

**Exploring Young Peoples' Constructions of a First Episode of Psychosis**

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## **ABSTRACT**

**Background:** Mental health services have been demonstrated to play a key role in shaping how people make sense of their experiences of psychosis. Past research has highlighted the dominance of the biomedical model within services, however, first-person accounts suggest this is not always meaningful or helpful for recovery. Early Intervention in Psychosis (EIP) services aim to provide a more holistic, non-stigmatising approach for young people experiencing a First Episode of Psychosis (FEP). However, there is very limited research exploring how these services might impact upon how young people construct their experiences. This study aimed to explore the culturally available narratives drawn upon by young people accessing EIP services and the consequences of these for service utilisation and subjectivity.

**Method:** Semi-structured interviews were carried out with five young people (aged 18-35) who were accessing an EIP service for a FEP. A Narrative Analysis (NA) approach facilitated exploration of how young people constructed their experiences of a FEP and how they narrated this had changed since accessing the EIP service.

**Results:** The participant's narratives emphasised the idiosyncratic ways they constructed their FEP, drawing on a range of culturally available discourses. While accessing the EIP service appeared to facilitate the exploration of a range of casual theories, often drawing on a biopsychosocial model, their narratives also highlighted the implicit power of the biomedical approach in shaping their sense of self and the future.

**Conclusions:** The findings support previous literature that highlights the importance of meaning-making for young people experiencing a FEP. The discourses available within EIP services appear to play a key role in shaping young people's constructions and this study highlights the value of privileging multiple perspectives when supporting people to make sense of their experiences of psychosis.

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# **1. INTRODUCTION**

## **1.1. Overview**

This chapter explores the ways in which ‘unusual experiences’, or ‘psychosis’, are constructed, and how these might be shaped by culturally available narratives. The role of mental health services in contributing to the sense people make of their experiences is then considered. A review of the literature exploring subjective experiences of a First Episode of Psychosis (FEP) highlights the importance of meaning making for young people’s help-seeking, identity and recovery. A gap in the existing literature is identified relating to how accessing an Early Intervention in Psychosis (EIP) service might shape young people’s constructions of their FEP, at a crucial time for identity development. In light of this, the rationale and research questions for this study are presented.

## **1.2. Literature Review**

Between September 2014 and February 2016, literature searches were conducted across EBSCO databases (Academic Search Complete, CINAHL-Plus, PsycINFO), Science Direct and Scopus. Search terms included “Psychosis”, “First Episode of Psychosis”, “Early Intervention in Psychosis”, “Explanations”, and synonyms such as “Beliefs” “Constructions”, “Discourses”, “Meanings”, and “Narratives”; terms were combined to refine the search. Literature was included based on relevance to the topic, however, qualitative research and peer-reviewed papers were prioritised. Literature focusing on specific diagnostic classifications (i.e. schizophrenia) or ‘psychotic symptoms’ were also included.

See Appendix A for additional details on the search procedure and inclusion and exclusion criteria.

### 1.3. Terminology and Language

There is much debate surrounding the use of labels to describe people who access mental health services (Beresford, 2005). McLaughlin (2009) highlights the risks associated with terms such as 'service users', 'clients' and 'patients' that can homogenise diverse groups. While there is no universally agreed upon alternative, some labels are more aligned to particular conceptualisations of distress (McLaughlin, 2009). In line with much service user activist literature (e.g. Campbell, 2013), the term 'service user' has been used throughout this research, and the term 'unusual experiences'<sup>1</sup> has been used where possible as an alternative to 'psychotic symptoms'.

The literature also uses a wide range of terms when referring to 'constructions' of psychosis depending on the methodological and epistemological approach to research. These include 'understandings', 'beliefs', 'explanations' and 'meanings'. Within this study, these terms are used interchangeably to refer to the narratives people co-construct to attribute causality, talk about, and make sense of unusual experiences<sup>2</sup>.

#### 1.3.1. Psychosis

There are numerous issues in defining 'psychosis' and the term is surrounded by much controversy and debate (Geekie & Read, 2009). One of the most influential conceptualisations of psychosis is provided by the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, now in its fifth edition (DSM-V; APA, 2013). The DSM-V does not define psychosis as a discrete diagnosis, but refers to 'schizophrenia spectrum and other psychotic disorders' including: schizophrenia, schizoaffective disorder, delusional disorder, schizotypal personality disorder, schizophreniform

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<sup>1</sup> 'Unusual experiences' is used to refer to experiences often viewed as outside of consensus reality and not to suggest they are uncommon in the general population.

<sup>2</sup> This study is underpinned by a social constructionist epistemological position, discussed further in section 2.1.

disorder, brief psychotic disorder, and psychosis associated with substance use or medical conditions. Psychosis is also associated with diagnoses such as bipolar affective disorder, psychotic depression, personality disorders and postnatal psychosis (Brewin, 2010; National Health Service, 2014). While psychosis is presented as an umbrella term it is often used interchangeably with diagnostic labels such as schizophrenia, leading to ambiguity around its meaning (Boyle, 2002b; Gray, 2011).

Psychosis<sup>3</sup> is used within this research as an umbrella term for changes in the way a person sees, thinks or understands their world, often perceived as 'out of touch with reality'. Examples of 'unusual experiences' associated with psychosis include hearing voices and seeing, tasting, smelling or feeling things that do not appear to 'objectively' <sup>4</sup> exist or holding strong beliefs that others do not share. Psychosis is also associated with difficulties in thinking and concentrating, and feeling or appearing inexpressive, withdrawn, listless, apathetic or unmotivated (British Psychological Society; BPS, 2014a).

### 1.3.2. First Episode of Psychosis

A FEP is typically defined as the first time an individual has 'psychotic symptoms' (Norman & Malla, 2001). However, this does not acknowledge that experiences such as hearing voices have been widely reported within community populations and may not be subjectively distressing (Beavan, Read & Cartwright., 2011; Murray & Jones, 2012). Thus, in line with the aims of this research and recommendations by Breitborde, Srihari and Woods (2009), a FEP is used to refer to an individual's first access to mental health services with experiences of psychosis.

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<sup>3</sup> The term psychosis is used pragmatically for ease of communication, rather than to reify any one explanation, acknowledging that 'psychosis' is in itself a particular construction of 'unusual experiences'.

<sup>4</sup> In line with a social constructionist epistemological stance knowledge and truth are viewed as social defined (Andrews, 2012).

### 1.3.3. Young People

This study is interested in the experiences of ‘young people’ aged 18-35. This age range is also referred to within the psychology literature as ‘young adulthood’ and associated with particular developmental issues distinct from those faced in early adolescence<sup>5</sup> (Arnett, 2000; Erikson, 1968; UNICEF, 2011).

## **1.4. Research in Psychosis**

The topic of psychosis is extensively researched, however, the majority of studies are quantitative in nature exploring aetiology and medication efficacy (e.g. Conus et al., 2015; Mayoral-van Son et al., 2015). The views of people who have first-hand experience of psychosis have been traditionally neglected, despite the knowledge and expertise they offer for informing service provision and understanding factors related to recovery<sup>6</sup> (Corstens et al., 2014). Since the 1980s there has been some increased attention paid to personal narratives of psychosis (e.g. Bassman, 2001,2012; Chadwick, 2007; de Jager et al., 2015). A key theme arising from this literature is the value many people place on making-sense of their ‘unusual experiences’, often by drawing on various social, psychological, spiritual and biological models. Furthermore, that the explanations and support offered by mental health services are not necessarily meaningful or helpful for personal recovery (May, 2000).

Research exploring how people make sense of psychosis has typically explored ‘causal factors’. Carter, Read, Pyle and Morrison’s (2016) review of this literature suggested that individuals make sense of their experiences in idiosyncratic ways, with implications for help-seeking, service engagement, levels of distress and recovery. However, the authors highlight the limits of the current research base; particularly, the inability of quantitative methods in

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<sup>5</sup> See section 1.6.2.

<sup>6</sup> It is acknowledged that for many people experiences such as hearing voices are valued and the word recovery may not be appropriate.

capturing the complex and fluid nature of people's explanations and the lack of knowledge about what might shape different explanations.

### **1.5. Psychosis and Black and Minority Ethnic Communities**

There is a great deal of literature exploring issues of race, culture and ethnicity in relation to the diagnosis, treatment and experiences of psychosis. People from Black and Minority Ethnic (BME) communities, particularly those from African and Caribbean backgrounds, are frequently reported to be over-represented in diagnostic categories associated with psychosis (Fearon & Morgan, 2006). Morgan and Hutchinson (2010) suggest a number of hypotheses to explain this, higher diagnosis rates of 'psychotic disorders' amongst BME groups. They propose the role of the wider context, including the higher prevalence of experiences of inequality, disadvantage, discrimination, adversity and trauma; all of which have been suggested as risk factors for psychosis (Bechdolf et al., 2010; Karlsen & Nazroo, 2002; Morgan et al., 2008). However, Sharpley, Hutchinson, Murray and McKenzie (2001) argue that misdiagnosis, due to differences in the presentation of distress across cultures, and institutional racism present in mental health services are also key factors that account for these differences.

Research also highlights that people from BME communities often have different experiences of accessing mental health services for psychosis in the United Kingdom (UK) than White British service users. For example, people from African Caribbean backgrounds are reported to experience more adverse pathways to services and significantly higher rates of compulsory detention and treatment (Mann et al., 2014; Morgan et al., 2005). Mann et al (2014) reported marked differences in detention rates for people accessing EIP services, with people who identified as Black African three times more likely to have been detained than their White British counterparts. Mann et al. argued that increased criminal justice involvement and service barriers in pathways to care and help-seeking behaviour may partially explain these differences. Related to this, Keating, Robertson, McCulloch & Francis (2002) have previously highlighted the role of fear and conflict in mental health care in perpetuating the

adverse routes of contact experienced by young males from African and Caribbean communities. They discuss the complex relationship between Black communities and mental health services, underpinned by prejudice, misconceptions, and at times, racism. Keating et al. suggests mental health staff can be wary of the Black community; in particular, young black men, due to generalised fear in the context of stereotypes around Black people as 'dangerous' (Barnes & Bowl, 2001). Furthermore, Black people often describe a fear of services, rooted in a legacy of racism, leading to reduced trust, engagement and help-seeking behaviour, which can result in restrictive and punitive interventions and replicate the experiences of racism and discrimination of people from BME groups in wider society. Consequently, 'circles of fear' are created and perpetuated, the impact of which are likely to have important implications for people from BME communities seeking support for a FEP.

Kalathil and Faulkner (2015) also highlight that while BME communities are arguably the most affected by how psychosis is conceptualised and treated, there is a continuing absence of professional or service user voices from racialised communities in the mainstream literature, such as the BPS (2014) report 'Understanding Psychosis and Schizophrenia'. As a result, differences in how people understand and communicate distress are often described as an issue of culture, potentially resulting in the articulation of cultural difference as 'alien' and the othering of minority or migrant cultures. Kathahil and Faulkner suggest this overlooks the everyday experiences of BME communities that can result in distress and mistrust and the complex relation between racialisation and psychology that underpins much practice within mental health services.

### **1.6. The Narrative Construction of Psychosis**

Experiencing a psychotic episode can result in a 'biographical disruption' in a person's sense of self and life narrative (Barker, Lavender, & Morant, 2011; Lysaker & Lysaker 2002). Narrative structures are viewed as central in shaping the way we interpret our experiences and understand the world (Bruner, 1991; Sarbin, 1986). The process of negotiating meanings is viewed as crucial for maintaining or re-establishing identity and wellbeing, enabling people to weave

together a sense of who they were prior to and following their experiences of psychosis (Roe & Davidson, 2005).

The postmodern turn in psychology acknowledges that making sense of psychosis happens within a social, political and historical context, and individuals draw upon culturally available narratives when constructing their experiences (Burr, 1995; Ricoeur, 1991). Within different contexts there will be 'dominant narratives', presented as more credible, which tend to be more influential in the experience of consensus reality (Ridgway, 2001). Indeed, prominent beliefs about psychosis differ between countries, suggesting the role of culture-specific discourses in shaping personal explanations (Carter et al., 2016). While psychosis is predominantly viewed and treated as a sign of a 'mental illness' in many Western countries, this varies across cultures, where experiences such as hearing voices are also often understood within a spiritual or religious framework and highly valued (Earl et al., 2015; Lim, Hoek & Blom, 2015; Rogers & Pilgrim, 2014). How people construct their experiences in light of dominant narratives is suggested to result in very real effects on people's lives, and how psychosis is viewed and treated within institutions and wider society (Parker, 1992).

While it is beyond of the scope of this chapter to detail the multiple ways in which psychosis has been conceptualised (for this, see Geekie & Read, 2009; Read & Dillon, 2013), it is important to consider what appear to be the most prevalent explanations available.

#### 1.6.1. Dominant Narratives in Mental Health Services

Mainstream mental health services in the UK are underpinned by the 'medical model' (Beresford, 2010). The prevalence of the medical narrative is evident in widely available National Health Service (NHS) mental health service information sheets, describing psychosis in terms of 'disorder' and 'illness' (e.g. National Health Service, 2014) and offering biomedical and biopsychosocial explanations of psychosis:

#### *1.6.1.1. Biomedical explanations*

A biomedical approach to psychosis has traditionally dominated within mental health services (Bentall, 2003; Read, Mosher & Bentall, 2004). This approach views unusual experiences as meaningless symptoms of psychiatric illnesses, most commonly schizophrenia (Georgaca, 2013). Psychiatry has been aligned with the medical model for most of the 20<sup>th</sup> Century, tracing back to early conceptualisations of ‘madness’ influenced by the work of German psychiatrists Emil Kraepelin and Eugene Bleuler, who viewed schizophrenia as a disease of the brain, beginning in adolescence and inevitably developing into a permanent dementia (Read & Dillon, 2013).

Much contemporary research is still driven by a biomedical approach, generating genetic, neurodevelopmental and biochemical theories concerning the aetiology of psychosis (e.g. Bora, 2015; Kendler, 2015). Theories typically focus upon internal deficiencies or abnormalities, to the exclusion of cultural, environmental and interpersonal factors (Deacon, 2013). The continuing strength of belief that schizophrenia is a disease of the brain has been questioned in light of the inability to yield any conclusive results, and the comparably robust findings linking the diagnosis to factors such as adverse life events and family stress (Boyle, 2002a). Conceptualising unusual experiences within a medical paradigm has contributed to the rise of symptom-based diagnostic classification systems, such as the DSM-V (APA, 2013), and facilitated a predominantly medical approach to ‘treatment’ within services, namely the use of anti-psychotic medication aimed at the eradication of ‘psychotic symptoms’ (Adame & Knudson, 2007).

#### *1.6.1.2. Biopsychosocial approaches*

Biopsychosocial approaches (Engel, 1977) suggest distress results from a combination of psychological, social and behavioural factors (Benning, 2015). Since the 1970s, the ‘stress-vulnerability model’ (Garety 2003; Zubin & Spring, 1977), has been highly influential in the practice of psychiatry and psychology, regarding psychosis as a result of predisposing vulnerability factors that interact with environmental stressors. Vulnerability factors include cognitive biases or deficits, emotional difficulties and biological factors of genetic and neuro-

developmental origin (Bramon et al., 2001). Environmental stressors might comprise difficult life events, trauma, hostile environments, social isolation and psychoactive drugs (e.g. Dickson et al., 2016; Kelleher et al., 2013; Rubino & Parolaro, 2014). Research has especially emphasised the role of high expressed emotion in families, and childhood adversity, in particular childhood sexual abuse (e.g. Şahin et al., 2013; Varese et al., 2012).

#### *1.6.1.3. Criticisms of the medical model*

Biomedical explanations of 'unusual experiences' have been extensively critiqued for their lack of validity and reliability, with critics arguing psychotic disorders are not distinct disease categories and overlap with 'normal functioning' (Bentall, 2009; Boyle, 2014). A continuing focus on internal deficits in research and practice is blamed for the maintenance of 'Kraepelian pessimism' and the widespread belief that psychotic disorders are lifelong debilitating diseases (Boyle, 2007; Johnstone, 2009). While a biopsychosocial approach seems to allow consideration of multiple factors in the understanding of psychosis, Boyle (2002, pg. 13) argues that the stress-vulnerability model "firmly maintains the primacy of biology" and does little to explore the meaning of stressful events on the 'vulnerable' individual.

