationship between avoidance, negative symptoms, and depression would help to clarify this.

# 4.2.3 Findings related to self-discrepancy and psychosis related autobiographical memory recall (Research Question Two)

Previous research findings with individuals with PTSD (Sutherland & Bryant, 2008) led this study to predict that a similar relationship may be seen in individuals recovering from first episode psychosis. The particular relationship that was predicted was that individuals who showed a high degree of discrepancy between their actual and ideal selves and their actual and ought selves would be more likely to recall memories that were related to their psychotic episode on an autobiographical memory recall task. Consistent with Sutherland and Bryant (2008) it was predicted that this finding might be restricted to the recall of memories in response to positive cue words but not in response to negative cue words. In the overall sample of participants no

significant correlation was found between these variables. However, when the same correlation was performed only considering individuals who reported traumatic symptoms as a consequence of their psychosis, the findings of Sutherland and Bryant were replicated. This suggests that, in a first episode psychosis sample, for those individuals who experienced psychosis as traumatic, a discrepant self-concept is associated with a tendency to recall more psychosis-related memories, but only in response to positive cue words.

However, these findings should be interpreted tentatively. Causation cannot be implied from these correlations and, given that rates of other traumas were high in this study, it is possible that these other traumas may have impacted upon self-discrepancy.

# 4.2.4 Findings related to the relationship between self-discrepancy, psychosis related autobiographical memory recall, and negative symptomatology (Research Question Three)

Finally, an exploratory multiple regression analysis was conducted to investigate whether the tendency to retrieve psychosis related autobiographical memories and discrepancies in selfconcept could be used to predict negative symptoms. Given that it has been proposed that negative symptoms may be a type of trauma response to the experience of psychosis (Stampfer, 1990), it was predicted that variables that have previously been shown to be significant in response to trauma might be related to levels of negative symptomatology. Overall psychosisrelated memory recall and self-discrepancy failed to load significantly into the regression model and therefore are not considered to be useful predictors of negative symptoms. Furthermore, avoidance of traumatic memories related to the experiences of psychosis was also not a useful predictor and depression was found to be the only significant predictor of negative symptoms. Again, this finding should be interpreted with caution since the study had a very small sample size for a multiple regression and depression showed a very high association with negative symptoms in the study. Further research with a larger sample of participants would be helpful. This would also allow a multiple regression analysis with just those individuals who experienced psychosis as traumatic to be conducted in order to establish if relationships between negative symptoms, psychosis related memory recall and self-concept discrepancy are seen in this group.

Before discussing the potential clinical and theoretical implications of these findings, the methodological limitations of the study must be considered. This includes issues related to the design, sampling, measures, and analyses used in the study.

# 4.3 Methodological strengths and limitations

### 4.3.1 Design

The study used a cross-sectional quantitative design using questionnaires and interviews to assess participants at one time point. Participants were all clients from Early Intervention Services (EIS) and Integrated Delivery Teams (IDTs) across East Anglia, and were all in remission from positive symptoms following a first episode of psychosis.

One of the main strengths of this study was that it investigated the possible psychological consequences of experiencing first episode psychosis (FEP) from a novel perspective. The study attempted to use existing psychological models and theories from two separate disorders (FEP and PTSD) to generate new knowledge. The use of a cross-sectional design meant that data was collected at only one point in time and, consequently, the problems of attrition, which often affect longitudinal studies, were avoided. The sample recruited a relatively large, heterogeneous sample of participants using a multicentre approach from regions across East Anglia.

Despite its strengths, there are some important limitations of the chosen design. The main limitation of a correlational design is that it does not allow the investigation of the causal nature of the relationships between the studied variables (Barker, et al., 2002; Coolican, 1999). For example, in a subset of participants who reported their episode of psychosis had a traumatic impact, a relationship was found between psychosis related memory recall in response to positive cue words and self-discrepancy. However, since the direction of causality cannot be inferred from the existence of this correlation it is not possible to conclude if having a more discrepant self-concept leads to a person recalling more memories relating to their psychotic episode or vice versa. Therefore, caution needs to be exercised when interpreting these findings.

Data was collected at a single point in time. This cross-sectional design did not allow for the observation of changes over time. This is especially relevant as there may be important changes over time in trauma symptoms following psychosis. For some individuals the point of assessment might have been too soon after their psychotic episode for PTSD-like symptoms to have developed, whereas for others the traumatic impact of their psychotic episode may have lessened over time. Several participants highlighted this later issue when filling in the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997) commenting that they would have endorsed more items if they had been filling in the questionnaire earlier on in their recovery. If there were no time constraints on the study, a longitudinal design could have been adopted to investigate causal relationships and observe any changes over time in the main study variables.

Several self-report measures were used in this study including the Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995), the Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997), The Life Events Checklist (LEC; Blake et al., 1995), and the Higgins Selves Questionnaire (Higgins, 1987). Reliance on self-report is a potential limitation of 114 the employed design since it has been established (Logan, Claar, & Scharff, 2008) that factors such as social desirability can influence results and that self-reports are susceptible to overendorsement of positive items.

Data collection took place either at participants' homes or at an Early Intervention Clinic. The aim of having flexibility in the assessment location was to facilitate increased participation in the study. However, conducting the research session in a home environment had a number of challenges including inevitable distractions and occasionally other individuals were present during the assessment session which may have potentially biased responding.

The quantitative design that was adopted in this study allowed for the collection of data from 51 participants and meant that the measures were relatively quick and easy to administer. If more time were available, a qualitative or a mixed-method design could have been used which would provide richer and more in-depth data relating to the study variables.

### 4.3.2 Sample

The strengths of the sampling used in the present study included the fact that the inclusion criteria were broad, which allowed for the recruitment of a heterogeneous sample.

The relatively small number of participants, and the fact that the study was underpowered, was a potential limitation. The failure to reach the required sample size of 68, which had been recommended by a sample size calculation, was a consequence of the time constraints in the study and recruitment difficulties. Recruitment was affected by a service redesign in Suffolk, which occurred immediately prior to the commencement of the study. Due

to difficulties with recruitment, two more sites (Essex and Bedfordshire Early Intervention Services) were added to the study in the later stages of the recruitment phase.

In addition to the service related difficulties in Suffolk, recruitment was also affected by a low uptake rate to the study. Only 31% of individuals who were initially identified as eligible for the study by their care coordinator eventually took part. Feedback from care coordinators provided anecdotal information about why participants were either ineligible or not willing to take part in the study. However, because not all care coordinators responded with a reason as to why service users did not participate, and because not all service users specified a reason when asked, it was not possible to provide complete data for reasons for non-participation. Anecdotally, it was observed that many individuals reported having moved on and not wanting to discuss their episode of psychosis. It is possible that this reluctance to participate in the study may have represented avoidance and therefore some of the individuals who decided not to participate might have had high levels of trauma symptoms related to their psychotic episode. This might have biased our sample towards over representing individuals who had made a good recovery in relation to coming to terms with their episode of psychosis and resulted in the traumatic impact of psychosis being underestimated in the sample.

A larger sample size would have increased the power of the study. However, despite the study being underpowered, there were still several significant associations found. The existence of these associations, despite a small sample size, suggests that they are robust.

Although potential participants were initially selected by their care coordinator as eligible for the study, it was ultimately the decision of the service user whether they took part. In this respect the participants who took part were a self-selected sample and potentially might differ, for example in terms of their mental state or demographics, from those who did not choose to participate. Although this potential for self-selection bias is unavoidable in this type of research it is worth considering the type of bias it may have introduced to the study. For example, because the study was introduced to potential participants as a research study looking into factors affecting recovery from psychosis, those who took part might have had strong views about recovery. It is also possible that those who participated were particularly motivated to take part in research or may have had a very positive relationship and good engagement with their EIS or IDT. Service users who did not have good engagement with the service would most likely not have been approached by their care coordinator. It is therefore possible that the recruited sample is not representative of all individuals with first episode psychosis. However, despite these potential biases the majority of the measures used in the study (with the exception of the PANSS, DASS, and AMT) were normally distributed, indicating that participants varied in terms of their symptoms.

Additionally, the exclusion criteria made it difficult to generalise the results of the study to populations of people who are illiterate, unable to speak English, have been diagnosed with a comorbid depressive disorder, have a primary diagnosis of organic disorder or substance abuse, or have had a brain injury.

The demographic data that was collected revealed that the sample was representative of an Early Intervention first episode psychosis sample in the East Anglian region, but not necessarily in the wider UK since there was very little ethnic diversity (92.2% white British). There was a large degree of heterogeneity in the diagnoses of participants in the study which could be considered a strength, allowing the inclusion of the spectrum of presentations of first

episode psychosis that are seen within EIS and providing the opportunity to compare and generalise the results of the study to both other research studies and clinical samples.