A common aim of the medical approach is to help people to gain 'insight' into their 'illness' (Bentall, 2003; Georgaca, 2013). A 'lack of insight' is viewed as a central feature of schizophrenia and a barrier to recovery, thus limiting opportunities for people to share their alternative explanations (López-Moríñigo et al., 2014). While some people find having a name for their experiences helpful (Craddock & Mynors-Wallis, 2014), psychiatric labels such as schizophrenia and bipolar affective disorder are linked to pervasive societal stigma and discrimination (Perlick et al., 2001; Thomas et al., 2013). Similarly, many people report benefits from taking anti-psychotic medications, however, for others this can lead to a wide range of distressing side effects that can hinder recovery (DiBonaventura et al., 2012). Furthermore, within a biomedical framework, recovery typically means a remission of 'symptoms' for a minimum of two years (Revier et al., 2015). This does not acknowledge that many people value experiences such as hearing voices and does not attend to other aspects

of recovery, such as improvements in functioning in psychological, personal and social domains (Windell, Norman & Malla, 2012).

### 1.6.2. Alternative Narratives

There is a growing body of research that positions unequal power structures, material deprivation and trauma as central in experiences of psychosis (Varese et al., 2012). For example, Wilkinson and Pickett (2010) highlight the role of social inequalities in increasing mental health problems, and Cromby and Harper (2009) describe the link between threatening and insecure environments and persecutory beliefs or 'paranoia'. More recently, alternative conceptualisations of psychosis are gaining precedence within mental health literature and guidelines, as demonstrated by the recent report on psychosis "Understanding Psychosis and Schizophrenia" (BPS, 2014a). This draws upon biological, psychological and social issues to indicate potential causes of unusual experiences. However, it emphasises that there is no "one size fits all" (p.36) and advocates a continuum approach that moves away from diagnosis and the medicalisation of 'normal experiences', suggesting unusual experiences are a natural reaction to adversity (Wiesjahn, 2016).

Progressively, psychiatrists and psychologists view life events, rather than underlying psychopathology, as key in the experience of psychosis (e.g. Bentall, 2009; Johnstone & Dallos, 2013). Consequently, emancipatory approaches are becoming more mainstream, for example, Hearing Voices groups, part of the 'Hearing Voices Network' (HVN), are increasingly found in community and statutory mental health services (Corstens et al., 2014). This approach is based on the work of Romme and Escher (1989, 1993), and promotes the view that hearing voices can be a normal human experience, often precipitated by overwhelming and disempowering circumstances. The HVN explicitly accepts all explanations for unusual experiences (Dillon, 2013), offering potential 'counter-narratives' to dominant conceptualisations of psychosis (Adame & Knudson, 2007).

### 1.6.3. Narratives of Psychosis in the Public Domain

Despite limited research exploring public understandings of psychosis, studies in the UK suggest that people predominantly cite biological and psychosocial causes (Furnham & Chan, 2004), with negative attitudes towards individuals viewed as 'psychotic' consistent over time (Read, Haslam, Sayce & Davies, 2006). Anti-stigma campaigns have aimed to shape constructions of psychosis; the axiom 'mental illness is like any other illness' is increasingly cited by members of the public (The Health and Social Care Information Centre, 2011). While this attempts to reduce negative attitudes, it has been criticised for encouraging essentialist thinking (Malla, Joober & Garcia, 2015). This in turn can exacerbate the media's portrayal of people labelled 'schizophrenic' as unpredictable and violent (Harper, 2008; Knight, Wykes & Hayward, 2006). Dominant cultural explanations of psychosis have real implications, powerful societal narratives shape how people see themselves and, over time, can lead to the internalisation of social stigma and contribute to a 'spoiled identity', with huge implications for an individual's sense of self and their future (Schneider, 2003; Thornicroft et al., 2009).

### 1.6.4. Constructions of Psychosis and Implications for Service Users

Mental health services are deemed to play a crucial role in shaping how people who experience psychosis make sense and talk about their experiences (Carter et al., 2016; McCabe & Priebe, 2004). A growing body of social constructionist research has explored the ways in which narratives or 'discourses' available in services are drawn upon by service users (e.g. Burns & Gavey, 2004; LaFrance & Stoppard, 2006). Much of this research has highlighted the prominence of the medical discourse and how this can have implications for service users' self-management and subjectivities (for a review see Georgaca, 2014).

There are limited studies exploring the impact of accessing mental health services on peoples' constructions of psychosis. However, it has been suggested that individuals' causal beliefs often change to more biomedical explanations in line with those held by mental health professions (Huguelet et al., 2010; Johnson et al., 2012). Terkelsen (2009) carried out ethnographic fieldwork in a Norwegian Psychiatric Unit. Young people diagnosed with

schizophrenia received a psycho-educational intervention, presented within a medical framework, where they were encouraged to accept they were 'ill'. For some, this shaped their view of their experiences, however, others developed strategies to resist the explanations provided; for example, withdrawing from support or discarding medications. Terkelsen argued that a "biomedical psychiatric power-knowledge framework" (2009, pg. 2012) was taken for granted by professionals, yet it had the potential to overshadow service users' experiences, with important implications for service engagement.

The power of the medical model can be also identified within narratives of recovery in psychosis. Thornhill, Clare and May, (2004) identified three broad genres of 'escape', 'enlightenment' and 'endurance' narratives, characterised by the extent to which service users drew upon, or resisted, dominant medical conceptualisations. 'Endurance' narratives were reminiscent of living with a long-term illness, with a focus on managing symptoms, resignation and stoicism, while stories of 'enlightenment' weaved together different narratives into a meaningful account often within a tale of personal growth. 'Escape' narratives encapsulated a desire to avoid the imposition of a certain belief system and maintain an identity separate from a 'chronic psychiatric patient'. This research highlights the role of the medical model in shaping personal narratives, identity and recovery.

### **1.7. First Episode of Psychosis**

Since mental health services play a key role in shaping how people make sense of their experiences of psychosis, there is an ethical responsibility to acknowledge the dominant narratives available in services and the implications of these for people who experience psychosis. This is likely to be particularly key during a FEP, when people are often attempting to make sense of their experiences and accessing mental health services for the first time (National Institute for Mental Health in England, 2008).

### 1.7.1. Prevalence and Impact of First Episode of Psychosis

It has been estimated that there are 32 new cases of people experiencing psychosis per 100,000 people in England per year (Kirkbride et al., 2012). This is higher for people living in densely populated urban areas, especially those with high levels of deprivation or inequality in income (Kirkbride, Jones, Ullrich & Coid, 2014).

People who have experienced a FEP report a gradual change in the way they perceive themselves, others and the world over a number of weeks, months or years prior to accessing mental health services (Yung & McGorry, 1996). FEP has been associated with high rates of depression, anxiety, suicidal ideation and self-harm (Barrett et al., 2010; Chang et al., 2014; Cotton et al., 2012; Harvey et al., 2008). Suicide rates during a FEP are 12 times higher than those in the general population (Dutta et al., 2010), and for people given a diagnosis of schizophrenia, life expectancy can be reduced by up to 25 years (Saha, Chant & McGrath, 2007). This is often due to an increased risk of physical illness, particularly cardiovascular disease, linked to anti-psychotic medication (Correll, Detraux, Lepeleire & De Hert, 2015). Carers, family members and friends of people experiencing a FEP also describe high levels of distress and stigma, highlighting the long term consequences for both individuals and their wider network (Bowman et al., 2014; Revier et al., 2015).

### 1.7.2. First Episode of Psychosis and Young People

The literature suggests 80% of people presenting with a FEP are between 16-30 years old, and the majority of people who experience a FEP will do so by the age of 35 (Kessler et al., 2007; Kirkbridge et al., 2006). Experiencing a FEP between the ages of 18-35, or during 'young adulthood' (Erikson, 1968) is thought to be particularly significant due to the focus on self-development during this period (Harrop & Trower, 2003). High levels of distress and difficulty engaging in everyday activities can have a serious impact on the achievement of 'age appropriate' developmental tasks (McGoldrick, Preto, & Carter, 2015). Within Western society, these might include establishing intimate relationships and peer relationships, individuation from family members and gaining employment or further education (Hagestad, 1990; Zarrett & Eccles, 2006). The

impact of a FEP can result in young people falling behind their peers in these areas, potentially reducing future opportunities and impacting on developing a sense of one's self as an autonomous adult (McGorry, 2000).

The age range 18-35 or 'young adulthood' is also viewed as critical for identity formation (Erikson, 1968; McLean, 2008). Trauma associated with a FEP can be disruptive to this process, with important implications for the way a person perceives their self, the environment and their future (Dunkley, Bates & Findlay, 2015). From a developmental contextualised perspective, beliefs about psychosis within individuals' micro and macro environments are likely to be particularly salient in shaping identities during this period (Adams & Marshall, 1996; Lerner, 1995).

### **1.8. Subjective Experiences of a First Episode of Psychosis**

There is a paucity of qualitative research exploring subjective experiences of people who have experienced a FEP. Published reviews have typically been quantitative in nature (e.g. MacBeth & Gumpley, 2007; Perkins et al., 2005), providing little insight into the views of service users. One exception is Boydell et al.'s (2010) review of 27 qualitative papers in FEP, which highlighted the importance people place on making sense of experiences of a FEP, with mental health services playing a crucial role in this process. Nevertheless, the review included studies with a variety of aims and methodologies across numerous service settings and the views of carers, families and service providers were also explored, potentially minimising the voice of young people.

Since this review, the literature into subjective experiences of young people during a FEP has mainly focused on issues such as recovery (Connell, Schweitzer & King, 2015) help-seeking (Anderson, Fuhrer & Malla, 2013; Barr, Ormond & Dudley, 2015), impact on sense of self (Romano et al., 2010) and trauma (Dunkley et al., 2015). However, the importance of how people understand their experiences continues to be a key theme raised.

## **1.9. Why are Young People's Constructions of a First Episode of Psychosis Important?**

### 1.9.1. Help-seeking

The literature suggests mental health services are commonly viewed as offering a predominantly medical approach and key barriers to help-seeking are fears around receiving a psychiatric diagnosis, and the perceived focus on psychiatric treatment (de Haan et al., 2002; van Schalkwyk, Davidson & Srihari, 2015). Furthermore, accessing support is often delayed due to many young people not attributing their experiences to a mental health problem; leading to confusion about where and how to access help (Judge, Estroff, Perkins & Penn, 2008; Tanskanen et al 2011). Anderson et al. (2013) suggest this is often due to a lack of knowledge or awareness of 'symptoms'. However, young people report seeking support that fits with their conceptualisations, despite knowledge of 'mental illness' (Islam, Rabiee & Singh, 2015).

### 1.9.2. Engagement with Mental Health Services

Young people's understandings of their psychosis affects the personal relevance of the support offered by mental health services. Kilkku, Munnukka and Lehtinen (2003) interviewed seven young people accessing mental health services for FEP in Finland. For some, psychoeducation that explained psychosis as an illness was experienced as normalising and providing relief. However, when this did not fit with personal explanations, the care was experienced as insignificant and confusing. Research also suggests that opportunities to explore personal explanations of FEP are a significant aspect of meaningful support (Anderson et al., 2013; Judge et al, 2008). van Schalkwyk et al. (2015) highlight the potential impact on engagement with services when young people do not feel they are given this opportunity. They interviewed 11 young people accessing an EIP service in the United States of America (USA), who reported their personal narratives were often at odds with the treatment offered by services, contributing to a 'misunderstood storyline'. They described how feeling pushed into taking medication, when this did not fit with their own conceptualisations, led them to consider disengaging.

### 1.9.3. Insight and Distress

Insight can be viewed as a multidimensional construct (Melle & Barrett, 2016), however, it is often defined as the recognition of having a 'mental illness'; compliance with treatment; and the ability to relabel unusual mental events as pathological (David, 1990). Consequently, it requires individuals to subscribe to an illness model of psychosis, problematising alternative beliefs as further signs of 'illness' (Adame & Leitner, 2008). A review of insight and suicidal behaviour in FEP (Melle & Barrett, 2012) highlighted its contradictory association with outcome. High levels of insight have been associated with better treatment adherence, social functioning and work performance (Mintz, Dobson & Romney, 2003; Lysaker, Bryson, & Bell, 2002). However, insight has also been linked to high levels of depression, hopelessness and a lower quality of life (Mintz et al., 2002; Carroll, Pantelis & Harvey, 2004; Hasson-Ohayon et al., 2006).

The disparity in findings suggests that the concept of measuring insight is likely to be too simplistic. Melle and Barrett (2016) suggest 'negative illness beliefs' about the course of the 'illness', or stereotypical attitudes towards the diagnosis of schizophrenia, account for the different ways insight impacts upon young people.

### 1.9.4. Stigma

Medical explanations of psychosis have been reported as helpful by some young people (Barr et al, 2015), however, they have also been linked to feeling devalued in society due to the stigmatising beliefs associated with mental illness (Birchwood et al., 2007). Windell and Norman (2013) found stigma to be associated with perceived loss of social worth and participation. They argued that the construction of 'alternative explanations' for psychosis may be motivated by a wish to reduce the experience of stigma attached to a 'severe mental illness'. This suggests that some people may actively resist medical explanations in an attempt to avoid both felt and enacted stigma (Scambler, 1998). Nevertheless, Islam et al (2015) highlighted that within some cultures, alternative beliefs to the illness model, for example, culturally specific spiritual and religious understandings of psychosis may also be associated with stigmatised attitudes. This emphasises the importance of considering how the

impact of wider narratives might differ based on an individual's sociocultural context.

#### 1.9.5. Recovery

Gaining a meaningful understanding of unusual experiences has been identified as an integral part of recovery in FEP (Romano et al., 2010; Tan, Gould, Combes & Lehmann, 2014) and the integration of a FEP into broader life experiences has been linked to positive outcomes (Thompson, McGorry & Harrigan, 2003; Werbart & Levander, 2005). The re-building of identities has also been proposed as central to recovery in a FEP (Romano et al., 2010). Viewing experiences with an illness framework appears to be associated with the emergence of a less positive sense of self or a 'loss of self' linked to feelings of powerlessness (Connell, Schweitzer & King, 2015; Judge et al, 2008; Windell et al. (2012). Connell et al. (2015) interviewed 12 young people experiencing a FEP in Australia. Participants were interviewed during the first month following the onset of psychosis and three months subsequently. The research suggests that feeling defined by an illness led to self-positions such as 'self as sick' or 'self as dependent' with negative implications for identity and recovery. The study was limited in that interviews were conducted relatively close together and it is unclear how identity may have continued to change over time.

Psychosis often places people in disempowered positions in society (Pitt et al., 2009) and regaining or maintaining a sense of agency over experiences is viewed as an important aspect of recovery (Andresen, Oades & Caputi, 2003; Connell, Schweitzer and King, 2014). Newton, Larkin, Melhuish and Wykes (2007) interviewed eight young people who had attended a Cognitive Behavioural Therapy (CBT) group for hearing voices. Explanations that promoted a sense of agency were those that tended to be situated internally, such as illness or sensitivity to distress. Passive explanations were those caused by an external source, such as supernatural or spiritual entities, contrasting with previous research (Connell et al., 2015; Judge et al., 2008). Newton et al. (2007) suggests that whether explanations are viewed as agentic or passive will depend on individual belief systems and the wider context. The

study also highlighted that young people's explanations may be particularly influenced by the dominant beliefs in their family and social network.

Hope has also been reported to play a critical role for recovery outcomes in FEP. Perry, Taylor and Shaw (2007) found that acceptance of an enduring psychotic illness was associated with loss of hope. However, the search for understanding and meaning in 'unusual experiences' helped young people maintain hope in the early stages of seeking support for a FEP. These findings were supported by Connell et al. (2015), who found young people who expressed hope for the future in the early stages of a FEP were more likely to have developed a personal theory that enabled them to make sense of their experience and incorporate it into a narrative of growth.

#### **1.10. Young People's Constructions of a First Episode of Psychosis**

A small number of qualitative studies have explored how young people make sense of their experiences of a FEP. In line with the broader literature (e.g. Carter et al., 2016), research carried out in New Zealand, the USA and Sweden suggests that young people hold multiple explanations that develop over time, these are often psychological, developmental, biological and spiritual in nature, with individuals holding multiple and seemingly contradictory theories (Geekie, 2004; Judge et al., 2008; Werbart & Levander, 2005). The findings and implications raised by the above studies may be limited in their relevance and generalisability to the UK. One qualitative study exploring personal meanings of FEP was carried out in England by Hirschfield, Smith, Trower and Griffin (2005). Six young men (aged 19-29) explained their experiences using predominantly medical terms, such as 'psychosis', 'illness' and 'schizophrenia', drawing upon psychological and social causal explanations; for example, difficulties gaining employment, early life events, social isolation and cannabis use. The authors suggested that gender-related role development may also influence constructions of FEP, highlighting the need to acknowledge individual factors in how young people talk about their experiences, and to pay attention to both the language and content of people's constructions.