#### 4.3.3 Measures

Demographic data and treatment related information was collected in order to assess the representativeness of the sample of participants recruited and also to consider the potential confounding variables on the main study analyses. A potential strength of this study was that it considered the impact of previous psychological therapy on the study variables. Previous research studies in the area have failed to do this (e.g., Harrison & Fowler, 2004). However, although some information was collected regarding whether individuals had received any psychological therapy or counselling since the onset of their psychotic episode, information about the nature of these therapeutic interventions was not routinely collected from participants. Therefore, it was unclear whether participants had received what might be considered a "therapeutic dose" of psychological therapy or not or perhaps might have disengaged from the therapy soon after commencing. It is also possible that any therapy received may have been for other comorbid difficulties such as social anxiety, depression or OCD.

The measures of positive and negative psychotic symptomatology that were used in this study (Positive Scale of the Positive and Negative Syndrome Scale [PANSS; Kay et al., 1987] and the Scale for the Assessment of Negative Symptoms [SANS; Andreasen, 1989]) are widely used in research and clinical practice with individuals with FEP. The SANS is the most widely used and comprehensive measure of negative symptoms. Historically there have been problems defining and assessing negative symptoms (as outlined in the introduction). Therefore, in order to obtain a valid estimate for negative symptoms in the current study, an adapted version of the

SANS was used, excluding item eight ("inappropriate affect") and the attention subscale, since previous research has shown that these items are unlikely to be related to the negative symptom construct (Milev et al., 2005; Peralta et al., 1992; Robinson et al., 2006). The inter-rater reliabilities for both the Positive Scale of the PANSS and the SANS were excellent in the current study suggesting that the two researchers who rated these measures (see Appendix 6 for a description of how data collection was shared with another Trainee Clinical Psychologist) did so reliably. Andreasen (1989) recommends that the SANS should ideally be based on multiple sources of information, for example by also interviewing family members or a care coordinator who works with the participant. The ratings were also made just at one time point and so it is possible that some of the ratings for the observational items (for example, poverty of speech) might not have been representative of how the participant typically is. Rating over a more extended time frame or again seeking information from other sources may have been useful in this regard. However, within the scope of this research study this was not possible.

The measures of cognitive ability used in this study (FAS and digit span) are frequently used with people with psychosis and have good psychometric properties and normative data was available for comparison. Controlling for cognitive ability was a strength of the study since this has often been omitted in previous research (e.g., Harrison & Fowler, 2004). Participants performed relatively poorly on the cognitive tests. Possible explanations for this might be the level of distraction of completing measures in a home environment for some individuals, or the high levels of negative symptoms in the sample might have influenced motivation or verbal fluency as a consequence of alogia.

The DASS is less frequently used with people with FEP and there is limited psychometric data to support its use with this group. However, Huppert et al. (2002) have provided evidence 119

that the DASS has good psychometric properties when used to measure anxiety and depression in individuals with schizophrenia and schizoaffective disorder.

The Impact of Event Scale – Revised (IES-R; Weiss & Marmar, 1997) was used to assess the traumatic impact of first episode psychosis. The overall total score on the measure was used and also the avoidance subscale. The IES-R has been previously used to assess trauma symptoms related to a first episode of psychosis (e.g., Jackson et al., 2004). The measure demonstrates adequate internal consistency and subscale validity and has been widely used in psychosis research (Weiss & Marmar, 1997). In the present study the internal consistencies for the overall scale and the avoidance subscale were both acceptable. The IES-R is not a diagnostic measure of PTSD and therefore can only be used to screen for the probable presence of PTSDlike symptoms. Future studies may benefit from including a diagnostic measure of PTSD, but it was not possible to do this within the present study since this would have resulted in the assessment burden on participants becoming too great.

The Life Events Checklist (LEC; Blake et al., 1995) was used to assess the incidence of previous trauma in the sample. Although not widely used in a psychosis sample, the Clinician Administered PTSD Scale (CAPS; Blake et al., 1995), which the LEC forms part of has been used widely and has good psychometric properties. The LEC alone has also been shown to have good psychometric properties in non-psychosis samples (Gray et al., 2004). By adapting the LEC to include two additional questions ("Did you feel as though there was a risk of death or serious injury to yourself or someone else as a result of the event?" and "Did you experience intense fear, helplessness or horror as a result of this event?"), the impact of previous events could be established in terms of whether they were of sufficient severity to meet DSM-IV criteria for a traumatic exposure (Criterion A1 in DSM-IV; American Psychiatric Association, 1994)

whilst keeping the measure brief and not increasing the assessment burden on participants. When filling in the self-report LEC, some individuals indicated that they were unsure whether to endorse items as having happened to them since they were unsure whether the event was a real event or part of their psychosis. One participant also commented that his family would say the event had not happened and was part of his psychotic experiences but he would say it was a real event. For these participants an "unsure" rating was used and therefore these experiences were not included in the descriptive analyses of previous traumas. Two additional questions were added to the end of the LEC in order to establish whether any events that had occurred were of sufficient severity to meet DSM-IV criteria for a traumatic exposure (Criterion A1 in DSM-IV; American Psychiatric Association, 1994). These questions may have resulted in a potential overestimation of the incidence of trauma in the sample since participants answered this question in response to any traumatic event they either experienced, witnessed, or learned about. Therefore, this must be taken into consideration when interpreting the high levels of past trauma in the sample. Using retrospective self-reports of previous trauma is a potential limitation since such reports may be unduly influenced by a number of factors, including forgetting (e.g., Piolino, Desgranges, Benali, & Eustrache, 2002), depressed mood (Lewinsohn & Rosenbaum, 1987; Wolkind & Coleman, 1983), traumatic amnesia (Feldman-Summers & Pope, 1994; Lewis, 1995), subsequent events (Rovee-Collier, 1990), a need to understand or justify mental illness (Gerlsma, Emmelkamp, & Arrindell, 1990), cognitive impairments (Saykin et al., 1991), or delusional beliefs (Young, Read, Barker-Collo, & Harrison, 2001).

It is possible that some of these factors may have led to either under- or over-reporting of past traumatic events on the LEC in the present study. However, within the ethical, time, and

financial constraints of the study, a more reliable approach such as obtaining collateral information from a family member or a longitudinal follow-up approach was not possible.

The standardised version of the Autobiographical Memory Test (AMT; Williams & Broadbent, 1986) was used in this study. However, instead of categorising memories according to whether they were specific, over-general or omissions, memories recalled were rated according to whether they were psychosis-related or not. This was how the AMT was used by Sutherland and Bryant (2008) in their study of individuals who had experienced trauma. Other than Sutherland and Bryant's study, no other studies have used the AMT in this way and so the reliability and validity of using the measure for this purpose is unknown, particularly in a psychosis sample. However, the study was investigating the applicability of a PTSD model to psychosis and so this method of assessment represented a novel use of the measure since this theory had not been applied to individuals with psychosis before. Memories were rated as psychosis related if they referred to the psychotic symptoms themselves or direct consequences of having experienced psychosis. This latter criteria was difficult to rate for some memories since it was sometimes ambiguous whether a memory was a consequence of a person's psychotic episode or not. In these cases clarification was sought from the participant following the administration of the measure. Ideally, an inter-rater reliability procedure would have been implemented in order to ensure that the ratings on this measure (i.e., whether memories generated related to the person's episode of psychosis or not) were reliable. However, this was not possible within the time constraints of the current study.

The Higgins' Selves Questionnaire (Higgins, 1987) was used to measure selfdiscrepancy. As described for the AMT, this study took a novel approach of applying a PTSD

model to FEP and therefore the Higgins' Selves Questionnaire has also not been widely used in FEP samples. The measure has adequate psychometric properties in other clinical groups.

The study attempted to control for potentially confounding variables such as depression, anxiety, cognitive ability and the presence of past traumas which can be considered a strength of the methodology.

### 4.3.4 Analyses

Given that the study was underpowered, one weakness of performing multiple independent significance tests was that this may have increased the probability of making a Type I error, that is rejecting the null hypothesis inappropriately (Field, 2009).

For some analyses the sample was split in order to compare those participants for whom the experience of first episode psychosis seemed to have a traumatic impact with those for whom it did not. This reduced the sample size further in some analyses. However, despite this reduction in sample size to include only those who scored above cut-off for PTSD symptoms on the IES-R, a significant correlation was still found between psychosis related memory recall in response to positive cues and self-discrepancy (both actual-ideal and actual-ought discrepancy) for hypothesis two. This suggests that this finding is robust. It was not possible to perform a multiple regression analysis with this reduced sample due to the small sample size and the relatively large number of predictor variables.

The study's main strengths and weaknesses were discussed. Overall, considering the above limitations, the results of this study need to be interpreted with some caution. However, despite the described limitations, given the time and financial constraints of this research and the

fact that the study took a novel approach to investigating an area that had not previously been explored, the method provided a useful opportunity to explore the relationships between the negative symptoms of psychosis, trauma, autobiographical memory recall, and self-concept discrepancy. The methodology adopted also attempted to address limitations that had been highlighted in other studies examining negative symptoms, trauma and autobiographical memories (e.g., Harrison & Fowler, 2004) by including measures of anxiety, cognitive ability, therapeutic interventions that the participant received, and other traumatic events that they had experienced.

### 4.5 Theoretical implications

This study only provided tentative agreement with previous research which has concluded that there may be a specific psychological process involved in the relationship between psychosis-related avoidance and negative symptoms (e.g., Harrison & Fowler, 2004). Although a relationship was found between negative symptoms and avoidance, this relationship did not remain significant when depression was considered. Since it was found that individuals who were avoiding traumatic memories of psychosis were also more depressed, and there was a strong correlation between negative symptoms and depression, it may be that depression was responsible for this avoidance and not negative symptoms. Therefore the initial correlation that was found might not represent a true association.

If the findings are more related to depression, the present study would be more consistent with the finding of McGorry et al. (1991) who found no significant association between trauma and negative symptoms by assessing individuals in the early stages of their psychotic illness.

The findings of this study suggest that the experiences of psychosis do appear to be traumatic for some individuals, and the model proposed by Sutherland and Bryant (2008) does appear to be applicable to a subset of individuals recovering from FEP who experienced their psychotic episode as particularly traumatic and are currently experiencing PTSD-like symptoms.

In particular, the findings suggest that participants who reported a self-discrepant image involving both an ideal self and an ought self were more likely to report psychosis related memories in response to a positive cue words. However, there was no significant association between psychosis related memory recall and a discrepant self-image in response to negative cue words. On first inspection this finding seems unlikely since it would be intuitive to assume that negative cue words might trigger more psychosis related memories for people who had a discrepant self-concept. However, Sutherland and Bryant (2008) conceptualise this finding as "perceiving that one is missing desired outcomes after trauma being linked to the trauma experienced". The same principle may apply in first episode psychosis. Sutherland and Bryant illustrate this idea with the following example in PTSD, "an individual who is raped and consequently fears a loss of their sense of safety, may draw on autobiographical memories that involve this rape experience". A comparable example in the present study might be an individual who previously felt threatened as a consequence of a persecutory delusion and, for example, felt unsafe in their own home. This individual might recall autobiographical memories related to these delusions in response to the word "safe" on the autobiographical memory task.

The association seen between the actual-ought discrepancy and a tendency to retrieve more psychosis related memories in response to negative cue words could be described with reference to Janoff-Bulman's (1992) shattered assumptions theory. Given that an experience of first episode psychosis that is perceived as traumatic might shatter an individual's beliefs

regarding their self-worth and world view, it is understandable that that individual's perception of how things "should" be is related to tendency to retrieve trauma-related memories.

The fact that this finding was consistent with findings in the PTSD literature provides further support for the potentially traumatic nature of a psychotic episode and the utility of applying models from the field of PTSD. This study has added to the existing literature by bridging two fields of research from psychosis and PTSD and suggesting that there may be a common cognitive process underlying the two disorders. However, it is important to consider that there may be other important factors underlying this preliminary finding. Processes linking autobiographical memory, self-discrepancy, and negative symptoms may fit within a trauma model. However, they might also fit within a depression and/or self-stigma following mental health difficulties model. Further research is needed in order to further explore these ideas and the mechanisms underlying the preliminary findings of this study.

Although this study has provided interesting initial findings, the psychological processes underlying negative symptoms and traumatic reactions to experiencing first episode psychosis require further investigation. Future research should repeat the study with a larger sample. This would provide more confidence in the tentative findings of the present study. It would also allow more detailed analysis of the relationships between the different variables in this study, for example by using pathway analysis or multivariate statistics to assess any potential relationship between self-discrepancy, psychosis related memory recall, and negative symptoms. Causal relationships could also be investigated since this was not possible in the present study.

#### 4.6 Clinical Implications

The findings of this study have important clinical implications. Firstly, this study has shown that people with FEP report high levels of PTSD and therefore PTSD related to psychotic experience should be routinely screened for in clinical services. Individuals who present with high levels of psychosis related PTSD symptoms should be offered psychological treatments that address the trauma of psychosis and its consequences. Furthermore, interventions targeted at treating traumatic reactions following psychosis should take into account the role of selfdiscrepancy and a bias in autobiographical memory recall towards recalling memories related to the experience of psychosis.

Although participants in this study had recovered from their positive psychotic symptoms, the levels of negative symptoms remained high. Therefore, clinicians should routinely screen for negative symptoms and appropriate psychological interventions should be utilised. Given the tentative findings of this study, such interventions could potentially conceptualise negative symptoms as being related to avoidance of psychosis related memories and therefore interventions could aim to address this underlying avoidance.

Although a mean self-discrepancy was not found in this study, there was a range in scores and some individuals did report a degree of discrepancy in self-concept (i.e., a discrepancy between how they feel they currently are and how they would ideally like to be or feel that they ought to be). For those individuals, cognitive therapy to address maladaptive perceptions of the self may be beneficial, particularly if this self-discrepancy and a negative self-image plays a role in a persistent focus on psychosis related trauma memories, perpetuating a PTSD response.

It is important to remember that not all individuals will experience an episode of psychosis as traumatic and some individuals may actually experience positive changes and post-traumatic growth (PTG, Tedeschi & Calhoun, 1996) following an episode of psychosis. Research from the area of PTG may be helpful in informing interventions with people who do experience psychosis as traumatic. According to Calhoun and Tedeschi (1998), clinicians can facilitate PTG by listening carefully to the individual's descriptions of traumatic events and accounts of how they showed strength in coping with the trauma. Brewin and Holmes (2003) emphasise that it is possible to assist the person in the development of PTG through positive reframing of the individual's beliefs about trauma and its consequences. NICE (2005) guidelines for PTSD recommend that individuals should be given the opportunity to describe their experience in detail as part of treatment. Services should facilitate the disclosure of the traumatic aspects of a psychotic episode and should encourage service users to share their experiences. This could be done either through one to one psychotherapy or via a group intervention.

# 4.7 Conclusions

This study aimed to explore the negative symptoms of first episode psychosis and in particular the idea that negative symptoms might represent a reaction to the traumatic experience of psychosis. The study provided a novel approach to investigating the symptoms of psychosis by bridging the fields of PTSD and first episode psychosis research. High levels of psychosis related trauma symptoms were found within the first episode sample recruited to this study and high levels of other traumatic events were also found. The findings of the study may provide support for the application of a model of post-traumatic stress disorder (PTSD), involving self-discrepancy and autobiographical memory, to individuals with FEP. This model of Sutherland and Bryant (2008) was used to show that there is a significant association between self-concept 128

discrepancy and the tendency to recall memories related to psychosis for a subset of individuals who experience their first episode of psychosis as particularly traumatic. This leads to suggestions how best to work with these individuals clinically and what interventions might be suitable. Inferences from this study are limited by the small sample size which limits confidence in statistical outcomes and it was not possible to make any causal inferences. Future prospective studies could track the changing relationship between self-concept discrepancy and autobiographical memory retrieval. Research with a larger sample size would also allow the relationship of self-concept discrepancy and memory retrieval with negative symptoms to be investigated in more depth.

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#### **List of Appendices**

#### Appendix 1. Measures (copyrighted measures, PANSS, SANS, and Digit Span, not

#### included)

Personal Details Form (demographic information)

COWAT – FAS Verbal Fluency Task

Autobiographical Memory Test (AMT) instructions

Autobiographical Memory Test (AMT) recording sheet

Higgins' Selves Questionnaire

Impact of Events Scale-Revised (IES-R)

Life Events Checklist (LEC)

Depression Anxiety Stress Scale (DASS)

#### Appendix 2. Confirmation letters of ethical approval

Letter of valid application for proportionate review from the NRES Committee West

Midlands - Solihull

Letter of ethical approval from the NRES Committee West Midlands - Solihull Letter of ethical approval for substantial amendment 1 from the NRES Committee West Midlands - Solihull

Midiands - Sonnuli

Letter of ethical approval for minor amendment from the NRES Committee West

Midlands - Solihull

Letter of R&D approval for Norfolk and Suffolk NHS Foundation Trust (NSFT)

Letter of R&D approval South Essex Partnership University NHS Foundation Trust

Letter of access from South Essex Partnership University NHS Foundation Trust

# **Appendix 3. Information Sheets**

Norfolk and Suffolk NHS Foundation Trust

South Essex Partnership University NHS Foundation Trust

# **Appendix 4. Leaflet for care coordinators**

# **Appendix 5. Consent form**

### Appendix 6. Further information about shared aspects of research

(For confidentiality reasons names and telephone numbers have been removed from the information sheet, consent forms, and leaflet for care coordinators)

# Appendix 1. Measures

Gender (please circle):	Male	Female	
Age (in years):			
Ethnicity (please circle):			
1. White			
2. Mixed / Multiple ethr	nic groups		
3. Asian / Asian British			
4. Black / African / Cari	bbean / Black British	l	
5. Other ethnic group (p	lease describe)		
What is your highest level of	educational qualifica	ation?	
1. None			
2. CSEs			
3. GCSEs/O levels			
4. A levels			
5. Degree			
6. Other (Please state			)
Are you working at the moment	t (paid or voluntary)? Y	YES/NO	
If so, is it full-time, part-time or	voluntary?		
What is your job?			
How long have you been attend	ing the EI clinic?		(months/years)
Have you been given a diagnosi	is? (please circle)	YES	NO
If so, what is it?			
How much time has passed s	ince your most recent	t psychotic episo	de (in months)?
What medication are you cur	rently taking? (Name	and dosage)	

**Personal Details Form** 

Have you previously had any psychological therapy or counselling?