While these studies have explored service users' causal beliefs about their 'unusual experiences', little attention has been paid to the role of context in shaping these constructions. In particular, how mental health services might influence how young people make sense and talk about their FEP.

### **1.11. Early Intervention in Psychosis Services**

EIP services are based on the 'critical period' hypothesis (Birchwood, Todd & Jackson, 1998) that suggests a greater 'Duration of Untreated Psychosis' (DUP) is linked to poorer social and vocational outcomes (Díaz-Caneja et al., 2015; Renwick et al., 2015). In the UK, EIP services were deemed a priority by the Department of Health (DoH) in 2001, following the National Service Framework for Mental Health service plan (DoH, 2000; 2001), aiming to reduce DUP and address widespread criticisms of mainstream mental health services (e.g. Lester, 2004). EIP services have traditionally offered support to people aged 14 to 35 presenting to mental health services with experiences seen as psychotic, beginning in the past three years, and for which they have not yet received treatment (Joseph & Birchwood, 2005; NIMHE, 2008).

EIP services adopt an assertive outreach approach to offering an intensive and youth-sensitive service (Lester et al., 2009; Singh & Fischer, 2007). They attempt to minimise stigma and focus on recovery by addressing biological, psychological and social domains (Marshall et al., 2004). They respond to the critiques of traditional services by practicing 'diagnostic uncertainty'. This takes into account the low predictive validity of diagnosis in FEP (Birchwood, Fowler & Jackson, 2000; Hesline et al., 2015). The stress-vulnerability approach often underpins interventions offered (Bird et al., 2010). For example, antipsychotic medication, CBT, and Family Therapy, as suggested by evidence-based guidelines; however, a range of social, vocational and practical support is typically offered (Kuipers, 2006; National Institute for Clinical Excellence; NICE, 2014).

### 1.11.1 Service User Perspectives on Early Intervention in Psychosis Services

The majority of research with people accessing EIP services has been quantitative in nature, with a focus on rates of 'psychotic symptomatology', 'relapse' and hospital admissions. These outcome studies suggest EIP services decrease the risk of further episodes of psychosis, rates of hospitalisation, and are cost effective (McCrone, Craig, Power & Garety, 2010; Riecher-Rössler & McGorry, 2016). However, low adherence rates to treatment are reported (Lambert et al., 2010), as well as disengagement rates of up to 30% (Conus et al., 2010; Doyle et al., 2014). While one of the central aims of EIP services is to reduce DUP, help-seeking continues to be delayed for people experiencing a FEP with the first point of contact often via crisis teams or acute in-patient services (Tanskanen et al., 2011).

There is minimal qualitative research exploring how young people experience accessing EIP services. Existing studies suggest the collaborative and 'human' approach is valued (O'Toole et al., 2004). The role of choice, hope and a strong therapeutic engagement with clinicians has also been shown to be important (Barr, Ormrod & Dudley, 2015; Lester et al., 2011; Uttinger, Pappmeyer & Riecher-Rössler, 2016). These studies propose EIP services may be achieving their aim of moving away from an 'expert-led' approach (Spencer, Birchwood & McGovern, 2001), however, others suggest dominant conceptualisations of psychosis within services risk impacting on service users' engagement. Bampton (2012) interviewed eight young people (aged 16-25) who were hearing voices and accessing an EIP service. They described feeling undermined or dismissed when sharing personal explanations. Support was experienced as symptom-focused and expert-led, leading some young people to withdraw from services.

### **1.12. Role of Early Intervention in Psychosis Services in Constructions of a First Episode of Psychosis**

Research carried out in an EIP program in Denmark (Larsen, 2004; 2007) highlighted that cognitive behavioural and biomedical explanations of 'mental illness' offered by the service were highly influential in shaping service users'

meaning-making. Moreover, staff typically drew upon two different recovery models, one of 'episodic psychosis' and one of 'chronic schizophrenia', with the latter having a more negative influence on service users' recovery. However, this research is limited in its relevance to UK EIP services, as narratives available within services and wider context are likely to reflect cultural differences.

A study carried out in the UK by Dudley et al. (2009) used q-methodology to ask 21 service users accessing EIP services about their explanations of psychosis. The main factors cited included drug usage, trauma, personal sensitivity and developmental vulnerabilities. Service users held a preference for psychological over biomedical explanations and the most common explanations were those compatible with the stress vulnerability model underpinning EIP services. However, service users were restricted to the choice of three out of 58 pre-operationalised explanations of psychosis, reducing the potential to explore idiosyncratic explanations of FEP or how seemingly conflicting or contradictory explanations might be integrated.

Only one study specifically explored how young people believed accessing an EIP service had impacted on their view of psychosis. Harris et al. (2012) interviewed eight service users (aged 21- 37). They drew upon understandings beyond those offered by the service, including explanations that fit with a continuum view of psychosis (Bentall, 2003), however, they cited the views of their care-coordinators as particularly influential. This study's IPA methodology did not allow attention to the role of dominant narratives in shaping constructions. Additionally, participants were predominantly White British and recruited from one EIP service in the UK. Thus, further research, carried out in diverse settings, is needed to ensure a wider range of perspectives are available.

Duff (2012) explored how EIP staff teams in the UK made use of different discourses to understand clients' presentations and inform treatment decisions. Three dominant discourses; medical, psychological and recovery, were highlighted. A broader discourse of individualism also appeared to locate

problems within service users, neglecting contextual factors and constructing clients as lacking self-agency. This suggests that dominant narratives employed within EIP services may still be similar to those in mainstream mental health services and may have important implications for people accessing services, despite EIP services aiming to take a more pluralistic approach. Yet, further understanding is required into the implications of these for young people and how they construct their experiences in light of the multiple explanations culturally available to them.

### **1.13. Summary and Relevance to Clinical Psychology**

A small but growing body of qualitative research has highlighted that how young people make sense of their experiences of a FEP has important implications for their well-being, help-seeking and recovery (Boydell et al., 2010). However, constructions of FEP are also shaped by dominant narratives available within mental health services (Larsen, 2007). Within EIP services, psychoeducation and the views of clinicians have been cited as particularly influential (Hirschfield et al., 2005; O'Toole et al., 2004). This raises a number of concerns, as dominant medical constructions of psychosis may not necessarily be helpful to all services users and have been associated with high levels of stigma and distress (Melle & Barret, 2012). Additionally, although EIP services aim to move away from the medicalisation of unusual experiences, explanations of FEP provided by EIP services are often not shared by young people, with important implications for engagement (Bampton, 2012). Despite EIP services being offered at the point where meaning-making is seen as crucial (Boydell et al., 2010), little is known about how young people in EIP services construct their experiences of a FEP and the role EIP services may play in this. The small amount of research that has explored this topic has either been carried out in a non-UK context or within generic mental health services (Larsen, 2004; 2007; Terkelsen, 2009). Only Harris et al. (2012) conducted a study with similar aims, but paid limited attention to the role of culturally available narratives in shaping service user's descriptions of their experiences.

The lack of research into this topic may be reflective of methodological challenges raised in interpreting and drawing conclusions from service users' narratives about past experiences. However, approaching this research from a position that acknowledges the socially constructed nature of individuals' accounts offers opportunities to do this in a meaningful way (Willig, 2008). Furthermore, such an attempt is worthwhile considering that raised awareness of more or less meaningful narratives or particularly 'empowering' or stigmatising conceptualisations of a FEP can inform service provision and the ways that young people are supported in meaning-making. Knowledge of the ways young people resist dominant narratives is also likely to be crucial for informing appropriate and culturally equitable interventions. This is particularly relevant to the aims of EIP; of increasing access and engagement, and in light of the low treatment adherence rates often reported (Perkins et al., 2006).

Finally, exploring how young people are positioned through narratives of psychosis can increase knowledge about abuses of power in psychology and the wider context. It can be argued that psychologists play an important role in policing these discursive practices by maintaining and legitimising narratives through their research and practice (Parker, 1997). Consequently, psychologists are well placed to raise awareness of the privileging of certain narratives over others. Along with other mental health professionals, psychologists play a role in scaffolding how young people construct their experiences and identities (Byrne & Swords, 2015). Therefore, there is a responsibility to increase knowledge of how services can support young people to help capture the most helpful and positive idiosyncratic constructions of their experiences (Perry et al., 2007).

#### **1.14. Research Aims**

This study aimed to explore how young people who were accessing an EIP service constructed their unusual experiences labelled a FEP and how they adopted or resisted narratives around psychosis available in EIP services. The study also aimed to understand constructions of a FEP within the wider social

and political context and how these might impact on a young person's subjectivity, experience and service utilisation.

### **1.15. Research Questions**

1. How do young people narrate how they made sense of their 'unusual experiences' prior to accessing an EIP service?
2. How do young people construct their experiences following input from an EIP service?
3. What wider narratives do these constructions draw upon and what subject positionings are subjugated or highlighted as a result?

## **2. METHOD**

This study employs a qualitative methodology to explore how young people accessing an EIP service construct their experiences of a FEP. This chapter addresses epistemological and methodological issues and the rationale for the choice of Narrative Analysis (NA).

### **2.1. Epistemology**

This study adopts a social constructionist epistemological stance (Harper, 2011). There is no single definition of 'social constructionism' and social constructionists take varying positions on 'truth' and 'reality'. These range from 'critical realist' to 'naïve social constructionism' (Burr, 2003; Smail, 2004). Nevertheless, these approaches tend to share several key assumptions (Burr, 2003). They are interested in the 'construction' of knowledge and how this is bound up with power relations. They question taken for granted ways of understanding the world and the view that knowledge is a direct observation of 'reality' (Gergen 1985). Additionally, they are concerned with why some reality claims are seen as more valid than others; viewing these within their social, historical and cultural context (Harper, 2011). Research from a social constructionist perspective attempts to identify the culturally available ways to construct social reality and consider the implications of this for human experience (Willig, 2008).

Taking a social constructionist position does not suggest experiences such as psychological distress do not exist, rather that they are socially constructed within a particular context (Harper, 2011). However, the more 'extreme relativism' of 'naïve social constructionism' has been critiqued for creating a 'moral vacuum' by privileging discourse and potentially obscuring agency and material realities (Nightingale & Cromby, 1999; Smail, 2004). Taking a relativist ontological position raises important issues for the current study. To not acknowledge the embodiment of experiences associated with psychosis, would risk further invalidation of people whose views and experiences are widely discredited. Furthermore, an acknowledgement of how discursive and material

practices inform each other is salient when recognising how dominant constructions of psychosis legitimise certain practices and have real implications for people labelled 'psychotic'.

In consideration of these issues, this research is underpinned by an epistemologically relativist, yet ontologically realist position. This recognises the reality of the agentic subject and the influence of discourse on beliefs and actions (Elder-Vass, 2012; Parker, 1992). Furthermore, within this position, identities are viewed not simply as an embodied self or a fixed characteristic of individuals (Burr, 1999; Schneider, 2003). Rather, they are constructed out of the discourses culturally available, with social structures and material environments playing a constitutive role (Cromby & Harper, 2009; Sims-Schouten, Riley & Willig, 2007).

## **2.2. Methodology**

### **2.2.1. Rationale for Qualitative Method**

Qualitative methodologies are more appropriate than quantitative methods to capture the complex and dynamic nature of how people understand and talk about their experiences of psychosis (Carter et al., 2016). The aim of the current study was not to discover a 'truth' but, rather present a rich and contextualised interpretation of how service users construct their experiences. Therefore, an in-depth qualitative study with a small sample of EIP service users was considered to be the most suitable approach.

### **2.2.2. Rationale for Narrative Analysis**

A Narrative Analysis (NA) was felt to be the most appropriate methodology to explore how young people construct their FEP within the context of an EIP service. Narrative has been suggested to be the organising principle for all human action (Sarbin, 1986) and narrative research can be useful to explore links between meaning, experiences, social structures and culture (Avdi & Georgaca, 2007; Mishler, 1986). How people talk about events in their lives can be described as a form of 'narrative' or 'story' and narratives are viewed as an essential part of meaning-making (Mishler, 1986). It is suggested that the urge

to develop a narrative account is particularly salient following a disruptive, traumatic or exceptional experience, leading to a discrepancy between 'ideal and real' or 'self and society' (Bruner, 1990; Crossley, 2000; Frank, 1993), such as a FEP.

NA can enable an exploration of how people construct their experiences of a FEP and what this means to them by acknowledging the importance of language and lived experience (Willig, 2013). NA recognises that narratives are told in a particular context, with people drawing upon more established narratives to make sense of their world (Harper, 2011). These narratives can be viewed as having real consequences for how people live their lives, in keeping with the epistemological position of this research. Furthermore, individual narratives can lead to insights into wider cultural discourses and rules (Bruner, 1991).

Narrative research has been described as particularly useful for exploring issues of identity and social agency (Somers, 1994); both important considerations in the current research. Narratives can be seen as constructing and constraining certain social identities, influenced by the narrator and the wider context (Ricoeur, 1991). NA encourages the analysis of constructions of self and identity as dialogical and relational and dependant on local interactive practices (McAdams, 2008). Furthermore, as NA attends closely to the co-constructed nature of stories and ensures intersubjectivity and reflexivity are considered (Riessman, 2008), this approach was deemed particularly appropriate for the current study where participants' narratives were co-constructed in the context of an interview with a researcher who may also have been positioned as a mental health professional.

Finally, whilst not the primary goal of narrative research, providing opportunities for participants to narrate their personal experiences can offer therapeutic benefit and lead to possibilities for action (Mishler, 1986). The careful attention paid to individual narratives can also work towards increasing the presence of service users' voices within health care systems, and ensuring 'counter-narratives' are made available to others (Orsini & Scala, 2006).

### 2.2.3. Consideration of Other Methodologies

Several qualitative approaches could be seen as compatible with the aims and epistemological position of this research. In particular, Interpretive Phenomenological Analysis (IPA) and Discourse Analysis (DA) were considered (Harper, 2006; Willig, 2008).

#### 2.2.3.1. *Interpretive Phenomenological Analysis*

NA and IPA are both interested in people's narratives, how experiences are understood and interpreted, and pay attention to the importance of language (Crossley, 2007). IPA aims to develop an in-depth understanding of individuals' lived experiences and how people assign meaning to these (Smith & Osborn, 2008). IPA attempts to come as close as possible to an individual's experiences and holds a distinct epistemological position drawing on phenomenology, hermeneutics and ideography (Griffin & May, 2012). This position suggests that it is possible to access an individual's cognitive inner world through careful and explicit interpretative methodology (Smith, Flowers & Larkin, 2009). Consequently, IPA gives greater precedence to internal, or 'real' subjective experience, whereas, NA is more concerned with how people draw upon or construct narratives to interpret the world (Frost et al., 2010), which is more in keeping with the research questions and assumptions of the current study.

#### 2.2.3.2. *Discourse Analysis*

Among the predominant approaches to DA are Discursive Psychology (DP) and Foucauldian Discourse Analysis (FDA) (Harper, 2006). FDA is concerned with 'mechanisms of power', and the role of language in forming how objects are constructed and positioned in society (Foucault, 1988). FDA was deemed appropriate to facilitate an analysis of the reproduction of knowledge about psychosis through discourses and social practice. However, it can be argued that NA allows the researcher to stay closer to service user narratives, drawing on multiple theories informed by the data, without necessarily subscribing to a predetermined 'lens' (Murray, 2008). Furthermore, discursive approaches, such as FDA, have been critiqued for emphasising language and context to such an

extent that the importance of the self is diminished (Augoustinos & Walker, 1995). Crossley (2007) argues NA enables the appreciation of linguistic and discursive structuring of 'self' and 'experience', whilst also maintaining a stronger sense of individual subjectivity.

While FDA facilitates a more 'macro-level' analysis of discursive resources, DP focuses on the 'micro-level' of discursive practices and considers the performative qualities of discourse (Holt, 2011). DP can explore "how people use discursive resources in order to achieve interpersonal objectives in social interaction" (Willig, 2008, p. 95). Therefore, DP can be particularly useful to explore how speakers manage issues of stake and interest. However, Willig (2013) highlights that while DP emphasises the role of language in context, this typically focuses on the researcher's speech in the immediate setting, rather than the wider material and social environment.

In consideration of the above issues, NA was a preferred approach as it can combine both micro and macro perspectives when interpreting data. For example, NA views individual subjectivity as a product of discourse, whilst also recognising that individuals produce and resist discourse (Burkitt, 1999). Emerson and Frosh (2004) argue that NA is particularly useful for integrating and exploring the relationship between subjective meaning-making and social processes in the construction of personal narratives (p.9). Such issues are central to the topic and aims of the current study.