If so, can you remember what type of therapy it was?

# From patient notes:

Length of time with the	EI clinic:		(months/years)	
Diagnosis given?	Diagnosis given? YES NO			
What is the diagnosis?				
Current medication and	dosage:			
Previous psychological	counselling:			

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## **COWAT Instruction and Record Sheet**

Say: "I will say a letter of the alphabet. Then I want you to give me as many words that begin with that letter as quickly as you can. For example, if I say "b" you might give me "bad, battle, bed..." I do not want you to use words that are proper nouns such as "Boston" or "Bob". Also, do not use the same word with different endings such as "eat" and "eating". Any questions? Begin when I say the letter. The first letter is F. Go ahead."

Begin timing immediately. Allow one minute for each letter (F, A, S). Say "good" after each one minute performance. If the participant stops before the end of the minute, encourage him or her to try and think of more words.

Write down all words said (even if repetitions or not within rules, these can be discounted at the end) in the order in which they were produced. If repetitions occur that may be acceptable if an alternative meaning was intended (e.g. "four" and "for", "son" and "sun"), ask what was meant by the word after the one-minute period. Include only acceptable words in total.

	nute period. Include only acc	
F	Α	S
-		$\sim$
Total =	Total =	Total =
10101 -	10tal –	10tal –

#### Autobiographical Memory Test (AMT) Instructions

"I am interested in your memory for events that have happened in your life. I am going to show you some words. For each word, I want you to think of an event that happened to you which the word reminds you of. The event could have happened recently or a long time ago. It might be a trivial event or an important event. I also want you to make sure that the memory is for a specific event, so something that happened at a particular day at a particular time. For example, if the word was 'good', it would not be OK to say 'I always enjoy a good party' because that does not mention a specific event. It would be OK to say 'I had a good time at Jane's party' because that is a specific event".

"Let us first try some words for practice" (show cards) enjoy

friendly bold

Allow 60 seconds for each.

Standard prompt – "Can you think of a particular time – one particular event?" When all responses have been collected, each participant will be asked to say how long ago each specific event occurred and this will be rated accordingly on the response sheet.

Auto	obiographical Memory Test (AMT) Reco	n unig St	icci
Latency	Response/s	Time	Psychosis
(seconds)			related? (to
		event	be rated after
			the session)
		Latency Response/s	Latency Response/s Time since

## Autobiographical Memory Test (AMT) Recording Sheet

When all responses have been collected, note the code for time since event for each using the following scale:

1 = up to one week	2 = up to a month	3 = up to $3$ months
4 = up to 6 months	5 = up to a year	6 = over a year

Also rate whether or not the memory is related to the participant's psychotic episode.

1) Please list up to 10 words that describe you:				
1.	1	2	3	4
2.	1	2	3	4
3.	1	2	3	4
4.	1	2	3	4
5.	1	2	3	4
6.	1	2	3	4
7.	1	2	3	4
8.	1	2	3	4
9.	1	2	3	4
10.	1	2	3	4

# Higgins' (1987) Selves Questionnaire

2) Now please circle a number to indicate HOW MUCH you are like this.

5) Flease list up to 10 words that describe now you would ideal	ту шке		e:	
1.	1	2	3	4
2.	1	2	3	4
3.	1	2	3	4
4.	1	2	3	4
5.	1	2	3	4
6.	1	2	3	4
7.	1	2	3	4
8.	1	2	3	4
9.	1	2	3	4
10.	1	2	3	4

# 3) Please list up to 10 words that describe how you would ideally like to be:

4) Now please circle a number to indicate HOW MUCH you are like this.

### 5) Please list up to 10 words that describe how you think you ought to or should be:

	/ · · · · · · · · · · · · · · · · · · ·			
1.	1	2	3	4
2.	1	2	3	4
3.	1	2	3	4
4.	1	2	3	4
5.	1	2	3	4
6.	1	2	3	4
7.	1	2	3	4
8.	1	2	3	4
9.	1	2	3	4
10.	1	2	3	4

6) Now please circle a number to indicate HOW MUCH you are like this.

#### The Impact of Event Scale – Revised

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to YOUR EXPERIENCE OF PSYCHOSIS, how much were you distressed or bothered by these difficulties?

difficulties?	Not at	A little	Moderately	Quite a	Extremel
Any romindor brought healt	all	bit		bit	У
Any reminder brought back	0	1	2	3	4
feelings about it	0	1	2	3	4
I had trouble staying asleep	0	1	2	3	4
Other things kept making me think about it	0	1	2	3	4
I felt irritable and angry	0	1	2	3	4
I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
I thought about it when I didn't mean to	0	1	2	3	4
I felt as if it hadn't happened or wasn't real	0	1	2	3	4
I stayed away from reminders about it	0	1	2	3	4
Pictures about it popped into my mind	0	1	2	3	4
I was jumpy and easily startled	0	1	2	3	4
I tried not to think about it	0	1	2	3	4
I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
My feelings about it were kind of numb	0	1	2	3	4
I found myself acting or feeling as though I was back at that time	0	1	2	3	4
I had trouble falling asleep	0	1	2	3	4
I had waves of strong feelings about it	0	1	2	3	4
I tried to remove it from my memory	0	1	2	3	4
I had trouble concentrating	0	1	2	3	4
Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	0	1	2	3	4
I had dreams about it	0	1	2	3	4
I felt watchful or on-guard	0	1	2	3	4
I tried not to talk about it	0	1	2	3	4

#### Life Events Checklist

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it *happened to you* personally, (b) you *witnessed it* happen to someone else, (c) you *learned about it* happening to someone close to you, (d) you're *not sure* if it fits, or (e) it *doesn't apply* to you. Be sure to consider your *entire life* (growing up as well as adulthood) as you go through the list of events.

Event	Happened to me	Witnessed it	Learned about it	Not sure	Doesn't apply
1. Natural disaster (for example, flood, hurricane, tornado, earthquake)					
2. Fire or explosion					
3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)					
4. Serious accident at work, home, or during a recreational activity					
5. Exposure to a toxic substance (for example, dangerous chemicals, radiation)					
6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)					
7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)					
8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)					
9. Other unwanted or uncomfortable sexual experience.					
10. Combat or exposure to a war-zone (in the military or as a civilian)					
11. Captivity (for example being kidnapped, abducted, held hostage, prisoner of war)					
12. Life-threatening illness or injury					
13. Severe human suffering					
14. Sudden, violent death (for example homicide, suicide)					
15. Sudden, unexpected death of someone close to you					
16. Serious injury, harm, or death you caused to someone else					
17. Any other very stressful event or experience (please state:					

If you have experienced, witnessed or learned about any of the events above:

a) Did you feel as though there was a risk of death or serious injury to yourself or someone else

as a result of the event? YES/NO (Please circle)

b) Did you experience intense fear, helplessness or horror as a result of this event?