In addition to the above issues, NA differs from other forms of qualitative analysis such as DA, IPA, Grounded Theory (GT) and Thematic Analysis (TA), in the tendency to keep individual narratives 'intact' for interpretative purposes, rather than coding data and contrasting themes across participants' accounts (Riessman, 2008; Willig, 2013). Riessman (1993) argues that NA avoids fragmenting the data to the same extent as other approaches, and therefore, both the context of what has been said, and the narrative flow, can be better preserved (Coffey and Atkinson, 1996; Riessman, 1993). This was deemed particularly salient for the current study due to the acknowledgement of the co-constructed nature of the participants' narratives. Furthermore, NA offers an

approach whereby each participant's stories can be analysed and presented individually, and the temporal structure of participants' narratives attended to (McAdams, 2008). Consequently, NA appeared to be the most appropriate approach to explore about how participants' constructed their experiences and how this may have changed over time.

#### 2.2.4 Narrative Research and Systemic Practice

The turn to language and narrative in the social sciences has influenced not only approaches to research, but also psychotherapy, in particular, systemic psychotherapies and narrative therapy (White & Epston, 1990; Lax, 1992). For example, Narrative Therapy is aligned with social constructionist and postmodern discourses and views problems as existing in, and mediated through, language (Anderson & Goolishian, 1990). Narrative Therapy aims to offer a space for the re-authoring of personal narratives, which is believed to offer possibilities for change for peoples' lives, problems and identities (Burck, 2005). Systemic approaches that draw on the narrative metaphor (Sarbin, 1986) are typically not aligned to positivist or naïve realist epistemological assumptions. Thus, evaluating systemically informed psychotherapy can present epistemological and methodological challenges for researchers. For example, Roy-Chowdhury (2015) argues that while the Randomised Control Trial (RCT) has been positioned as the 'gold standard' for providing evidence about the effectiveness of psychotherapy, research that enables an analysis of talk and interactions in line with a social constructionist epistemology, such as DA approaches and NA, may be better placed to explore the practice and effectiveness of systemic psychotherapy (Burck, 2005; Roy-Chowdhury, 2015).

Qualitative research situated in the social constructionist paradigm (Guba & Lincoln, 1994), such as NA, acknowledges that the relationship between the researcher and the participants will affect the production of the research material, similar to the emphasis in systemic therapy on the contributions brought forth by therapists in therapeutic sessions (Fine, 1994). Consequently, the attention paid to the co-construction of talk in therapy, can allow exploration of how the therapist draws upon their own world view and dominant social and cultural discourses in a particular interaction, perhaps illuminating aspects of

therapy such as the quality of the therapeutic relationship, which are likely to be overlooked by research underpinned by positivist assumptions (Roy-Chowdhury, 2015).

### **2.3. Researcher Reflexivity**

Reflexive engagement is required on the part of the researcher to ensure consideration of their experiences, assumptions and values and the ways in which these may have impacted upon the research process (Langdrige, 2007). Within this research, young people's narratives are viewed as co-constructed with the researcher within a particular context; this will be further attended to in the 'analysis' section (Riessman, 2008; Stephens & Breheny, 2013). Therefore, it is important to reflect here on my position as a Trainee Clinical Psychologist (TCP) and how my experiences, beliefs and interest in this topic may have shaped this research.

My experience of Clinical Psychology training has been underpinned by critical approaches to distress. The role of context, rather than individual pathology, has been discussed extensively throughout training, and has resonated with me. Furthermore, I have experience of working with people who have been given a diagnosis of a 'psychotic disorder', and my experiences have led me to question the usefulness of dominant discourses within mental health services. However, it has also highlighted that the implications and influence of these appear to vary hugely across individuals. These experiences would have had an impact on my focus of attention during interviews and interpretation, and played a key role in the design of this study.

Across all of the narrative interviews, it is also important to consider that participants were aware of my role as a TCP. As a mental health professional, this may have limited what experiences participants felt they were able to share or the language used in describing these. Furthermore, interviews were carried out at the EIP service for participant convenience. This may have led to associations between me and the EIP team. While every effort was taken to explain confidentiality and attend to issues of power, discussing experiences or

beliefs that might be viewed by mental health professionals as 'lacking insight' or 'not engaging with care' may have raised concerns for participants.

It is also important to reflect that difference and similarities between myself and participants such as gender, age and culture and difference may also have privileged certain discussions or potentially censored others. I have reflected further on these issues and my personal interests for this topic in section 4.4.1. and Appendix B. Peer and formal supervision was made use of to consider my personal influence on the study and a reflective diary was kept throughout the research process (Appendix C).

## **2.4. Consultation**

Consultation meetings with three clinicians working in different EIP services were carried out to discuss the design of the study. This highlighted potential difficulty in recruiting young people accessing EIP services, and led to suggestions around practical arrangements, such as where to hold interviews. Consultation also informed the interview questions and decisions made around inclusion criteria, discussed below.

## **2.5. Participants**

### **2.5.1. Inclusion Criteria**

1. *Individuals aged between 18 and 35 years of age* - This age group was of particular interest, as it is often reported as the most common age group accessing EIP services in the United Kingdom (e.g. Greenfield et al., 2016). Furthermore, how young people aged 18-35 make sense of their FEP was felt to be particularly salient in light of the different developmental challenges associated with this age group, which differ from those faced in early adolescence (Arnett, 2000).
2. *Services users who have been accessing an EIP service for a FEP for between six months and three years* - It was hoped that this time frame would facilitate the recruitment of young people who could recall how

they made sense of their experiences prior to their contact with EIP, but had been accessing an EIP service for several months, and thus may be more likely to have had opportunities to discuss their experiences with mental health professionals.

### 2.5.2. Exclusion Criteria

With the aim of prioritising participant well-being, service users who were experiencing high levels of distress, presenting with significant risk issues, or deemed not to have capacity to consent, were not included in the study. Non-English speakers were excluded for methodological reasons, due to the additional complexities arising in analysis when considering the role of interpreters in the co-construction of narratives (Ditton & Lehane, 2010). This is recognised as a limitation of this research. Suitability to take part in the study, based on the exclusion criteria, was determined in the first instance by the EIP clinicians involved in the young person's care. A further risk and capacity assessment was undertaken by the researcher prior to interview.

### 2.5.3. Participant Demographics

Basic demographic details are presented with the aim of preserving the anonymity of participants. While specific diagnoses were not viewed as necessary for the inclusion criteria of this study, these are presented here to provide methodological context.

**Table 1: Participant Demographics**

Name	Gender	Age	Ethnicity	Religion	Approximate Age of FEP	Length of Time Accessing EIP	Current Diagnostic Label
Leo	Female	24	Black-British	Protestant	23	1 year 2 months	'Paranoid Schizophrenia'
Shoma	Female	22	British-Asian	Muslim	20	11 months	'Psychotic Disorder'
Frank	Male	31	Black-British	Roman Catholic	27	2 years 8 months	'Drug induced Psychosis'
Jade	Female	28	Black-British	Atheist	24	3 years	'Bi-Polar Affective Disorder'
Joseph	Male	35	Black-British	Atheist	31	3 years	'Paranoid Schizophrenia'

#### 2.5.4. Sample Size

A small sample of five participants was deemed appropriate for the research questions and methodology employed. There are no exact guidelines about the number of participants that determines an adequate sample size for qualitative research (Baker & Edwards, 2012). However, Baker and Edwards suggest this will depend upon the theoretical and epistemological underpinnings of the study, the population under study and any practical limitations. As discussed, the aim of the study was not to present generalisable findings but rather to provide an in-depth contextualised analysis, this would likely have been compromised with a larger sample size given the scope of the current study (Potter & Wetherell, 1987).

It is widely recognised that a small sample is appropriate for qualitative research employing a narrative analysis, which requires richness and depth of analysis to answer research questions and the prioritising of data quality over quantity (Hancock, Ockleford & Windridge, 2009; Kvale, 1996). Smith et al. (2009) argue that interview research that has an idiographic aim requires a sufficiently small

sample size to allow for an intensive analysis and to ensure each individual cases has a locatable voice within the study. Smith et al. (2009) suggest a rough guide of between four and ten interviews for Professional Doctorate research using IPA, which has similar idiographic commitments to the current study. Recruiting five participants ensured individuals within the sample could be given a defined identity, whilst also providing scope for exploring any cross-case generalities (Robinson & Smith, 2010).

## **2.6. Procedure**

### **2.6.1. Recruitment**

A purposive sampling method was employed to recruit participants from London-based NHS EIP services. This sampling method was deemed appropriate to identify people aged 18-35 years accessing a who met the inclusion criteria for the study. Lead clinicians from three EIP services were contacted to discuss the aims of the study, and were provided with the research proposal. Following approval, the research was presented at team meetings or to individual clinicians in each team. It was requested that clinicians distribute the participant information sheet to service users who met the inclusion criteria detailed above.

An identified clinician at each team agreed to collate the details of any service users interested in participating. This resulted in the recruitment of five participants, all accessing the same EIP service<sup>7</sup>. Participants were provided with the researcher's contact details to discuss any questions regarding the study. Clinicians agreed a convenient time for meeting with potential participants to discuss the research further and conduct the interviews, where agreed. This was typically prior to, or following, a regular appointment at the EIP service to minimise any inconvenience.

Participants were recruited from an EIP service that offered support for people aged 14-35, for up to five years. The service was typical of many EIP services,

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<sup>7</sup> Discussed further in section 4.3.1.1.

providing a range of interventions including medication, social activities, employment support, support groups and psychological therapy, predominantly CBT and family therapy. The service is situated in an inner-city borough of London which has an ethnically diverse population.

### 2.6.2. Materials

The resources required to carry out the research included a password protected computer, an encrypted USB device, a private room for interviewing and audio recording and transcription equipment.

## **2.7. Data Collection**

### 2.7.1. Interviews

Data was collected through individual semi-structured interviews lasting approximately 60 minutes. Interviews were carried out in a private room at the EIP service and were audio-recorded for subsequent transcription.

Individual interviews were deemed appropriate for eliciting narrative accounts. In NA the requirement for researchers to build “openness and trust” with interviewees is seen as key (Marshall & Rossman, 2006, p.118). Individual interviews can offer a space that enables rapport building, potentially facilitating talk that may be inhibited within other contexts, such as a group. Riessman (2008) argues that the set-up and style of the interaction are crucial for the development of the NA interview. I explained that extended accounts were welcomed, and attempted to ensure participants felt listened to attentively, whilst also giving neutral responses and avoiding interrupting participants’ speech (Wengraf, 2001).

Semi-structured interviews are often recommended in narrative research, in particular when addressing a particular event or topic rather than gathering a life history (Given, 2008; Langdridge, 2007). The interview schedule attempted to guide questioning in light of the aims of the research, however, the specific questions and the order in which they are asked were drawn upon flexibly, influenced by participants’ responses (Parker, 2005).

### 2.7.2. Development of the Interview Schedule

The semi-structured interview schedule (Appendix D) was informed by the research questions. It aimed to elicit narratives about young people's experiences that led up to them accessing an EIP service, how they made sense of their FEP, whether this had changed over time, what they felt might have influenced this and their experiences of accessing an EIP service. Terminology such as 'psychosis' or 'mental health' was not used unless first drawn upon by participants, instead, questioning attempted to be curious and non-directive.

The development of the schedule was also influenced by salient issues identified in the literature review and consultation with clinicians working in EIP services. This highlighted that the majority of young people were likely to have accessed acute mental health services prior to EIP and for this to be considered when exploring conversations young people may have had with mental health professionals.

## **2.8. Ethical Considerations**

### 2.8.1. Informed Consent and Protection of Participants

The participant information sheet was provided to all participants by clinicians in the EIP service (Appendix E). When meeting with potential participants, I ensured that they had read the information sheet and understood the interview process and any potential risks involved. Prior to interview, all participants were asked to read and sign the consent sheet (Appendix F). Demographic details were gathered from participants before and during the interview, and consent was obtained to liaise with care-coordinators regarding length of time in the service and any formal diagnoses when this was unknown.

In light of the potentially emotive nature of the research topic, steps were taken to avoid and reduce any distress caused during or following interviews. Participants were informed of their right to withdraw from the study at any point,

or re-schedule interviews and take breaks as required, without any consequences for their treatment in the EIP service. Participants were reminded that they were not obliged to discuss any information that they did not feel comfortable sharing. The limits of confidentiality as described in the consent form were reiterated; this included the sharing of information in the event that the researcher became concerned about the safety of the participant or another person. In the event of participants becoming distressed, a plan of who to contact in the team was discussed prior to interview.

Following the interview, participants were invited to discuss any additional questions or concerns during a debrief. Participants were provided with the researcher's contact details should they require any further information about the study. Options for signposting for further support had been considered and prepared in the event of any participants becoming distressed.

#### 2.8.2. Confidentiality and Anonymity

All participant details were anonymised and kept confidential in accordance with the Data Protection Act (1998). Audio-recordings were transferred to a password protected computer following interview, and subsequently deleted from the audio recorder. Pseudonyms were used during transcription and any identifying information was changed to ensure anonymity. Interview data and any information relating to participants was stored securely on an encrypted USB device and an encrypted file on a password protected computer. Confidentiality has been preserved within interview extracts and participants were informed that interview transcriptions may be kept securely for up to three years before being destroyed.

#### 2.8.3. Payment of Participants

Participants were offered a £10 high street voucher as a token of gratitude for taking part in the research. Ethical considerations when offering a monetary gift were considered carefully (e.g. British Psychological Society, 2014b; Grant & Sugarman, 2004). This remuneration was deemed of an appropriate value for the participant age group but not of a substantial enough value to risk coercion.

#### 2.8.4. Ethical Approval

Ethical approval was obtained from the UEL School of Psychology Research Ethics Sub-Committee (Appendix G), the NHS Research Ethics Committee (Appendix H) and Research and Development approval for East London Foundation Trust (Appendix I).

#### **2.9. Feedback of Results**

A summary of the research findings will be provided to research participants and clinicians at the participating EIP service.

#### **2.10. Analytic Approach**

Narrative approaches to research differ in their theoretical assumptions and methods by focusing on different features and asking different questions of the narrative. Reissman (2008) proposes several models of NA including thematic, structural and dialogic/performance approaches. These were used as a starting point to consider an analytic approach appropriate for the aims of this study. In light of the research questions, an approach was sought that considered the content of the narratives but also how these were produced within the broader socio-cultural context and the immediate context of the interview. A broad definition of narrative was taken in this research (Reissman, 2003). This included verbal interactions, such as narrative segments, and stories that focused on themes related to the topic such as the experiences of accessing an EIP service.

##### 2.10.1. Levels of Analysis

Murray (2000) has suggested four levels at which narratives can be understood as mediating experiences of the world: personal, interpersonal, positional and ideological. He emphasises that narratives include all of these levels all of the time. Stephens and Breheny's (2013) 'integrated approach to analysing stories' offers a framework incorporating these different levels. This approach might be

viewed as falling with a dialogical/performance model of NA (Reissman, 2008), as it emphasises the meaning people bring to their experiences, while also capturing the social, cultural and moral significance of their story. This is suggested as particularly useful for exploring talk about 'illness' or traumatic experiences, as people's accounts are both ideological and dilemmatic (Radley & Billig, 1996; Stephens & Breheny, 2013).

The approach to analysis in this study was adapted from Stephen and Breheny's (2013) structured integrative framework. This framework suggests three intertwined and interacting levels at which narratives can be analysed:

1. The personal story is seen as the basis of narrative psychology (Mishler, 1984). An analysis at this level can provide an insight into how people make sense of their experiences, whilst also acknowledging the social purpose of their story. It can also explore how narratives define identities and how they might support the maintenance of a coherent sense of self in the face of adverse events and biographical disruption (Bury, 1982; Williams, 1984).
2. At the interpersonal level, narratives are viewed as co-constructed between the interviewer and participant in a particular social context (Mishler, 1986). Analysis at this level acknowledges that the interviewer represents a broader social world to which the narrative is orientated and asks questions about the specifics of the interview situation and the immediate and wider audience (van Enk, 2009; Noone & Stephens, 2008).
3. The positional and ideological level (Murray, 2000), or 'public narrative', pays attention to the wider social systems of common beliefs in which narratives are embedded. This can help consider how people position their personal stories within wider cultural narratives (Murray, 2003; Stephens & Breheny, 2013) or how an individual's narrative can be

shaped by the ideological stories shared within particular institutions (Cain, 1991).

## **2.11. An Integrated Approach to Narrative Analysis**

In taking an integrative approach based on Stephens and Breheny's (2013) framework, a number of theories were drawn upon to help ensure consideration of each of the above levels, whilst also acknowledging their interacting nature and the process by which they mutually inform each other (Emerson & Frosh, 2004).

### **2.11.1. Positioning Theory**

The analysis was informed by positioning theory across all levels (Davies & Harré; 1990, 1999; Harré et al., 2009). Positioning theory fits with a poststructuralist research paradigm as it recognises both the constitutive force of discursive practices in providing subject positions, and individual agency over those practices (Davies & Harré, 1990). Positioning theory is underpinned by a tri-polar relationship between position, storyline and speech act (van Langenhove & Harré, 1999). It can be integrated across analytic levels as subject positions can be understood in both specific interactions and the wider sociocultural context (Avdi, 2012). Positioning theory allows exploration of how available discourses offer certain subject positions that can be ascribed, taken up, contested or resisted, and the relationship between discourse and subjectivity (Davies & Harré, 1990; Harré & van Langenhove, 1991). Subject positions are associated with sets of rights and duties, which can set boundaries for social action, highlighting issues of power and resistance. This is relevant to this research because how people position themselves, and how they are positioned by wider discourses, determines access to cultural resources and has implications for identity and experience (Willig, 2008).

### **2.11.2. Analysis at the Personal Level**

Analysis at this level was concerned with the content of each individual's personal narrative, such as characters, settings, plots and outcomes (France &

Ulhin, 2006). A focus on 'what' is being said when individuals explain their experiences risks shifting to a phenomenological position. Therefore, personal stories were explored within the current study by identifying 'key narratives' in context and taking a 'small story'<sup>8</sup> approach (Georgakopolou, 2006; Phoenix, 2008). Boenisch-Brednich (2002) suggests people develop key narratives as a result of important events in their life history, and these are often retold until they become "well-worn accounts that are used to explain and justify people's actions and decisions" (Phoenix, 2008, p.67). Phoenix (2008) describes how key narratives are often associated with sense-making processes and can highlight why emotions, characters and events are constructed in a particular context. The 'tone' (Crossley, 2000; McAdams, 1993) and 'form' (Gergen & Gergen, 1986; Thornhill, Clare & May, 2004) of key narratives was also attended to when considering their implications for subjectivity.

#### 2.11.3. Analysis at the Interpersonal Level

The analysis paid attention to how narratives were co-constructed within the context of the interview and the wider audience. Attention was paid to features such as gaps and omissions, the interviewer's dialogue and the interviewee's attempts to engage the audience (Riessman, 2008). Questions were asked of the data influenced by Frank's (2012, p.33) Dialogical Narrative Analysis (DNA) approach, such as "What stakes does the storyteller have riding on telling this story?"

#### 2.11.4. Analysis at the Ideological Level

The concepts of 'counter' and 'master' narratives were drawn upon to aid analysis at this level (Bamberg & Andrews, 2004). Master Narratives are 'dominant discourses' or 'dominant cultural storylines' (Jones, 2004); for example, those associated with the medical model of psychosis. While they are not dichotomous entities, counter narratives exist in relation to master narratives

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<sup>8</sup> A small story approach attends to "under represented narrative activities" (Georgakopolou, 2006, pg. 123) for example, what is alluded to or not said in everyday interactions. This can help to highlight how individuals negotiate conflicting subject positions and canonical narratives (Bruner, 1990; Wetherall, 1998).

(Bamburg & Andrews, 2004). They have been defined as “the stories which people tell and live which offer resistance, either implicitly or explicitly, to dominant cultural narratives” (Andrews, 2004; pg,1). The analysis aimed to connect participants' narratives to the social context, and consider how they move between counter and master narratives and the implications of this for action and agency. Jones' (2002) status of narratives and storylines as dominant or counter is determined not by content but by participants' orientations or by explicit analyst identification. Master and counter narratives can be identified by how a participant orientates themselves to telling a narrative (e.g. overtly disagreeing with a statement or using phrases such as ‘I know most people wouldn't agree’), and also based on the analyst's knowledge as an interpretative resource (Potter & Wetherell, 1987); for example, familiarity with dominant narratives of psychosis and reflexivity about the interview and the researcher's assumptions (Jones, 2002).

## **2.12. Analytic Procedure**

### **2.12.1. Transcription**

Individual interviews were transcribed verbatim, including all speech from both participants and the researcher, as these were viewed as fundamental to the narrative co-construction (Riessman, 2008). Transcriptions were punctuated for readability and a transcription framework based on Banister et al. (2011) was used (see Appendix J). This enabled transcription of inaudible sounds, overlapping speech, length of pause, non-verbal actions and non-speech sounds such as laughing or coughing. A more detailed transcription was not felt to be warranted, as micro-level linguistics were not analysed for the purpose of this research.

### **2.12.2. Interpretive Analysis**

The same analytic procedure was carried out for each individual interview (see Appendix K). Each transcript was read to gain an overview of the form and tone of the story (Murray, 2007). Transcripts were then re-read, each time holding in mind a different level of analysis. Alongside this, how participants were positioning themselves or being positioned was considered across readings.

Finally, narratives were compared to highlight any shared consistencies or contradictions. It should also be noted that whilst each re-reading attempted to attend to a different level of analysis these were not viewed as distinct stages and analyses across the different levels overlapped (Murray, 2000).

### 2.12.3. Presentation of the Analysis

Each narrative has been presented separately. A summary of each story is presented followed by the key interpretations made at each level and excerpts are provided to illustrate the points made. In presenting the analysis and discussion, it was held in mind that participants would be invited to provide feedback on the research and therefore may read the analysis of their narratives (see section 4.3.3.5.) Thus, the write up also attempted to stay well connected to each participant's narrative and attended to the use of language.

### 2.12.4. Evaluating Quality

Traditional notions of reliability and validity are most appropriate for evaluating the quality of research that adopts a naïve realist epistemological position (Winter, 2000). For research to be 'reliable' it should demonstrate that the research findings are replicable or repeatable (Golafshani, 2003). This fits within a positivist paradigm, which assumes research can uncover and measure an 'objective reality' (Glesne & Peshkin, 1992). Consequently, the traditional concept of reliability is not appropriate for evaluating the current study, which assumes knowledge is socially constructed and narratives are fluid across context and time (Mishler, 1990). In qualitative research, attention should be paid to issues concerning the rigour of procedures and ensuring transparency and accountability (Riessman, 2008; Spencer & Richie, 2011).

Similarly, the traditional criteria for measuring validity is often defined in quantitative terms, relating to "whether the research truly measures what it intended to measure" (Joppe, 2000, p.1). While NA offers an innovative analysis, this is very much influenced by the interpretations of the researcher (Crossley, 2007). In narrative research the concept of validity generally means "well-grounded and supportable" (Polkinghorne, 1988, p. 175). In an attempt to ensure the research met these requirements, the suggestions outlined by

Riessman (1993) for evaluating the quality of NA have been attended to; these include, persuasiveness and plausibility, correspondence, coherence and pragmatic use (see section 4.3.3).

### 3. ANALYSIS

This chapter presents the narrative analysis of each participant's account. Brief biographies of participants are provided and their key narratives are illustrated with extracts from their transcript; highlighting pivotal events and the form and tone of the story. Interpretations related to the interpersonal and dialogical aspects of each narrative are discussed, paying attention to the performative aspects of participants' talk. At the ideological level, extracts are presented that illustrate how participants might draw upon and resist master or counter-narratives.

Each level of analysis is presented separately here for clarity; however, these levels are viewed as interrelating and, therefore, they intersect at times. How the self and others are positioned in light of personal and social narratives, and the potential consequences of these narratives for identities and action, were considered at each level of analysis.

Extended extracts have been included in Appendix L and an example of the analytic procedure can be found in Appendix K. Extracts are presented in line with the transcription conventions outlined in Appendix J. Where deemed particularly salient the interviewer's speech is included to highlight the co-constructed nature of the narratives (in bold).

### 3.1. Leo's Story: "I don't blame mental health, I just blame life"

Leo is a Black British female in her twenties. She was referred to the EIP service approximately one year ago, following her admission to an acute mental health ward. Prior to being admitted to hospital she was having experiences such as seeing unusual things, holding unshared beliefs, and hearing voices. At the time of the interview she reported no longer having any 'unusual experiences' associated with a FEP.

#### 3.1.1. Personal Level

Leo's key narrative had an optimistic and redemptive tone. She described a difficult but ultimately rewarding journey, leading to personal revelations and a positive and hopeful view of the future.

Leo narrated the experiences that led her to being admitted to an acute in-patient mental health ward as a build-up of stress and unexpressed anger. She drew on psychological and social explanations, locating her experiences within the context of her past history. This appears to provide a normalising and compassionate account and facilitates her to resist being positioned as having a 'mental health problem'. However, Leo also suggested that smoking cannabis may have triggered her 'unusual experiences', an explanation that resonates with the stress–vulnerability model of psychosis. Furthermore, she located responsibility internally, in her own coping strategies. This potentially affords her agency over her experiences, yet risks perpetuating a sense of self-blame:

*[18-21] I felt like the whole family turn against me (3) and then I had a friend who was going through issues with her boyfriend smoking (1) I was smoking weed with her, but it wasn't any weed it was like skunk like this mix with a chemical.....*

*[22-23] plus, I had.... so much on my head that I was really overthinking things and I started to picture things and hear voices.*

*[113-120] I had a lot of anger inside me ... that I had been holding from when people mistreated me and I hadn't said anything, I've let things slide and like I've just brushed it off, like it was still there .... I held on to it, and I had all the anger inside of me but that's when I realised that .... I'm not mental, I'm .... just going through some things and I'm angry and .... I didn't reflect on it.*

Leo explained that when she first noticed her 'unusual experiences' she made sense of them within a spiritual framework. This appeared to be a strong narrative within her family and one that rendered her experiences meaningful and ultimately positive:

*[125-128] I just (1) thought it was a mission at one point. I really thought it was a mission from God, that I was on this journey and I had to go through certain things to learn things and understand things a bit more and get to know myself a bit more.*

*[134-135] I've been brought up in a church from birth, so I just thought it was spiritual thing, a godly thing.*

Leo described reservations about accessing the EIP service; however, despite her initial doubts she narrated a positive experience, with psychological therapy playing a key role in her sense-making. Although Leo reported clinicians at the EIP service allowed her to develop her own explanations, she described a scaffolding process whereby these were re-framed within a psychologically informed trauma model:

*[214- 216] Well, they didn't really give me, like an explanation, they allowed me to explain. So they just they kind of like, I said what I had to say and they transferred it back, just what I said in another content....*

*[217-221] What I got from it was that everything that I've been through was a pattern from like something I've held in from the past from people and [my psychologist] allowed me to reflect on certain experiences in my*

*life that I held on, or certain traumas and stuff like that that made me understand a bit more.*

Leo described how therapy helped her to realise that one of the voices she heard was that of an old friend whom she still felt anger towards. This appeared to have a powerful impact on the subsequent ways she attempted to gain control over her 'unusual experiences' and provided options that supported her narrative of personal growth:

*[232-235] So I think I could probably hear her voice and certain things like that and I met up with her recently and she explained her side of the story, I explained mine and we came to some mutual ground.*

Further into her narrative, Leo confirmed that she has still held on to her initial spiritual understanding, offering a strong sense of hope for the future, and framing her experiences as transient and meaningful. Leo acknowledged the traumatic aspects of her journey, yet she positions herself as a survivor, with the potential to step into an advocate role; further resisting a more passive identity associated with accessing mental health services:

*[239-242] I didn't go through it for no reason. I didn't, it's for a purpose, God's purpose I believe. I believe it's my testimony it's my story to know that like (2) where I come from, what I went through and where I am now and the fact I can be a voice for a lot of people.*

*[350-352] I just see my future like, it's going to be big and bright as ever before (1) because I don't know, I like, to me yeah I've faced death, I've seen death so I'm not scared of failing or dying anymore I just want to live my life....*

### 3.1.2. Interpersonal Level

At the beginning of the interview, Leo warns the listener about her 'brutal honesty', drawing in the audience and potentially minimising any pre-determined attacks on the credibility of her narrative. As she described her life

prior to her FEP, she positioned herself as someone who typically provided support for others, perhaps drawing similarities between herself and I, and abating any perceived power differentials. She also described her previous acting experiences and reiterated this is still what she does, perhaps indicating a preferred identity:

*[5-12] Okay [deep breath] (2) I was going through (2). I'm going to keep it brutally honest with you .... because I'm not ashamed of it no more. I can like just get it off my chest.... I just got promoted and I was also acting because that's what I do. I had a YouTube Channel and I was doing [my job], running my own little business. Erm so I like, money wasn't an issue, I was doing my thing (1) but the people around me had a lot of issues that I got involved in. Like I've always been the type of person that like, everyone feels comfortable and to tell me their secrets, and their problems and everything.*

Nevertheless, it is possible my professional role, and Leo's desire to emphasise her positive experience of the EIP service, might have silenced parts of her story. For example, when Leo talked about her experience of receiving professional knowledge about psychosis she described valuing her doctor's opinion. However, she also suggested it lacked personal meaning and her inability to recall this information suggests it had little impact upon her understanding. Leo possibly felt obliged to clarify that she had considered other understandings whilst narrating her own beliefs, that contrast with medical explanations. It may be that this helped Leo to hold her own in her story that risks being discredited by more powerful others, myself included:

***[485-491] Did you see a doctor here as well?***

*Yeah I don't remember her name though, I saw her twice (1) she would always come in like when we had reviews, she was always there....*

***Did she give any different explanations?***

*Yeah, she spoke, sorry, on the intellectual side of things, so she used a lot of smart grammar, that I couldn't understand, but in, in hindsight I did*

*really understand where she's coming from, but yeah, I can't really remember....*

Additionally, Leo reiterated her current state of well-being throughout the interview, narrating the positive aspects of her journey and her sense of agency over her experiences as something she 'did'. It is possible she felt under pressure to emphasise this, particularly as conversations with mental health professionals are often associated with having one's mental health scrutinised. It may also be that Leo's imagined wider audience included other service users, for whom she wished to ensure she imparted a hopeful and empowering message:

*[249] 'But I'm so happy (2) where I am now, I'm very very happy'.*

*[507] 'I wouldn't, wouldn't change my experience for the world (2) I'd do it all again if I had to'.*

*[518] 'I swear it was a negative. But now it's all positive'*

### 3.1.3. Ideological Level

Leo drew upon social, psychological and spiritual narratives when talking about her experiences. Her lack of reference to medical narratives of psychosis was striking. When Leo was asked directly about her experiences of being faced with psychiatric explanations it was clear that this was associated with a sense of powerlessness and an attack on her self-agency; the powerful experience of being forcibly positioned as someone with schizophrenia appeared to be associated with a passive, dehumanised identity:

***[261-264] And how did you feel when they said, gave you that explanation [schizophrenia]?***

*I felt kind of vulnerable (2) and I felt like, no one was trying to, I felt alone, yeah, I felt isolated that I didn't have a say in anything of my life. I just thought I was a muppet, I was controlled.*

Leo's laughter at her spiritual explanation suggests she was aware she was drawing on a counter narrative. She appeared to predict this would be deemed incredible by others with the power to subjugate her personal sense-making. In an attempt to resist this, she highlights the implausibility of undermining her subjective experiences, an explicit attack on the master medical narrative and its attempts to define reality:

*[124-128] I just thought there was like evil spirits [laughter] that someone had put on me.*

*[241-243] What I went through was real for me and no one can ever take that away from me .... and I pray and I, I still believe it's a spiritual thing.*

Leo also drew upon her experiences of speaking to other service users to give credibility to a counter-narrative of psychosis as a normal reaction to adverse events, which she used to explicitly challenge mainstream notions of mental health:

*[542-545] I just think (3) mental health is not the issue. I don't think it's an issue as people might think it is. I think there are a lot of people out there that are really going through some hard times in their life and they don't have anyone and they just really need someone to talk to.*

Whilst Leo drew upon normalising discourses, when talking about other service users, this appeared to pose difficulties for negotiating her identity as separate from people deemed to have mental health problems. As such, she positioned herself as distinct from other people she met on the ward, potentially highlighting the pervasiveness of internalised societal stigma and the power this has to maintain dominant discourses:

*[317-320] I see other people in the hospital and I, I, I used to reflect myself to their character and be like I don't I don't act like that. I think I'm I'm more sane than everyone in here. So I, I personally don't think I have mental health like that [laughing] .... I know it sounds messed up but*

*that's how I thought in my head I felt (1) no I'm not like no I'm not I'm not crazy.....*

Finally, the power of the master medical narrative is also implied when attending to what goes unsaid in Leo's account. For example, when talking about how her family perceive what happened, she briefly mentioned '*my mum's had a similar experience, and she's still on medication*' [379]. Leo did not elaborate on this further, it may be that this was not relevant for her sense-making, alternatively it is possible that she was aware that this might be used against her to support a biomedical explanation and, therefore, can be viewed as a further act of resistance and owning her story.