YES/NO (Please circle)

#### DASS Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. The rating scale is as follows: 0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time 3 Applied to me very much, or most of the time I found myself getting upset by quite trivial things I was aware of dryness of my mouth I couldn't seem to experience any positive feeling at all I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion) I just couldn't seem to get going I tended to over-react to situations I had a feeling of shakiness (e.g., legs going to give way) I found it difficult to relax I found myself in situations that made me so anxious I was most relieved when they ended I felt that I had nothing to look forward to I found myself getting upset rather easily I felt that I was using a lot of nervous energy I felt sad and depressed I found myself getting impatient when I was delayed in any way (e.g., lifts, traffic lights, being kept waiting) I had a feeling of faintness I felt that I had lost interest in just about everything I felt I wasn't worth much as a person I felt that I was rather touchy I perspired noticeably (e.g., hands sweaty) in the absence of high temperatures or physical exertion I felt scared without any good reason I felt that life wasn't worthwhile

0 Di 1 Ap	Reminder of rating scale: 0 Did not apply to me at all 1 Applied to me to some degree, or some of the time 2 Applied to me to a considerable degree, or a good part of time				
3 Ap	oplied to me very much, or most of the time				
22	I found it hard to wind down	0	1	2	3
23	I had difficulty in swallowing	0	1	2	3
24	I couldn't seem to get any enjoyment out of the things I did	0	1	2	3
25	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
26	I felt down-hearted and blue	0	1	2	3
27	I found that I was very irritable	0	1	2	3
28	I felt I was close to panic	0	1	2	3
29	I found it hard to calm down after something upset me	0	1	2	3
30	I feared that I would be "thrown" by some trivial but unfamiliar task	0	1	2	3
31	I was unable to become enthusiastic about anything	0	1	2	3
32	I found it difficult to tolerate interruptions to what I was doing	0	1	2	3
33	I was in a state of nervous tension	0	1	2	3
34	I felt I was pretty worthless	0	1	2	3
35	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
36	I felt terrified	0	1	2	3
37	I could see nothing in the future to be hopeful about	0	1	2	3
38	I felt that life was meaningless	0	1	2	3
39	I found myself getting agitated	0	1	2	3
40	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
41	I experienced trembling (e.g., in the hands)	0	1	2	3
42	I found it difficult to work up the initiative to do things	0	1	2	3

Appendix 2. Confirmation letters of ethical approval



NRES Committee West Midlands - Solihull

East Midlands REC Centre The Old Chapel Royal Standard Place Nottingham NG1 6FS

Telephone: 0115 8839437

29 April 2013

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Dear Miss Stubbins

Study title:	Investigating the relationship between negative symptoms,
•	autobiographical memory and the concept of self in people
	recovering from psychosis.
<b>REC reference:</b>	13/WM/0196
Protocol number:	N/A
IRAS project ID:	126122

Thank you for your application for ethical review, which was received on 26 April 2013. I can confirm that the application is valid and will be reviewed by the Proportionate Review Sub-Committee on 08 May 2013. To enable the Proportionate Review Sub Committee to provide you with a final opinion within 10 working days your application documentation will be sent by email to committee members.

One of the REC members is appointed as the lead reviewer for each application reviewed by the sub-committee. I will let you know the name of the lead reviewer for your application as soon as this is known.

Please note that the lead reviewer may wish to contact you by phone or email between  $1^{st}$  May 2013 and 8<sup>th</sup> May 2013 to clarify any points that might be raised by members and assist the subcommittee in reaching a decision.

If you will not be available between these dates, you are welcome to nominate another key investigator or a representative of the study sponsor who would be able to respond to the lead 169

reviewer's queries on your behalf. If this is your preferred option, please identify this person to us and ensure we have their contact details.

You are not required to attend a meeting of the sub-committee.

Please do not send any further documentation or revised documentation prior to the review unless requested.

#### **Documents received**

The documents to be reviewed are as follows:

Document	Version	Date
Advertisement	Care Coordinator Leaflet 1	01 April 2013
Advertisement	Team Poster 1	01 April 2013
Covering Letter		24 April 2013
Evidence of insurance or indemnity		15 April 2013
Investigator CV	Dr Joanne Hodgekins	
Investigator CV	Prof. David Fowler	12 November 2012
Investigator CV	Miss Claire Stubbins	
Letter of invitation to participant	1	01 April 2013
Other: The Depression Anxiety Stress Scales	1	01 April 2013
Other: the Impact of Events Scale	1	01 April 2013
Other: Life Events Checklist	1	01 April 2013
Other: Personal Details Form	1	01 April 2013
Other: Scale for the Assessment of Negative Symptoms	1	01 April 2013
Other: COWAT Instruction and Record Sheet	1	01 April 2013
Other: The Autobiographical Memory Test	1	01 April 2013
Participant Consent Form	1	01 April 2013
Participant Information Sheet	1	01 April 2013
Protocol	1	09 February 2013
Questionnaire: Higgins (1987) Seles Questionnaire	1	01 April 2013
REC application		10 April 2013

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

#### Notification of the sub-committee's decision

We aim to notify the outcome of the sub-committee review to you in writing within 10 working days from the date of receipt of a valid application.
If the sub-committee is unable to give an opinion because the application raises material ethical issues requiring further discussion at a full meeting of a Research Ethics Committee, your application will be referred for review to the next available meeting. We will contact you to explain the arrangements for further review and check they are convenient for you. You will be notified of the final decision within 60 days of the date on which we originally received your application. If the first available meeting date offered to you is not suitable, you may request review by another REC. In this case the 60 day clock would be stopped and restarted from the closing date for applications submitted to that REC.

#### **R&D** approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at <u>http://www.rdforum.nhs.uk</u>. There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

#### **Communication with other bodies**

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

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

#### 13/WM/0196Please quote this number on all correspondence

Yours sincerely

AAA

## Maria Morledge Committee Co-ordinator

Email: NRESCommittee.WestMidlands.Solihull@nhs.net

Enclosure:[Further information about REC membership]

Copy to: Mrs Sue Steel Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust



**NRES Committee West Midlands - Solihull** 

East Midlands REC Centre The Old Chapel Royal Standard Place Nottingham NG1 6FS

09 May 2013

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School, University of East Anglia Norwich NR4 7TJ

**Dear Miss Stubbins** 

Study title:	Investigating the relationship between negative
	symptoms, autobiographical memory and the concept
	of
	self in people recovering from psychosis.
REC reference:	13/WM/0196
Protocol number:	N/A
IRAS project ID:	126122

The Proportionate Review Sub-committee of the NRES Committee West Midlands - Solihull reviewed the above application on 08 May 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Maria Morledge

#### **Ethical opinion**

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to

management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

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

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

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

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

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

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

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

#### **Approved documents**

Document	Version	Date
Advertisement	Care Coordinator Leaflet 1	01 April 2013
Advertisement	Team Poster 1	01 April 2013
Covering Letter		24 April 2013

The documents reviewed and approved were:

Evidence of insurance or indemnity		15 April 2013
Investigator CV	Dr Joanne Hodgekins	
Investigator CV	Prof. David Fowler	12 November 2012
Investigator CV	Miss Claire Stubbins	
Letter of invitation to participant	1	01 April 2013
Other: The Depression Anxiety Stress Scales	1	01 April 2013
Other: the Impact of Events Scale	1	01 April 2013
Other: Life Events Checklist	1	01 April 2013
Other: Personal Details Form	1	01 April 2013
Other: Scale for the Assessment of Negative Symptoms	1	01 April 2013
Other: COWAT Instruction and Record Sheet	1	01 April 2013
Other: The Autobiographical Memory Test	1	01 April 2013
Participant Consent Form	1	01 April 2013
Participant Information Sheet	1	01 April 2013
Protocol	1	09 February 2013
Questionnaire: Higgins (1987) Seles Questionnaire	1	01 April 2013
REC application		10 April 2013

# Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

#### Statement of compliance

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

#### After ethical review

#### Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and
- investigators
- Notification of serious breaches of the

protocol • Progress and safety reports

• Notifying the end of the study

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

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website. information is available at National Research Ethics Service website > After Review

# 13/WM/0196 Please quote this number on all correspondence Image: Correspondence

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

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

Yours sincerely

Dr Rex J Polson Chair

Enclosures: review	List of names and professions of members who took part in the
	"After ethical review – guidance for researchers" [SL-AR2]
Copy to:	Mrs Sue Steel Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust

# NRES Committee West Midlands - Solihull

# Attendance at PRS Sub-Committee of the REC meeting on 08 May 2013

## **Committee Members:**

# Present

Name	Profession
Mrs Irene Linder	Assistant Manager, Local Authority – Retired
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management - Vice Chair
Ms Gill Tomlinson	Head of Radiology, Solihull Hospital

### Also in attendance:

Name	Position (or reason for attending)
Miss Leni Smith	Assistant Committee Co-ordinator (minutes)



# **NRES Committee West Midlands - Solihull**

East Midlands REC Centre The Old Chapel Royal Standard Place Nottingham NG1 6FS

Tel: 0115 8839435

08 August 2013

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Dear Miss Stubbins

Study title:	Investigating the relationship between negative symptoms, autobiographical memory and the concept of self in people recovering from psychosis.
<b>REC reference:</b>	13/WM/0196
Protocol number:	N/A
Amendment number:	Amendment 1 09.07.13
Amendment date:	16 July 2013
IRAS project ID:	126122

Thank you for submitting the above amendment, which was received on 06 August 2013. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

#### **Documents received**

The documents to be reviewed are as follows:

Document	Version	Date
Participant Information Sheet	2	09 July 2013
Protocol	2	09 July 2013
Investigator CV	Sian Coker 1	09 July 2013
Advertisement	Poster - 2	09 July 2013
RCG Outcome Letter 060613	1	06 June 2013
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1 09.07.13	16 July 2013
Care Coordinator Leaflet	2	09 July 2013

#### Notification of the Committee's decision



The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

# R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

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

13/WM/0196:

Please quote this number on all correspondence

Yours sincerely

Leni Robson Assistant Committee Co-ordinator

E-mail: NRESCommittee.WestMidlands-Solihull@nhs.net

# **NRES Committee West Midlands - Solihull**

East Midlands REC Centre The Old Chapel Royal Standard Place Nottingham NG1 6FS

Tel: 0115 8839435

27 August 2013

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Dear Miss Stubbins

Study title:	Investigating the relationship between negative symptoms, autobiographical memory and the concept of self in people recovering from psychosis.
REC reference:	13/WM/0196
Protocol number:	N/A
Amendment number:	Amendment 1 09.07.13
Amendment date:	16 July 2013
IRAS project ID:	126122

The above amendment was reviewed on 14 August 2013 by the Sub-Committee in correspondence.