### 3.2. Shoma's Story: "I feel like they can protect me"

Shoma was a British Bengali female in her twenties. Shoma was hearing malevolent voices, having 'visions' and experiencing unusual sensations, she was referred to a Community Mental Health Team (CMHT) by her G.P. However, due to her high levels of distress she presented to her local Accident and Emergency (A&E) department, from where she was referred to a day centre and then to the EIP service, approximately one year ago.

#### 3.21. Personal Level

Shoma narrated a tale of personal resilience and resistance in the face of adversity and oppression, her story taking a progressive turn as she described learning to manage her 'unusual experiences'. Shoma described hearing malevolent voices that escalated to a point where she feared for her safety. She described feeling powerless, facing numerous barriers to receiving support as she was dismissed by health care professionals and her family. Yet, against these odds, she positioned herself as exerting a strong sense of personal agency, resisting the demands of the voices and ensuring her needs were heard:

*[7-10] I started seeing two people and also erm (1) the voices I heard most of the time, there's two people I can hear them (1) clearly (1) they say that I'm not worth in this world, I shouldn't live in this world, I should do something to myself (1) I should, I should die....*

*[22-25] I couldn't control myself I feel like to cut myself or harm myself .... and I was scared. I been calling them, I went to the GP and er (2) they're not doing anything and er the GP er (2) called [the CMHT] and told them but then they weren't doing much and then I went to er A and E....*

*[37-38] I told my family members (1) my sister but they, they didn't believe me at first, they said it might be nothing.*

Shoma explained that prior to accessing mental health services she drew upon supernatural explanations, meaningful in the context of her past history. Shoma described the sexual abuse and neglect she had experienced throughout her childhood. She made sense of the voices as a source of protection against further harm, perhaps offering her a position of being cared for and validated, that she had been previously denied:

*[101-103] I thought it might be ghosts, the thing I can't see I thought ghosts, erm and I think also er the people I used to see and hear, I used to think there's someone trying to protect me from something wrong.*

*[105-107] I know they are saying rude things (1) and they are saying bad things about my family, but then I know the reason why because (1) ... my family history wasn't that good.*

*[145-147] They want to protect me (1) so because no one ever did anything, for me that much. I think they are looking out ... over me.*

Following her referral to the EIP service, Shoma described receiving explanations of her experiences in line with the medical and biopsychosocial model of psychosis. This presented the possibility of recovery through the use of medication and appeared to offer her a new narrative that contextualised her experiences. However, it also appeared to conflict with Shoma's prior sense-making, rendering her experiences as meaningless symptoms:

*[219-222] They told me er this is er (1) psychosis, people experience this (2) I might think it's real, but its semi-conscious, it's not real so it just that er I need to understand (1) and (1) keep trying more about erm working on taking my medication and get better...*

*[270-274] The doctor said, because it is building up so much pressure inside you and it has to bust one time, one day. So it happened now, so I was like yeah it's right (1) because (1) from that age, young age, that from that day I understood, erm (1) started realising (1) until my er now, I*

*couldn't say to anyone what happened to me (1) and I couldn't keep it to myself, I was suffering inside.*

Shoma described how the support offered by the EIP service had helped her to regain a sense of independence and pursue her goals such as going to university; her choice of course perhaps an insight into her belief in the medical narrative. While Shoma narrated her future with an optimistic tone, she attributed her current well-being to the help of the EIP service and alluded to continuing dependence, perhaps undermining her personal agency:

*[367-370] I don't think I would be able to do it, what I'm doing now ... without their help. I guess, because I'm planning, I thought I wouldn't be able to do anything, but now I plan to go to Uni, I've applied for it .... to do medicine*

Shoma described how medication and 'reality testing', as part of psychological therapy, had reduced the impact of her distressing experiences. However, she appeared ambiguous about letting go of her voices and accepting them as purely symptomatic. Subscribing to the medical narrative appeared to threaten to subjugate the meaningfulness of her experiences and potentially pose further challenges to her ontological security. While Shoma constructs her experiences in seemingly contradictory ways, drawing on both supernatural and medical frameworks, this appears to offer hope but also on-going protection and support, factors that appear particularly salient within the context of her story:

*[453-456] I'm happy about it and also I'm sad about it because I don't want the voices and the people I see to go away (1) But then I don't want them to say anything wrong .... But then I'm happy about it but I don't want them to disappear fully. Now that they the way they are I'm okay with it.*

### 3.2.2. Interpersonal Level

Shoma gave an open account of her past abuse; this was highly relevant in the context of the interview and my questions about how she made sense of her

experiences. However, it is possible her narrative was also shaped by my professional background and her previous conversations with psychologists. Shoma also emphasised that she benefitted from talking about her experiences, perhaps associating the interview with a therapeutic space:

*[186-188] When I talk to someone, when I'm open to someone I feel more relieved inside .... when I speak to my care-coordinator, er (1) then I feel like all er everything's, I'm like light so I quite like it.*

As Shoma talked about her attempts to access support from mental health services, she spoke angrily, with a sense of determination, potentially emphasising the distress and feelings of powerlessness that this had caused. It may be that this feedback had been difficult to voice outside of the confidential setting of an interview, due to a lack of opportunity or in light of implicit power differentials, yet was something she was keen for her audience to hear:

*[172-180] The psychiatrist saw me, she like oh its nothing it erm just tell you family, keep an eye on you. I told them I can't control myself I feel like I'm going to cut myself. They not taking seriously (2) tell me hide all the knives and this and that (1) and tell your family to keep an eye on you. They just send me back home (1) and that night I felt really scared (1) it's like someone's controlling me like I'm, I'm you know the string doll.*

When speaking to a real or imagined audience of health care professionals, it is possible Shoma perceived there to be a lot riding on the account she gave, influencing the version she privileged. Throughout the narrative Shoma repeatedly used the term 'now I know' to reiterate the knowledge she had gained from accessing the EIP service. It is possible Shoma felt under some pressure to ensure the audience were convinced of her progress towards recovery, often associated with gaining 'insight' within a medical framework:

*[201-202] Now I know the difference between who to avoid and who not to avoid.*

***[225-228] Did that explanation fit with you, psychosis?***

*It did because (1) the more I think about it my er symptoms and the more I compare with the symptoms they told me about it, it's similar, so now I know it's not something, I shouldn't worry for no reason about ghosts and it's just an illness*

3.2.3. Ideological Level

Shoma constructed her experiences predominantly drawing upon a biopsychosocial model. She contextualised her experiences in light of her past trauma; however, she used medical terminology of 'illness' [558] and 'symptoms' [37]. The power of the medical narrative is overt in her account. She positions health care professionals as possessing expert knowledge and, thus, privileges their opinion:

*[95-97] For me it's like when doctors, or any other health care professional says something, that erm that calms me down .... because I know erm they are qualified; they won't say anything for no reason.*

Shoma described that her families' predominant understanding of experiences such as hearing voices was 'black magic'. She also highlighted that people in her community hold negative attitudes towards 'mental illness' and services. Her account highlights the potential for culture-specific discourses to play a role in the help-seeking process. She explicitly resisted these narratives, described black magic as 'nonsense' [141], it is possible this narrative threatens to position Shoma within a stigmatised identity in her community, obscuring the responsibility of others for the abuse she suffered:

*[135-138] My mum she was saying, maybe it's black magic. But I don't believe in those.... whenever she used to say things, even with other people, I was like no, this sort of thing doesn't happen.*

*[463-468] People think that mental health illness is something wrong, and if you go to doctor they make it worse.*

Shoma draws on the master medical narrative when talking about her 'illness', this offers her a label, perhaps affording her resources and legitimising her experiences in the face of widespread silencing of victims of abuse. Nevertheless, it arguably serves to sanitise her experiences, and the troubled subject positions associated with psychiatric labels are highlighted in her account. She described how health care professionals question her legitimacy in light of her diagnosis, furthermore while she emphasised that she is able to achieve her goals and participate in a 'normal' life, she concurrently appeared faced with an altered sense of self as not 'normal', perhaps with implications for how she continues to construct her identity in the future:

*[379-382] GP used to take me seriously .... but since the mental health started when I say to them something, they don't take it seriously (1) they always say, oh because you are taking the er, mental health medication.*

*[560-563] They told me it can be part of my life for the rest of my life, but they can help me to live my life as normal and now I know it is a part of my life but I can now, with their help I now know I can live my life normally.... like other people can.*

### 3.3. Frank's Story: "When I take drugs I turn into a psychopath"

Frank is a Black British Male in his early thirties. He was admitted to an in-patient mental health ward on three occasions due to experiencing 'persecutory beliefs' and displaying aggressive behaviour. Frank had been accessing the EIP service for approximately three years.

#### 3.3.1. Personal Level

Frank's key narrative appeared to centre on a struggle to escape from unwanted psychiatric treatment and to maintain his former sense of self. He positioned himself as a previously agentic character for whom things went '*a bit downhill*' [28]. However, Frank narrated a learning curve, seemingly associated with recognising his own fallibility. From here the tone turned more reflective as he described hopes of engaging in further sense-making to facilitate a progressive narrative.

Frank emphasised that he accessed the EIP service as a result of excessive drug use. This appeared to be a well-worn account that he repeated throughout his telling; potentially reducing a sense of responsibility or shame associated with having a 'mental health problem'. Frank constructed his experiences as 'paranoia', meaningful in the context of his reality at the time and perhaps as an extreme version of normal fears. He compared his experience to a celebrity breakdown and referred to his '*gangster mentality*' [59], associating himself with a powerful and admired identity within youth culture. This might serve to both glamorise his previous lifestyle and trivialise a sense of self that he no longer identifies with:

***[1-4] What kind of experiences led up to you accessing this service?***

*Basically (1) I used to binge on drugs. On a cocktail of drugs .... and then (1) like you hear about the celebrities just freaking out on the drugs, I just got too high, erm, and just freaked out.*

*[30-33] I was involved in criminal activity at the time so I was doing a lot of dodgy things. So then I got really paranoid that people were following me that police were following me .... That erm police were watching me from erm my TV....*

*[57-59] I had that gangster feeling (1) erm bad boy (3) just doing my thing getting more high during the day.*

Frank narrated a strong sense of agency by emphasising how he initially resisted the help offered by the EIP service, eventually engaging on his own terms. In hindsight he described valuing the assertive outreach approach, in doing so, positioning himself in need of help; indicating a shift in his sense of self or possibly a requirement to comply. Frank reported that the biomedical information about his experiences provided by the service was both simplistic and prescriptive. This appeared to obscure the role of contextual and environmental factors and led Frank to question whether his experiences held any personal meaning:

*[216-219] But the more time that they don't give up on you (1) if that makes any sense, the more times that they stay there and when you do your stupidity they kind of don't react to it, it kind of makes you realise that you do need a service.*

***[271-279] You said you had lots of conversations with different people, have different people said different things or similar things? They are all similar, they are all similar, it's too similar (1) if you get what I mean it's too textbook....***

*If you take drugs, you get paranoid, you start seeing stuff in the TV and everything maybe it is as straightforward as that (1) and (1) the reason why they do it so textbook is because it was.*

Frank appeared to draw upon the narratives available in the EIP service to begin to engage in sense-making. He drew upon a biomedical narrative of psychosis, which appeared to inform the assessment process at the EIP

service, to construct his experiences as potentially genetic in nature. In the absence of opportunities to explore this further, this potentially posed a serious threat to Frank's sense of self:

*[323-326] They were asking questions about, has anyone else had any problems in the past and then I said no because I never knew this and then she said oh it does run in certain families, certain traits.... that's why they ask about family.*

*[334-335] So I think madness runs in my family literally and then because I've taken drugs, it just bro- it just brings it out.*

Within Frank's narrative he contrasts his past lack of understanding, 'I was in denial' [204], with a current recognition that 'there is a problem with me' [158], and his wish to make changes for his future. Frank described his plans to go to University, abstain from drugs and buy a house. However, these appear heavily influenced by his father and the EIP service. Frank constructs himself as playing a passive role in shaping his future, yet this might also be an act of resistance against a dominant 'good life' narrative, promoted by the service, that he does not necessarily subscribe to:

*[454-455] [Laughing] My dad's going to buy me a house if I stay sober literally, literally that's it but realistically but stay sober, or stay drug clean, go to university.*

*[462-466] Yeah all that has been encouraged through the service, because they sit down, the first day (1) the first day you meet them they ask you and you tell them your plans for the future and then you tell them plans or they give you examples of plans and once you've said that, each week they drill it in.*

### 3.3.2. Interpersonal Level

Although Frank performed a strong sense of agency throughout the interview - for example, he was able to interrupt me to ensure he narrated key aspects of

his story - his repeated use of the word 'literally' was notable. It is possible Frank felt the need to emphasise the legitimacy of his account and his 'normal' identity, particularly in the face of a mental health professional viewed as having authority over what constitutes 'reality'. Frank talked about accessing the EIP service in a way that suggested this posed a threat to his previous sense of self, one strongly associated with dominant narratives of masculinity and the non-expression of emotion. Frank's apparent discomfort may reflect the influence of discourses of hegemonic masculinity that can serve to legitimise patriarchy and deny male expression of vulnerability or distress. It is possible the interview situation brought similar concerns to the forefront, shaping the tone of the narrative and potentially leading Frank to self-censor some of his more difficult experiences:

***[212-216] Do you know when you first got referred to early intervention how did you feel about accessing the service?***

*I was embarrassed, I was, I felt like I don't need it, I felt embarrassed in a sense that people are degrading me because I'm a grown man and I've got to come see a lady and talk to her and everything.*

Nevertheless, there were points in the interview where Frank appeared to use the phrase 'to tell you the truth' [302;395] to introduce a more psychologically informed counter-narrative. It is possible that this may have also been shaped by my role as a psychologist, with Frank feeling obliged to engage in reflexive sharing:

*[197-201] The only thing that I could honestly say that affected me was me breaking up with my girlfriend and being really upset because I loved the girl and not really knowing if I loved her or not loved her, but having that upset in my life because I really did for a long time.*

However, Frank also clarified that he had not talked about these experiences "in depth" prior to the interview and indicated a desire to engage in further meaning-making in therapy. Thus, the interview possibly offered a context for

Frank to begin to integrate alternative narratives into a more multi-dimensional and coherent description of his experiences:

*[497-502] My name is down for talking to someone, I haven't actually seen them yet, but my name is down so when that comes it will help my progression.*

***How do you think it might help?***

*Because even talking to you now it's kind of (1) it's off my chest a bit*

*[508-513] Tell you the truth, you're probably the only person that I've spoken to in depth.*

3.3.3. Ideological Level

Frank drew on everyday language to talk about his experiences of turning 'crazy' [169] resisting more formal psychiatric terminology. In relaying the explanation given to him by professionals (possibly drug-induced psychosis), he described how taking drugs turned him into a 'psychopath'. Frank was possibly drawing on dominant narratives available in popular culture to make sense of the psychiatric explanations offered to him. This potentially highlights how associations between psychosis and the media representation of a 'psychopath' are made in everyday discourse:

*[101-103] I ain't been diagnosed with but they say I'm a psychopath when I binge on the drugs. That's why they say it's not really psychosis or schizophrenia, it's just literally I take so much drugs I turn myself crazy.*

Frank repeatedly refers to himself as a 'psychopath' throughout his narrative. It is possible this construction of his experiences is more tolerable to Frank than being positioned as a passive patient with a psychiatric illness. Psychopathy with its notions of 'badness' as opposed to 'illness' may afford a position of power and agency more compatible with Frank's existing sense of self and associated with a preferable array of rights and duties. Nevertheless, being

positioned in this way appears to have had a profound impact on Frank's subjectivity. In drawing upon both a lay understanding of psychopathy, and the stress vulnerability model, Frank reflects how he has questioned the intrinsic nature of his difficulties. This narrative appears to endanger Frank's efforts to preserve a 'normal' identity, allocating blame internally and obscuring the role of the wider context:

*[185-188] At first it's funny you know ha ha ha you turn into a psychopath when you take too much drugs but erm when you're by yourself, you kind of get worried, like is it a part of you when you're sober is it going to come out naturally as you get older? Or is it only coming out because of the drug?*

Frank explicitly challenges the usefulness of professional explanations and jargon that maintain power differentials and hold limited relevance for personal meaning-making. He also draws on a discourse akin to a recovery narrative that challenges the legitimacy of the use of certain anti-psychotic medications that inhibit personal and social recovery. Franks' argument provides an insight into how he might perceive he is indirectly positioned by society as a perpetrator of crime rather than a possible 'victim' of his circumstances, potentially intersecting with powerful narratives around young black males within the media and the wider culture. Whilst Frank's argument against certain medications echoes that of other psychiatric survivors, he clearly feels the need to add credibility to his account by clarifying that he is not 'paranoid'. As such, Frank appeared acutely aware of the potential for diagnostic overshadowing and the power of the medical narrative to subjugate any views that challenges its legitimacy:

*[339-342] They use words like drug induced thing and you're not really understanding it, they don't use literal words if you get what I mean, they use coded words, so if there was just, if the wording was more upfront .... and formal it would register more personally I think.*

*[460-463] I actually thought yeah that they made [risperidone] deliberately gave it to people who were criminals .... just to zone you*

*out. That's actually, that's not me being paranoid it's literally made to zone you out and not do any criminal activities.*

### 3.4 Jade's Story: "All I did was have my baby and then I went bipolar"

Jade is a Black British female in her late twenties. She began to have unusual experiences following the birth of her first child. Jade spent three months in a mother and baby unit and three months on an in-patient mental health ward prior to accessing the EIP service, approximately three years ago.