# **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

# **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Care Coordinator Leaflet	2	09 July 2013
Protocol	2	09 July 2013
RCG Outcome Letter 060613	1	06 June 2013
Investigator CV	Sian Coker 1	09 July 2013
Participant Information Sheet	2	09 July 2013
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1 09.07.13	16 July 2013
Advertisement	Poster - 2	09 July 2013

# Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

# R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

## Statement of compliance

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

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

13/WM/0196:

Please quote this number on all correspondence

Yours sincerely

pp:Dr Rex J Polson Chair

E-mail: NRESCommittee.WestMidlands-Solihull@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust Mrs Sue Steel

# **NRES Committee West Midlands - Solihull**

# Attendance at Sub-Committee of the REC meeting on 14 August 2013

Name	Profession	Capacity
Dr Rex J Polson	Consultant Physician - Chair	Expert
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management - Vice Chair	Expert

Copy to:

Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust Mrs Sue Steel



## **NRES Committee West Midlands - Solihull**

East Midlands REC Centre The Old Chapel Royal Standard Place Nottingham NG1 6FS

Tel: 0115 8839425

24 January 2014

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Dear Miss Stubbins

Study title:	Investigating the relationship between negative symptoms, autobiographical memory and the concept of self in people recovering from psychosis.
<b>REC reference:</b>	13/WM/0196
Protocol number:	N/A
Amendment number:	Minor Amendment – addition of 2 NHS Trusts &
	Extension request
Amendment date:	09 January 2014
IRAS project ID:	126122

Thank you for your letter of 09 January 2014, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

#### **Documents received**

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment		09 January 2014
Participant Information Sheet 3	3 (CPFT version)	17 January 2014
Participant Information Sheet	3 (SEPT Version)	17 January 2014
Protocol	2.1	09 January 2014

#### **Statement of compliance**

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

13/WM/0196:	Please guote this number on all correspondence

Yours sincerely

W Rees

#### Wendy Rees REC Manager

# E-mail: <u>NRESCommittee.EastMidlands-Leicester@nhs.net</u>

Copy to: Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust Mrs Sue Steel

# Norfolk and Suffolk

NHS Foundation Trust

Research and Development The Knowledge Centre Hellesdon Hospital Drayton High Road Norwich NR6 5BE

Telephone 01603 421255 E mail: RDofficemailbox@nsft.nhs.uk

Miss Claire Stubbins Department of Psychological Sciences Norwich Medical School University of East Anglia Norwich NR4 7TJ

19<sup>th</sup> June 2013

Dear Miss Stubbins,

#### Re: 2013MH14: Memory and Self-Concept after Psychosis

Thank you for submitting the above project for local research governance approval. I am pleased to inform you that your project has been given full approval and you may begin your research at the following site:

Norfolk & Suffolk NHS Foundation Trust

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research and Development office, at the above address, and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval. **Under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.** 

Any researcher(s) whose substantive employer is not the Norfolk & Suffolk NHS Foundation Trust must have a Letter of Access or Honorary Research contract and evidence of Good Clinical Practice (GCP) training before coming on site to conduct their research in this project. Please note that you cannot take part in this study until you have this documentation. If a Letter of Access / Honorary Research Contract has not been issued – please contact us immediately.

If you have any queries regarding this or any other project, please contact, Tom Rhodes, Research Governance Administrator, at the above address.

The reference number for this study is: 2013MH14, and this should be quoted on all correspondence.

Yours sincerely,

Dr Jon Wilson Deputy Medical Director (Research)



Chair: Gary E Page Chief Executive: Aidan Thomas Trust Headquarters: Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE Tel: 01603 421421 Fax: 01603 421440 www.nsft.nhs.uk





Your research governance approval is valid providing you comply with the conditions set out below:

- 1. You commence your research within one year of the date of this letter. If you do not begin your work within this time, you will be required to resubmit your application.
- You notify the Research and Development Office should you deviate or make changes to the approved documents.
- You alert the Research and Development Office by contacting the address above, if significant developments occur as the study progresses, whether in relations to the safety of individuals or to scientific direction.
- 4. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.
- 5. You comply fully with the Department of Health Research Governance Framework and Trust Research Policies, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.
- 6. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.
- 7. UKCRN Portfolio Studies only: You will make local Trust research team members aware that it is expected that the "first participant, first visit" date should be within 70 days of the full submission for Trust Research Governance Approval, and this date must be reported to the Research and Development office using the email address above. Delay to recruitment due to study-wide developments must be reported to the Trust as soon as possible.
- UKCRN Portfolio Studies only: You will report and upload Trust recruitment to the UKCRN portfolio accurately and in a timely manner, and will provide recruitment figures to the Trust upon request.

#### List of Approved Documents:

Documents	Version	Date
Protocol	1	09.02.13
Patient Information Sheets and Consent		
Participant Consent Form	1	01.04.13
Participant Information Sheet	1	01.04.13
Other Study Docs		
Care Coorinator Leaflet	1	05.03.13
Team Poster	1	05.03.13
Letter of invitation to participant	1	05.03.13
The Depression Anxiety Stress Scales	1	05.03.13
The Impact of Events Scale	1	05.03.13
Life Events Checklist	1	05.03.13
Personal Details Form	1	05.03.13
Scale for the ssessment of Negative Symptoms	1	05.03.13
COWAT Instruction and Record Sheet	1	05.03.13
The Autobiographical Memory Test	1	05.03.13
Higgins (1987) Seles Questionnaire	1	05.03.13



Chair: Gary E Page Chief Executive: Aidan Thomas Trust Headquarters: Hellesdon Hospital, Drayton High Road, Norwich, NR6 5BE Tel: 01603 421421 Fax: 01603 421440 www.nsft.nhs.uk





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25<sup>th</sup> February 2014

Ms C Stubbins Department of Psychological Studies Norwich Medical School University of East Anglia Norwich NR4 7TJ Research Department Pride House Christy Close Laindon Essex SS15 6EA

Tel: 01268 407725 sarah.thurlow@sept.nhs.uk

Dear Claire

# Research Study – The influence of negative symptoms, autographical memory and the concept of self in people recovering from psychosis.

Further to my email of the 4<sup>th</sup> February and subsequent email of 6<sup>th</sup> February, I am pleased to confirm that your research study was reviewed by the Research Governance Group (RGG) at their meeting on 30<sup>th</sup> January and your study was given final approval by Chair's action on the 6<sup>th</sup> February. You will need a letter of access to conduct your research in SEPT and I will send this under separate cover in due course.

The Trust has to meet rigorous standards set by the Department of Health for research governance so your research must be carried out subject to the following conditions:

- The research must be carried out in strict accordance with the protocol submitted and any changes to that protocol must be approved by the University of Essex and SEPT's RGG before the research is undertaken or continues.
- You must report any adverse events/serious untoward incidents relating to this research to me as soon as practicable. I can be contacted by telephone on 01268 407725 or 07940 425856. In my absence, incidents should be reported to Mrs Sarah Browne, the Associate Director of Clinical

Governance & Quality on 01582 708986 or 07813 068871. In addition, you must complete one of the Trust's adverse incident forms and follow the requirements as set out in the Trust's adverse incident reporting policy. A copy of this form must be submitted to **me** as soon as possible. A copy of the Trust's adverse incident reporting policy can be located on the Trust's intranet or alternatively, please contact me and I will be happy to supply you with a copy.

- In cases where the research will take place over a period of more than 12 months, you are required to send to me a copy of the report on the study progress.
- Any research terminated prematurely must be notified to me immediately.
- The full final report from the study should be sent to me within 3 months of final report so that the RGG can consider it. You are also required to supply a summary or abstract of the study that would be suitable for dissemination.
- As a result of the Research Governance Framework for Health and Social Care, the Trust now has an obligation to monitor research being undertaken within the Trust.

You might be required to complete a short questionnaire although this will be no more than once a year. The questionnaire will be completed for you with as much information already known in order to reduce the amount of your time that you have to spend on this. In addition, the Trust is required to randomly select 10% of research studies to be audited. If your study is selected as part of this audit process, you will be notified to ensure your availability.

The RGG, on behalf of the Trust, will revoke or suspend its approval to any research that does not comply with these conditions or where there is any misconduct or fraud.

I would like to reassure you that these conditions are applied simply to ensure that the Trust meets its obligations under the Research Governance Framework for Health and Social Care. Please contact me if I can help with any issues that might arise for you as a result. I wish you every success with your research and look forward to receiving a copy of the study report in due course.

Kind regards

Yours sincerely

Co huld

Sarah Thurlow **Head of Research** 

- Cc: Dr Joanne Hodgekins Academic supervisor
- Cc: Dr Sian Coker Academic supervisor Cc: Mrs Sue Steel Sponsor contact
- Cc: Dr Sarah Cooke Clinical Psychologist, Early Intervention





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26<sup>th</sup> February 2014

Ms C Stubbins Department of Psychological Studies Norwich Medical School University of East Anglia Norwich NR4 7TJ Research Department Pride House Christy Close Laindon Essex SS15 6EA

Tel: 01268 407725 sarah.thurlow@sept.nhs.uk

Dear Claire

### Letter of access for research Research Study – Investigating the relationship between negative symptoms, autobiographical memory and the concept of self in people recovering from psychosis

This letter confirms your right of access to conduct research through South Essex Partnership University NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on the 26<sup>th</sup> February 2014 and ends on 31<sup>st</sup> December 2014 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation.

The information supplied about your role in research at South Essex Partnership University NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation.

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

While undertaking research through South Essex Partnership University NHS Foundation Trust, you will remain accountable to your employer North Essex Partnership University NHS Foundation Trust and the University of Essex but you 190 are required to follow the reasonable instructions of Sarah Thurlow in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any

investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with South Essex Partnership University NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with South Essex Partnership University NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on South Essex Partnership University NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust R&D department on 01268 407725 prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<u>http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf</u>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

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

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research or your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation and the Chair of the Research Governance Approval Group.

Yours sincerely

Co hult

Sarah Thurlow Head of Research South Essex Partnership University NHS Foundation Trust

Cc: Dr Joanne Hodgekins – Academic Supervisor Cc: Dr Sian Coker – Academic Supervisor Cc: Mrs Sue Steel – Sponsor Contact Cc: Dr Sarah Cooke – Clinical Psychologist, Early Intervention, SEPT

#### **Appendix 3. Information sheets**

### **Researcher: Claire Stubbins**

Trainee Clinical Psychologist Faculty of Medicine and Health Sciences Elizabeth Fry Building University of East Anglia, Norwich NR4 7TJ email: phone:



**Participant Information Sheet** 

Memory and Self-Concept after Psychosis v2 LREC Reference Number: 13/WM/0196

We would like to invite you to take part in a research study. Before you decide, we would like to explain why the research is being carried out and what it will involve for you. Please read the following information carefully, and take time to decide whether or not you wish to take part.

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

The aim of this study is to explore some of the reasons that influence people's recovery following a psychotic episode. We are looking into how people react following an episode of psychosis and how these reactions are related to memory and how people view themselves. The study is being carried out as part of a clinical psychology doctorate course at the University of East Anglia under the supervision of Dr Joanne Hodgekins and Dr Sian Coker. This study has been reviewed by the Research Ethics Committee and the Research and Development Department at the Norfolk and Suffolk Foundation Trust, and has received ethical approval.

#### Why have I been invited?

You have been invited as you are currently under the care of the Early Intervention Service, and we think you will be able to contribute valuable information to the study by telling us about your experiences. We are hoping to talk with a number of people (at least 68 participants) across East Anglia.

#### Do I have to take part?

It is up to you whether or not to take part in this study. If you decide not to take part, this will not affect any health care treatment you receive either now or in the future. If you decide to take part and then change your mind, you can withdraw from the study at any time without giving a reason.

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

If you think you might like to take part, you can phone or email Claire Stubbins (see contact details at the top of this page), or you can tell the person who told you about the study (e.g. your care coordinator) that you would like to take part and they will arrange for Claire to phone you. She will discuss the study with you and give you the chance to ask any questions. After that, if you decide to go ahead and take part, you will be asked to meet with a member of the research team (\_\_\_\_\_\_\_ or Claire Stubbins). This can either be at the clinic you

usually attend or at your home, whichever is most convenient for you. You will be asked on the day to sign a consent form to say that you are willing to take part in the study and to let us use the information from the interview and questionnaires for research purposes. You will have plenty of opportunity to ask any questions on the day, or you can phone us or ask your care coordinator prior to the meeting. You will have an interview about your symptoms and experiences of psychosis. You will also be asked to fill in four questionnaires about your thoughts and about events that might have happened to you, and to do some short problemsolving tasks. There is also a short memory interview that we will ask you to complete. The whole process will take about an hour and a half to two hours, and you can take breaks during the interview if you like. There is also the option to split the interview up into two separate sessions if you would prefer. With your permission we will also look in your medical notes to gain further information that is relevant to the study.

#### How will my information be recorded?

We will take written notes during the interview, and the interview will be recorded on a digital audio recorder. This will not happen without your permission.

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

All of the data we collect is stored anonymously, with name and address removed. Written and audio-recorded information will be kept in a locked cabinet on university premises. Information that we enter into the computer will be password protected. Once the study is completed, all the information will be stored in a locked drawer at the University of East Anglia for 15 years, in line with the current policy. All the collected data will be kept confidential, unless you tell us that you would like information shared with your care team. The only exception to this would be if you told us something which suggested that you or someone else could be at a serious risk of harm. In this case we would have a duty to pass this information on to your care coordinator.

#### What are the risks and benefits of taking part?

Your taking part in the study will help us to understand more about the nature of psychosis, which will help us to develop better treatments to help people and improve services in the future. As a thank you for taking part, you will be entered into a raffle to win a £50 Amazon voucher.

It is not expected that there will be any risks to taking part. However, because some of the questions will ask about your current and past experiences, it is possible that you might find parts of the interview upsetting. However, you will not be forced to discuss anything you do not wish to talk about during the assessments. At any point you may stop the assessment without having to give a reason. Support will be available via your care coordinator if you do feel upset following the assessments.

#### What will happen to the results of the research study?

The information collected will be written up as a report, which will be assessed as one of the requirements for our Clinical Psychology Doctorate studies. The results may also be published in a relevant journal. You will not be able to be identified in any of these reports. If you wish to find out about the results of the study, a summary report will be available to you and services involved in the research after the research has finished. If you decide to participate, you can let us know at the session if you want to find out about the results.

#### Complaints

If you have any further concerns about any aspect of the study you should contact Dr Joanne Hodgekins, who is the Academic Supervisor representing the University of East Anglia. Her contact details are:

Dr Joanne Hodgekins Doctoral Programme in Clinical Psychology Department of Psychological Sciences Norwich Medical School University of East Anglia Norwich NR4 7TJ

If you remain unsatisfied and wish to complain formally you can do this by contacting the Patient Advice and Liaison Service (PALS) on free phone 0800 279 2535

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

This research is organised Claire Stubbins who is a Trainee Clinical Psychologist. The research is funded by the University of East Anglia.

#### Has this study been approved?

The study has been reviewed by the Research Ethics Committee (LREC Reference: 13/WM/0196) and the Local Research and Development Department. The study received a favourable ethical opinion and approval.

#### **Further information**

If you would like more information about the study, please speak to your care-coordinator or contact Claire Stubbins on ( ) or email .

Thank you very much!

#### **Participant Information Sheet**

# **Researcher: Claire Stubbins**

Trainee Clinical Psychologist Faculty of Medicine and Health Sciences Elizabeth Fry Building University of East Anglia, Norwich NR4 7TJ email: phone:



#### **Participant Information Sheet**

Memory and Self-Concept after Psychosis v3 (SEPT version) LREC Reference Number: 13/WM/0196

We would like to invite you to take part in a research study. Before you decide, we would like to explain why the research is being carried out and what it will involve for you. Please read the following information carefully, and take time to decide whether or not you wish to take part.

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

The aim of this study is to explore some of the reasons that influence people's recovery following a psychotic episode. We are looking into how people react following an episode of psychosis and how these reactions are related to memory and how people view themselves. The study is being carried out as part of a clinical psychology doctorate course at the University of East Anglia under the supervision of Dr Joanne Hodgekins and Dr Sian Coker. This study has been reviewed by the Research Ethics Committee and the Research and Development Department at the South Essex Partnership University NHS Foundation Trust, and has received ethical approval.

#### Why have I been invited?

You have been invited as you are currently under the care of the Early Intervention Service, and we think you will be able to contribute valuable information to the study by telling us about your experiences. We are hoping to talk with a number of people (at least 68 participants) across East Anglia.

#### Do I have to take part?

It is up to you whether or not to take part in this study. If you decide not to take part, this will not affect any health care treatment you receive either now or in the future. If you decide to take part and then change your mind, you can withdraw from the study at any time without giving a reason.