#### 3.4.1. Personal Level

Jade's key narrative appears to be one of endurance and adaptation, beginning with an angry tone and depicting her survival of the distressing experience of being admitted to an in-patient mental health ward. The tone changes to appreciative as Jade reports feeling rescued by the EIP service. She described a process of accepting an altered sense of self and the future in light of her diagnosis.

Jade narrated how her life changed suddenly and dramatically after the birth of her baby. She described an abrupt end to her 'happy life' [92], when she began to feel depressed and 'paranoid' [19]; leading her to become increasingly socially withdrawn:

*[4-7] I literally I just started out having depressive symptoms .... Not wanting to go out, not wanting to see friends, not wanting to talk on the phone .... erm and then I started getting psychotic symptoms, like not wanting to go out because I thought people were following me and stuff like that ....*

Jade described not recognising the extent of these experiences until her distressing experience of being admitted to an acute mental health ward. She explained how the absence of any meaningful explanation and the strict ward environment "made me think even more psychotic thoughts" [137]. Drawing on language such as "locked up" [37], Jade's narrative is reminiscent of being sent to prison, in stark contrast to a therapeutic environment. She positioned herself as lacking any agency or rights during her stay on the ward, facing the dehumanising threat of forced treatment if she resisted medication. However,

her anger and forcefulness when narrating this experience clearly demonstrated her resistance and a current sense of entitlement to speak out about her treatment:

*[7-9] I got put into the hospital (1) which was the worst move to this day I'll say they ever made, because they didn't even tell me it was a mental health hospital, they just kind of threw me in the hospital and left me there.*

*[69-71] They didn't explain it's for my mental health and they (1) all I got told was just take your medication and if you don't we're going to inject you.*

Jade narrated having little control over her referral to the EIP service; '*I don't know what happened, right, but the service found me*' [265]. The diagnosis provided by the EIP service framed her experiences within a biomedical narrative, linked to a hormone imbalance in the brain and triggered by the birth of her child. Jade appeared to value being provided with an explanation, however raised doubts about its legitimacy, seemingly discarding it and laughing at the overly simplistic and abstract nature of her diagnosis, as well as its supposed chronicity:

*[132-138] [EIP] diagnosed me with bipolar, so I knew what that was, so I understood it a bit better.... but in the hospital they didn't tell me I'd got any diagnosis, they just kept pumping me with meds and injecting me, you know? So erm, they said I'd got bipolar and said it was triggered from breast feeding my child (1) which I didn't know (1) I just thought it was a pile of poo [laughing] because how can you go from being normal to having a total psychotic mental health issue from having a baby? ... A permanent one as well?*

Despite Jade's dissatisfaction with this explanation, her narrative highlights her ultimate lack of power over her diagnosis or being positioned within a stigmatised identity. While she resigned herself to have to 'get used to it', she

resisted the dehumanising effects of being labelled by undermining the significance of her label and challenging the dichotomy between mental illness and having a 'normal' life:

*[154-156] I've got used to it. At first it was like oh my god I've got bipolar, but now it's like I'm this, I'm that, I'm this, I'm that I'm whatever. The main thing is I'm human I'm breathing I'm taking my meds and I'm keeping it moving, you know, so I'm not too bothered now.*

When discussing the support offered by the EIP service, Jade predominantly spoke about medication, congruent with a biomedical approach. She positions herself as equal to the EIP clinicians in making treatment decisions by demonstrating her knowledge and repeatedly using the pronoun 'we' to emphasise a collaborative approach. Nevertheless, Jade indicated a sense of dependency on medication and, ultimately, the EIP service, revealing the implicit power of institutional practices and undermining her attempts to construct an autonomous identity:

*[220-225] We introduced aripiprazole and (2) what the plan was was to introduce the aripiprazole, increase the aripiprazole and reduce the lithium, increase the aripiprazole, reduce the lithium.... until I can just be on aripiprazole.... That's the idea but I know that (1) lithium is effective....so I don't want to kind of do that and wobble again because my life has just started getting back on track again.... Yeah so I don't want to risk it.*

Jade described her aims for the future included maintaining the stability of her current well-being and adapting to her life with a permanent mental health problem. She described numerous losses due to the side effects of medication and the perceived limitations her diagnosis placed on her future aspirations. Her compliance in the face of these losses perhaps indicated how compelled she is by the biomedical argument and the ongoing threat of 'relapse' associated with this:

*[305-306] It's changed my whole image, it's changed all the clothes I've bought .... It's changed my whole life.*

***[313-316] Do you think it's had an impact on anything else in your life?***

*.... yeah my career (2) like I haven't actually been back to work since and I erm, the thought of working a full like week, a full like a full-time job like thirty-six to forty hours a week. I don't think I am capable of doing that (1) right now.*

#### 3.4.2. Interpersonal Level

Jade emphasised her strong relationship with the EIP team, reiterating her appreciation *'it's the best thing that's happened to me'* [125-126]. While alluding to some negative experiences, she provided a persuasive account of the supportive nature of the clinicians involved in her care. Perhaps her perception of this genuine care facilitated her treatment compliance. It is possible Jade's imagined audience might have included these professionals, with the interview viewed as an opportunity to communicate her gratitude. Alternatively, it is also conceivable that acknowledging, and perhaps drawing upon, professional explanations affords Jade some access to power, in turn, inhibiting alternative narratives from being mobilised:

*[187-188] They are doctors and stuff but around that they actually care about our conversations...*

*[416-418] We've had some bumpy rides and some trial and errors and, I don't know (1) I feel like they are like part of my family to some degree, they have been so helpful.*

The timing of the interview is also worth noting as Jade had attended the interview following a psychological therapy appointment *"I have psychology now too, that's where I've just come from"* [194-195]. Whilst she predominantly drew upon biomedical narratives, she also narrated psychological and social explanations for her 'unusual experiences'. These alternative narratives may

have been co-constructed in the context of her recently starting psychological therapy, my role as a psychologist and my choice of questioning, which directly asked about her wider context:

***[41-48] Was there anything else happening around that time?***

*I split with my son's father but we actually split before I had my son. We split when I was six months pregnant so .... but he was quite aggressive and trying to harass me and get access and stuff like that, so it was quite stressful and my mum....*

*She had cancer so was having chemotherapy, and I think she had just finished all her chemotherapies and I was university as well, so I think it was all just a combination of stressful times.*

Jade laughed on numerous occasions throughout her narrative, typically when relaying medical explanations that positioned her as having chronic mental illness or unhelpful psychiatric practices. It is possible this served to highlight her scepticism, without having to explicitly challenge professional narratives. She may also have assumed I held a critical view, alluding to a shared understanding or a wish to elicit validation and permission to discuss this:

*[172-174] They said the chemical balance changed in my brain which can be triggered through pregnancy .... and .... as a result, you're one of the unlucky ones [laughing].*

### 3.4.3. Ideological Level

Jade's story primarily drew upon an individualistic biomedical narrative of psychosis, constructing her experiences in terms of a chemical imbalance. Thus, she was directly positioned as having an illness requiring ongoing treatment. Her adoption of this professional narrative appears incongruent with her previous scepticism about her diagnosis, perhaps highlighting taken for granted medical discourses. However, by emphasising that her 'unusual experiences' were triggered by the birth of her child, she also drew distinctions between herself and others with 'long term' mental health difficulties, possibly an act of othering to preserve her preferred 'normal' identity against a 'chronic'

label. This account of causality obscured alternative explanations, including her difficulties being due to a psychological problem or social factors. Paradoxically, this might serve to reduce personal responsibility and afford protection from societal blame:

*[198-202] I was totally fine, like I've got a friend who has had mental health issues since she was seventeen and she's like thirty-two now, so she's been taking different medications for years and she's aware that she could be ADHD or borderline personality disorder, she knows about all of them so I was just living a normal life, all I did was have my baby and then I went bipolar [laughing] you know?*

Jade also narrated the power of diagnostic overshadowing as she recalled attacks on her credibility from health professionals. She described a lack of autonomy in challenging these, again highlighting the power of the medical narrative in defining realities. Jade alludes to her ultimate fear of being admitted back into hospital. As such, she is positioned as being at the mercy of the decisions of professionals and narrates a huge sense of powerlessness. Jade is presented with limited options, requiring the support of the EIP service to protect against this ongoing threat and possibly a need to maintain her identity as a 'good patient':

*[401-409] [The GP] goes 'oh [vomiting] doesn't sound like a physical problem, tell me more about your bipolar' (2) you know, so he tried to make it sound like there's nothing wrong with me but I've just got like a mental health issue.... which I found quite rude, it like, you shouldn't just assume because someone's got a mental health issue that, you know (1) it's a mental problem.*

***How did you manage that?***

*I was crying, I was in tears on the phone to my mum, like he says I've got bipolar, he's asking me about that and I think he's going to try and put me back in hospital.*

### 3.5. Joseph's Story: "I was just going through a lot of stress"

Joseph is a Black British Male in his 30s. He had been accessing the EIP service for approximately three years, after he began to have unusual experiences such as hearing voices. He had engaged in psychological therapy and is taking medication as part of his support from the EIP service.

#### 3.5.1. Personal Level

Joseph's key narrative was akin to a quest in which he actively engaged in a search for meaning. Joseph's narrative had an educative tone, presenting his journey as an opportunity for increased knowledge about himself and the world. His story moved from being told with a passive voice depicting the oppressive circumstances of his past, to him gaining a more active voice, where Joseph appeared to be in the process of developing his preferred sense of self as an activist or helper to others.

Joseph described the onset of his FEP as extremely traumatic, he experienced hearing distressing voices and intense anxiety. Joseph emphasised the confusing process of attempting to make sense of these experiences, at first drawing upon a range of theories, such as religious or supernatural explanations. In clarifying that he is not a religious man, he highlights the extent to which these experiences led him to question his beliefs and required him to step outside his usual way of viewing the world:

*[19-22] Hearing voices basically (1) yeah anxiety, fear and worry and anxiety, fears and ... just on edge .... just very on edge all the time.*

*[63-68] I'm not a religious person but, you know, I thought I had all these thoughts of like, you know, someone's probably done some curse on me or someone's done something to like, you know, I just, maybe there are ghosts or something like that, I don't know, I was going through all of these things in my head .... at the time it was just very traumatic....*

Joseph described his discomfort in receiving a psychiatric diagnosis from the EIP service, highlighting an awareness of being positioned as having a stigmatised mental illness. Joseph suggested the explanations provided by the service were predominantly medical, focusing on his 'symptoms'. He resists passively, accepting the assumptions of this diagnosis while explicitly questioning the validity of expert knowledge. It is possible this allows opportunities for Joseph to construct his own causal theories in the face of having little power over his label:

*[161-166] Basically they talked very much about the symptoms, they talked more and they emphasised on the symptoms, you know, do you see here what it says, and do you (1) you know .... They said this is something to do with, you know, there's no normal, you know, they're still, they're still trying to understand mental disease, basically they don't understand what triggers it....*

*[248-252] They basically said psychotic episode and the alternative is erm paranoid schizophrenia*

***And how does that fit with you?***

*Woah (1) you know again, you know, like the first response, no I'm not, no I don't want that label.*

Joseph emphasised his open-mindedness to multiple explanations of his experiences and he described engaging in a holistic array of support options within the EIP service. However, it is possible that Joseph was not entirely satisfied with the range of explanations provided, since he described seeking sources of additional information in his search for meaning. Within this narrative he also positioned himself as someone with an array of interests, potentially wishing to be viewed as a multi-faceted person, an identity that his label threatens to obscure:

*[279-284] There's many courses.... you know like, information about people and ... keeping active and doing.... being proactive and doing*

*different things and your life, your social life, your social arena, your friends and those sort of thing, and esteem building.*

*[335-357] I've always had like little bits of information from different places, you know... because I've done, like I've studied holistic healing and stuff like that.*

Joseph explained how the support provided by the EIP service and his personal research had facilitated self-reflection and knowledge. In light of this, he constructed his experiences predominantly within a psychological and social framework:

*[270-276] I've learnt a bit about myself .... sometimes when you have .... something happens to you or when you have family members that .... hurt you or, you know, sometimes you will just hold things in and it's builds up into some big thing and then you just blow up and they're like 'where did that come'.... I've totally changed more in that sense, to just say something before I get.... upset about something.*

Joseph narrated his goals for the future in an optimistic tone, planning to develop his own business with the support of the EIP service. Nevertheless, being positioned as a patient with a chronic mental health problem, Joseph described an on-going requirement to be vigilant over his symptoms and a pressure to ensure he takes the 'right' psychological approach to maintain his stability, perhaps presenting a barrier in his quest for increased autonomy and productivity:

*[392-395] I wish to start my business, .... and I sort of need some help to help me erm, what's the word, just to balance me so if anything happens, I've got that service there to erm ask someone, my colleague or erm care coordinator*

*[486-489] That sort of conflict between trying to be relaxed about it, but know that you have to keep positive at the same time, know that it could*

*happen but keep positive at the same time (1) and be, you know, prepare yourself for the worst, but expect the best at the same time.*

### 3.5.2. Interpersonal Level

Joseph narrated his experiences using expressive sounds and repetition (e.g. “*you know*”), perhaps attempting to recruit the audience into his narrative and drawing attention to key parts of his story:

***[465-469] How do you feel about [hearing voices], that it's gone?***

*Woah, well relief really, relieved, yeah I feel relieved, you know I feel, you know it does, it does hurt when I think about it as well you know and erm (1) but I just feel like you know, to know that erm that's it gone I just feel erm (1) just a lot of relief.*

At other times in Joseph’s narrative he appeared to be possibly unsure or cautious when giving his opinion. For example, he used phrases such as ‘*How can I put this?*’ [340] or ‘*What can I say?*’ [334]. Joseph also checked with me on several occasions whether he was using the right terminology, e.g. ‘*diazepam I think it is or something, I can't remember is it, is it diazepam?*’ [140-141] potentially assuming expert knowledge on my part. It is possible Joseph felt under pressure to give the ‘right’ answer at times, this might be linked to assumptions about my role as a health care professional and the implicit power differentials associated with this. It appeared at times as though Joseph felt required to self-censor some of his views or provide a caveat ‘*I'm not saying I do believe in it or not but those things were running through my mind?*’ [97-98]. This might be an act of self-preservation with an awareness of the colonising quality of mental health diagnoses that threatens to pathologise ‘alternative’ views.