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

If you think you might like to take part, you can phone or email Claire Stubbins (see contact details at the top of this page), or you can tell the person who told you about the study (e.g. your care coordinator) that you would like to take part and they will arrange for Claire to phone you. She will discuss the study with you and give you the chance to ask any questions. After that, if you decide to go ahead and take part, you will be asked to meet with a member of the research team (\_\_\_\_\_\_\_ or Claire Stubbins). This can either be at the clinic you usually attend or at your home, whichever is most convenient for you. You will be asked on

the day to sign a consent form to say that you are willing to take part in the study and to let us use the information from the interview and questionnaires for research purposes. You will have plenty of opportunity to ask any questions on the day, or you can phone us or ask your care coordinator prior to the meeting. You will have an interview about your symptoms and experiences of psychosis. You will also be asked to fill in four questionnaires about your thoughts and about events that might have happened to you, and to do some short problemsolving tasks. There is also a short memory interview that we will ask you to complete. The whole process will take about an hour and a half to two hours, and you can take breaks during the interview if you like. There is also the option to split the interview up into two separate sessions if you would prefer. With your permission we will also look in your medical notes to gain further information that is relevant to the study.

#### How will my information be recorded?

We will take written notes during the interview, and the interview will be recorded on a digital audio recorder. This will not happen without your permission.

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

All of the data we collect is stored anonymously, with name and address removed. Written and audio-recorded information will be kept in a locked cabinet on university premises. Information that we enter into the computer will be password protected. Once the study is completed, all the information will be stored in a locked drawer at the University of East Anglia for 15 years, in line with the current policy. All the collected data will be kept confidential, unless you tell us that you would like information shared with your care team. The only exception to this would be if you told us something which suggested that you or someone else could be at a serious risk of harm. In this case we would have a duty to pass this information on to your care coordinator.

#### What are the risks and benefits of taking part?

Your taking part in the study will help us to understand more about the nature of psychosis, which will help us to develop better treatments to help people and improve services in the future. As a thank you for taking part, you will be entered into a raffle to win a £50 Amazon voucher.

It is not expected that there will be any risks to taking part. However, because some of the questions will ask about your current and past experiences, it is possible that you might find parts of the interview upsetting. However, you will not be forced to discuss anything you do not wish to talk about during the assessments. At any point you may stop the assessment without having to give a reason. Support will be available via your care coordinator if you do feel upset following the assessments.

#### What will happen to the results of the research study?

The information collected will be written up as a report, which will be assessed as one of the requirements for our Clinical Psychology Doctorate studies. The results may also be published in a relevant journal. You will not be able to be identified in any of these reports. If you wish to find out about the results of the study, a summary report will be available to you and services involved in the research after the research has finished. If you decide to participate, you can let us know at the session if you want to find out about the results.

#### Complaints

If you have any further concerns about any aspect of the study you should contact Dr Joanne Hodgekins, who is the Academic Supervisor representing the University of East Anglia. Her contact details are:

Dr Joanne Hodgekins Doctoral Programme in Clinical Psychology Department of Psychological Sciences Norwich Medical School University of East Anglia Norwich NR4 7TJ

If you remain unsatisfied and wish to complain formally you can do this by contacting the Patient Advice and Liaison Service (PALS) on free phone 0800 013 1223

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

This research is organised Claire Stubbins who is a Trainee Clinical Psychologist. The research is funded by the University of East Anglia.

#### Has this study been approved?

The study has been reviewed by the Research Ethics Committee (LREC Reference: 13/WM/0196) and the Local Research and Development Department. The study received a favourable ethical opinion and approval.

#### **Further information**

If you would like more information about the study, please speak to your care-coordinator or contact Claire Stubbins on ( ) or email ( ).

Thank you very much!



#### Appendix 4. Leaflet for care coordinators

#### What is the research about?

This research is looking into recovery from psychosis, and particularly the negative symptoms of psychosis. Claire and Megan are looking into silghtly different aspects of negative symptoms. Claire is investigating the links be tween negative symptoms, autobiographical memories and people's concept of self, whereas Megan is looking into the relationship between negative symptoms, motivation and social functioning. Claire and Megan are using many of the same assessments in their studies and have therefore combined their assessments into one research session.

However, since these are two separate studies, with separate information sheets and consent forms, individuals can choose to take part in just one of the studies if they would like.

#### What will participants be asked to do?

Once they have consented to take part in the study, participants will be asked to:

Meet up with a researcher for a research session lasting between 90 minutes and 2 hours (this can be split over two sessions if preferred). This can be at their home or an Early Intervention clinic.

- Complete question naires, interviews about symptoms and how people spend their time, a task asking about memories, and some cognitive assessments.
- Participants will be entered into a prize draw to win a £50 Amazon voucher.

#### Who can take part?

We would like to invite people to take part if:

- They are aged between 18-65
   They have been with the Early Intervention Service for 12 months or more
- They are in the recovery stage of their psychotic episode and have no significant positive symptoms at present
- They have a basic level of English language and literacy (in order to complete the questionnaires).

Unfortuna tely people will not be eligible to take part if:

 They have a history of head injury
 They have a primary diagnosis of substance dependence, depressive disorder, or organic psychosis.

# What will I be asked to do as a care coordinator?

As a care coordinator in an Early Intervention Service we would like you to:

- Identify any service users who might be eligible to take part.
- Pass on the information sheets about the research to any individuals who are eligible and interested in taking part.
- Where service users verbally agree to be contacted by the study team, pass on their contact details to Claire and Megan so that they can contact them about the study.

Claire and Megan will visit the Early Intervention Service regularly to remind you about the study and see if there are any service users who are eligible to take part.

If you have any questions about the study please feel free to contact Claire or Megan on the contact details given in this leaflet.

Care coordinator lea flet v2 07.09.13

**Appendix 5. Consent form** 

# PARTICIPANT CONSENT FORM



Memory and Self-Concept after Psychosis v1.0 LREC Reference Number: Researcher: Claire Stubbins, Trainee Clinical Psychologist Email: <u>c.stubbins@uea.ac.uk</u>

# Please read each statement and tick the box beside it if you agree.

1. I have read the Participant Information Sheet (*version and date*). I understand what the study is about and have had a chance to ask questions.

2. I understand that my participation in the study is voluntary and that I can stop taking part at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that my personal information and information I provide about myself will be kept anonymous and confidential. However, if the researcher is concerned for my safety or the safety of others I understand that they are obliged to inform services (e.g. my care coordinator).

4. I am happy for information gained in the study which might help my treatment to be passed on to the Early Intervention team.

5. I consent to my interview being audio recorded.

6. I am willing to let the researcher access my medical notes.

7. I wish to be informed about the results of this study. Please send information to:

8. I agree to take part in this study.

Your name (PLEASE PRINT)

Your signature

Date

Researcher's name (PLEASE PRINT)

Researcher's signature

Date

# Thank you for your time

3 copies required – top copy for researcher, one copy for research participant, and one copy for patient's clinical notes.

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#### Appendix 6. Further information about shared aspects of research

Recruitment and data collection for this research was shared with another trainee clinical psychologist who was also conducting research in the same population. The following tasks were shared equally between both researchers:

- Liaison with clinical teams, including initial contact with team leaders, presentations to teams, and liaison with care coordinators regarding referrals
- Recruitment of participants, including initial telephone calls to explain both studies and arranging research appointments
- Carrying out research sessions with eligible and consenting participants.
   Where participants were willing, written informed consent was obtained for both studies using separate consent forms. Participants could chose to participate in just one of the research studies if they preferred, but all participants chose to take part in both studies. Measures for both studies were conducted within the same appointment by one researcher, so that each participant only needed to meet with one researcher on one occasion to participate in both studies (to minimise participant burden)
- Carrying out research appointments with consenting participants, including gaining informed consent and collecting data using measures for both studies
- Reviewing participants' medical notes following their appointment, and putting consent forms and a brief note about study participation on file
- Scoring and data entry

Both researchers were trained in the measures and familiar with the details of both studies, and a small number of early appointments were undertaken jointly with both

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researchers to enable checks that the assessments were being carried out consistently and accurately. Inter-rater reliability calculations were performed on 20% of the data from the PANSS and SANS measures to ensure that both researchers were rating consistently on these measures. There was considerable overlap in the measures used, and measures for both studies could easily be completed within the same research session which typically lasted 90 minutes to 2 hours.

The additional measures that were completed within research appointments (which are not discussed within this thesis as they were solely for the other trainee clinical psychologist's research) were:

- The General Self-Efficacy Scale (GSES; Schwarzer & Jerusalem, 1995)
- The Brief Core Schema Scales (BCSS; Fowler et al., 2006)
- The Time Use Survey (adapted from Short, 2006)
- The Task Motivation Questionnaire (TMQ; adapted from MacCarthy, Benson, & Brewin, 1986)