On several occasions, Joseph stepped outside of telling his personal story to make suggestions about mental health service provision. For example, incorporating religious beliefs into the EIP service’s support. In doing this, he often positioned himself as talking on behalf of other service users. Joseph may have deemed this necessary to prevent the potential for criticism that his story

is told in self-interest, or this may also have served to strengthen Joseph's preferred identity associated with an advocate role. It is also worth considering that the language and tone of my questioning may have shaped Joseph's responses:

*[346-351] You know, in the future I just hope to contribute to this sort of thing as well, because I think it's very helpful like the services that they have here are very helpful*

***[411-417] And is there anything else that you think would have been helpful or would be helpful that you haven't got? ....***

*I'm not saying the service should be religious or anything like that but I just think there should be sort of ...it might benefit them to ... actually incorporate ... .I don't know, maybe historical or (1) because people have different religions, they have different interpretations of what they experience, so maybe that would help other people, not, I've just heard from other people, what they feel.*

### 3.5.3. Ideological Level

Joseph drew upon narratives of both madness and disease, using everyday terms such as 'crazy' [40] as well more medicalised language such as 'mental illness' [83]. Despite Joseph's acknowledgement of the role of medication in reducing experiences such as hearing voices, he overtly challenged the medical approach, by highlighting the iatrogenic effects of psychiatric practice. Consequently, there appeared to be some tension in Joseph's narrative, as he negotiates his position as a patient but also identifies with more of an activist role. In challenging the medical narrative, he articulated the dehumanising experience of being attributed an identity dependent on drugs:

*[190-193] Woah, no one wants to go on medication really, you know, any, any human they feel like, you know, they feel (1) it's sort of like to know that you depend on something to keep you, you know, you don't feel human.*

Joseph's narrative also highlights the pervasiveness of societal stigma surrounding the diagnosis of paranoid schizophrenia. He refers to prevalent cultural beliefs associating the label with violence and unpredictability. While he talks about holding these views in the past, it is unclear how these powerful essentialist discourses may continue to hold implications for Joseph's sense of self. Joseph appears acutely aware that he may be positioned as a potential danger to himself or others, illustrated by his attempts to challenge and resist this narrative:

**[224-231] So what were your views about mental health before?**

*There are people like extreme cases that do, you know, have problems something like triggers off in their brain and they just go crazy and do something (1) but erm I was always like 'that person's crazy and they might switch on me' or something, but that's not the case, that's not always the case basically.*

Finally, Joseph appeared to draw upon counter narratives to highlight the role of social factors and an oppressive context in his 'unusual experiences'. He alludes to being a victim of violent crime in the past, this contextual information rendering his distrust of others, or 'paranoia' as overtly meaningful. Despite this, Joseph talks about 'treatment' or ways of managing his distress that predominantly relies on internal change. This reflects individualistic narratives dominating Western culture, which serve to obscure these environmental issues:

*[100-107] It was like very violent where I live (1) and the violence is just so erm (1) you know...every time I fall asleep I just (1) something would just boom, or there would be loud music (1) and then I wouldn't be able to sleep ....and then there was the noise pollution the er, the woman downstairs she ....was in an abusive relationship....so all that was coming up and then you had people upstairs as well who were making noise, so it was just a lot of tension as well at the same time.*

*[303-306] I feel much better.... I feel much er (1) you know, able to think about things, and more relaxed (1) and, you know, learning how to, you know, learning how to deal with aggression and anger, and pent up anger.*

## **4. DISCUSSION**

In this chapter, the key findings of the study are outlined in relation to the research questions and the existing literature. A critical evaluation of the research is presented and the implications of the findings are discussed in terms of service provision for young people experiencing a FEP. In light of these, recommendations are made regarding future research, policy and practice.

### **4.1. Revisiting Research Aims**

This study aimed to explore how young people narrated how they made sense of their 'unusual experiences' prior to, and following, accessing an EIP service. The study also aimed to identify the wider narratives young people's constructions drew upon and the implications this had for their subjectivity, experience and service utilisation.

### **4.2. Summary of Findings**

One of the benefits of using NA is that it enabled exploration of each of the participant's individual accounts. This highlighted the idiosyncratic and complex ways in which they constructed their experiences of a FEP, drawing upon multiple and seemingly contradictory discourses, including spiritual, psychological, biological and social explanations. The young people described how their understandings of their 'unusual experiences' had changed over time, influenced by narratives available in their immediate and wider contexts. In particular, they reiterated explanations provided to them by professionals within the EIP service, suggesting the discourses drawn upon by clinicians play a pivotal role in the co-construction of young people's identities.

In line with the assumptions underpinning many EIP services (e.g. Marshall et al., 2004), the young people drew upon biopsychosocial explanations of psychosis to different extents in their accounts. In some cases, this appeared to

legitimise their distress, yet also promoted deterministic causal theories with consequences for the young people's sense of self and the future. The multiplicity of narratives evident in several of the participants' stories suggested that their engagement with EIP services had facilitated the consideration of a range of perspectives to support meaning-making. Nevertheless, by considering the performative aspects of the young people's speech, and the extent to which they drew upon wider discourses, the powerful influence of the master biomedical narrative, in both tacitly and formally positioning the young people within stigmatised identities, was also evident. The extent to which each participant adopted or resisted this master narrative within their accounts differed, with the young people both explicitly, and more subtly challenging its legitimacy to maintain a sense of hope and agency. While the participants who took part in this study could be viewed as being at different stages in their recovery, the extent to which they were able to construct identities, outside that of a chronic mental health patient, appeared to somewhat protect against the losses associated with a FEP<sup>9</sup>.

#### 4.2.1. How do Young People Narrate how they Made Sense of their 'Unusual Experiences' Prior to Accessing an EIP service?

In line with previous research, the young people in this study narrated the first time they experienced 'unusual experiences', such as hearing voices or holding 'unshared beliefs', as an extremely distressing and confusing time (Reed, 2008). They described engaging in meaning-making during this period to different extents. Two of the service users narrated difficulty in making any sense of their experiences. Rather they saw them as 'normal' at the time, or understood them in the context of their current experiences, echoing findings reported by Judge et al. (2008). Three of the service users described drawing predominantly upon spiritual or supernatural explanations, often beliefs held within their family and local community, supporting findings that young peoples'

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<sup>9</sup>When considering the findings, it should be noted that there was limited attention paid to issues of race and ethnicity during the interview process and analysis. This is discussed further in section 4.4.

social networks may play a key role in their initial constructions (Newton et al., 2007). Nevertheless, Joseph described a process of stepping outside his usual belief system in his search for meaning. This might support the hypothesis that a FEP is akin to a prolonged trauma, having the potential to shatter a person's view of themselves and the world and lead to a biographical disruption (Barker et al., 2001; Dunkley et al., 2015).

The ways in which the young people described making sense of their experiences appeared linked to their help-seeking behaviours. The majority of service users did not narrate understanding their experiences within a medical framework and, thus, did not seek medical help; a common finding reported in the existing literature and cited as a major barrier for accessing mental health services (Judge et al., 2008). Only one participant described believing her experiences may be due to a 'mental illness', consequently she sought help from mental health professionals, however, she storied this taking multiple attempts and delaying access to support, a concern previously raised by Boydell et al. (2010).

Resonating with the findings from other FEP research, all of the service users described accessing mental health services due to reaching a 'crisis point' (Tanskanen et al., 2011), this was typically precipitated by others expressing concerns over their 'unusual behaviour'. For some participants, this resulted in being admitted to an acute ward prior to accessing the EIP service. Participants reported minimal opportunities for sense-making in hospital. Instead, this experience was described as highly distressing. In particular, Jade's account resonated with 'imprisonment' and 'escape' narratives described by Thornhill et al. (2004). The threat of forced treatment and the process of being diagnosed was perceived as coercive and dehumanising, leading to a profound sense of powerlessness and exacerbating her distress. Similar experiences are often described in first-person psychiatric survivor accounts (Adame & Knudson, 2007), an important finding when acute wards can be a person's first experiences of mental health services, potentially having long-term implications for their relationship to professional help (Rickwood, Deane, Wilson & Ciarrochi, 2005).

#### 4.2.2. How do Young People Construct their Experiences Following Input from an EIP Service?

In line with previous research, the young people appeared to view meaning-making as an important aspect of their recovery and their support from the EIP service (Boydell et al., 2010). All of the young people narrated that their understandings of their 'unusual experiences' had changed since accessing the service. They predominantly described receiving explanations from EIP clinicians congruent with a biopsychosocial model of psychosis (Cairns, Read, Murray & Weatherhead, 2015). For example, they frequently used medical terminology and diagnostic labels to name their experiences, yet described causal theories that incorporated a range of social, psychological and biological factors. However, while the young people initially constructed their experiences within a biomedical or biopsychosocial model of psychosis, alternative constructions often emerged throughout the course of their narrations. At times these appeared to contradict their 'official' explanations. For example, several participants drew upon spiritual or supernatural narratives, in keeping with their initial understandings. The young people's constructions supported previous claims that people have complex and idiosyncratic explanatory models for their FEP that are fluid over time (Werbart & Levander, 2005). However, the co-constructed nature of these constructions was also highlighted, challenging the usefulness of previous attempts to uncover static causal theories (e.g. Dudley, Siitarinen, James & Dodgson, 2009).

The current study supports Harris, Collinson and Das Nair's (2012) finding that young people in EIP services draw on discourses beyond those offered by the service. However, the young people often relayed the explanations and diagnoses provided to them by their doctors and care-coordinators. Furthermore, they drew upon implicit narratives in their interactions with clinicians. For example, Frank described how the questions asked about his family history, led him to consider a genetic explanation for his experiences. In the absence of further opportunities to make sense of this, this appeared to pose challenges for his sense of self and the future in light of notions of biological determinism. This highlights how discourses drawn upon by clinicians within the EIP service are influential in shaping young people's constructions,

supporting research that has highlighted the role of mental health professionals in service user's sense-making (Harris et al., 2012).

In attending to the young people's constructions, those who had actively engaged in more formal means of sense-making (e.g. through psychological therapy or support groups), appeared to construct more multi-dimensional understandings of their 'unusual experiences', drawing upon a wider range of narratives. These were also constructed as meaningful within the context of their personal histories, offering opportunities for gaining agency over experiences such as hearing voices. Furthermore, these progressive narratives suggested the experience of having a FEP could offer opportunities for personal growth, reminiscent of the 'enlightenment' genre identified by Thornhill et al. (2004). This study supports Connell et al.'s (2015) finding that young people who develop their own personal theories and incorporate them into a narrative of growth often express increased hope for the future and support. Furthermore, that for some people a personally meaningful narrative might be considered as an outcome domain in psychosis (France & Uhlin, 2006).

On the other hand, the young people who described less opportunities for sense-making, referred predominantly to bio-medical narratives to construct their experiences. These participants also raised dissatisfaction with the seemingly over-simplified explanations offered by psychiatric labels. This resonates with the critiques of diagnostic labels as sanitising past histories and obscuring context and meaning (Johnstone, 2000). These stories featured more examples of the 'endurance' narratives highlighted by Thornhill et al. (2004), centred around a hope for restitution or stability, rather than transformation, possibly in the face of the huge losses associated with being labelled as having a chronic 'illness' (Perlick et al., 2001; Thomas et al., 2013).

The young people in this study often had seemingly contradictory and conflicting ways of constructing their 'unusual experiences' again resonating with previous findings (Geekie, 2004). Finding personal meaning within the context of their life histories, rather than the consistency of their narratives, appeared to help maintain a positive sense of self. This supports Roe and

Davidson's (2005) assertion that a 'coherent' narrative should not be judged on the content, but rather the opportunity to provide the narrator with ownership over their story. Moreover, the extent to which young people adopted an illness narrative or gained 'insight' was not associated with their stage of recovery, a factor previously suggested to be important (e.g. Lysaker et al., 2002).

#### 4.2.3. What Wider Narratives do These Constructions Draw Upon and what Subject Positionings are Subjugated or Highlighted as a Result?

The master medical narrative of psychosis was present in all of the young people's constructions. For some participants, this was adopted and appeared to offer a way to legitimise their distress and access support that they had been previously denied. However, all of the young people were aware of being given a psychiatric diagnosis that positioned them not only as a passive patient, with little agency, but also lacking rationality. This is significant considering maintaining agency has been previously suggested to be key in recovery from a FEP (Andresen et al., 2003). Despite the participants drawing upon counter discourses, highlighting that multiple perspectives are encouraged by the EIP service, the power of the medical narrative was apparent when attending to the performative aspects of the young people's stories. As they challenged medicalised discourses within their narratives, they did this by ensuring they provided justification of their own views, and emphasised and dramatised their accounts to persuade the audience. Furthermore, they appeared to attempt to ensure credibility by pre-positioning themselves as having expert knowledge and evidencing their account with the views of other service users. Moreover, the young people described their fears of being misunderstood by professionals with the risk of being re-admitted to hospital hanging over them. This was associated with a pervasive sense of powerlessness, perhaps leading to the self-censoring of some of their more critical views. This suggests that the extent to which young people feel they can draw upon alternative narratives, in the presence of professionals, may be restricted by the taken for granted assumptions of the medical model and its power to define reality (Benamer, 2010); potentially with important implications for collaborative meaning-making.

Similarly, to Connell et al.'s (2015) research, participants who adopted the medical narrative to a greater extent described a 'loss of self', due to their reliance on medication in the face of distressing side-effects and a need to monitor signs of relapse. Thus, this shaped an identity associated with powerlessness and a diminished sense of hope for their future achievements. The young people's identities were also threatened, as they constructed their experiences drawing upon other culturally available detrimental narratives linked to psychosis. Several of the participants adopted narratives of 'madness' using words such as 'crazy' and 'psychopath' when describing their behaviour. In doing this, they risked positioning themselves as dangerous and unpredictable, reflecting pervasive cultural stereotypes of people who have been given a diagnosis of a 'psychotic disorder' (Knight et al., 2006). The young people also described both felt and enacted stigma by virtue of receiving a psychiatric label (Scambler, 1998). In an attempt to distance themselves from an unwanted identity, several of the young people engaged in 'othering' of other service users, who were viewed as more 'crazy', perhaps highlighting internalised societal stigma (Schneider, 2003) and inadvertently maintaining stigmatising discourses. Consequently, while the young people described valuing the 'human' touch of the EIP service, and the focus on 'real' issues, as highlighted in previous research (O'Toole et al., 2004), this did not appear to substantially afford them protection from a stigmatised identity.

The young people drew on a range of counter narratives in addition to, or in opposition to the medical model. These were predominantly spiritual, psychological and social in nature, often in line with a survivor discourse, constructing 'unusual experiences' as personally meaningful (Adame & Knudson, 2007). Three of the five participants described hearing malevolent voices associated with difficult interpersonal relationships or abuse, and all of the participants described 'paranoia' or suspicion of others in the context of tangible threats of harm, surveillance or deceit. For some participants, these alternative discourses appeared to help them to resist being positioned as to blame for their experiences and offered alternative, more agentic identities, such as those associated with advocating for others. Despite constructing their experiences in these alternative ways, discourses of individualism were also

prevalent in participants' narratives. An individualistic discourse has been found to be a prominent narrative drawn upon by clinicians working in EIP services (Duff, 2013). Within this study, participants located the responsibility for change within themselves; while this appeared to offer a sense of control, it also served to obscure the role of material realities and experiences of oppression described (Pilgrim, 2007). Again, this highlights the potentially insidious ways discourses available in mental health services shape service user's subjectivity (Terkelsen, 2009).

### **4.3. Critical Evaluation**

#### **4.3.1. Methodological Issues**

##### *4.3.1.1. Sample and recruitment*

A small sample was recruited in line with the aims of the study and a NA approach (Hancock et al., 2009). This had drawbacks by limiting the range of narratives shared. However, a larger sample would have restricted the detail attended to in each account, thus reducing meaningfulness. The recruitment process was somewhat challenging, as no participants were recruited from the first service approached. However, clinicians at the participating service played an active role in identifying and discussing the research with potential participants. The majority of people approached agreed to take part. Whilst this may indicate that the topic was of interest, it could also highlight a source of bias in recruitment. It is possible that key workers approached young people with whom they had a good relationship or they felt would be responsive to an interview situation. This potentially meant that the voices of service users experiencing greater levels of distress, or perhaps less positive experiences of the EIP service, had less opportunity to have their stories heard.

Nevertheless, the sample also had a number of strengths in terms of gathering a diverse range of perspectives. Both male and female participants were recruited across the 18-35 age range. There appears to be a dearth of research reporting the demographic characteristics of people accessing EIP services

across the UK, however, Fisher et al. (2008) collected data regarding 533 service users accessing EIP services in London. They reported the majority of the sample were men (68%), with a mean age of 23 years. The largest ethnic groups were cited as Black Caribbean (27%), White British (22%) and Asian (13%). The participants who took part in the current study identified as being Black British or British Asian. Whilst this sample may not be a representative of all EIP services, this was seen as a strength of the current study as previous research in EIP has predominantly been based on the views of White British service users (e.g. Harris et al., 2012). BME service users in EIP services have been reported to face higher rates of compulsory detention and hospital admissions and, thus, often have different experiences of accessing mental health services (Mann et al., 2014).

The present study also included participants from a range of religious faiths and educational and occupational backgrounds, adding richness to the stories told, although, in hindsight, gaining additional biographical data may have further contextualised their narratives. Participants also reported a range of experiences leading up to their referral to EIP and had been accessing the EIP service for various amounts of time, reducing homogeneity in the sample. It is also worth noting that the majority of participants involved in this study had previously been admitted to a day centre or an in-patient ward prior to the EIP service, these experiences may also have influenced how the young people constructed their experiences of a FEP.

#### *4.3.1.2. Design*

An alternative approach to the research design may have been to observe how a FEP is co-constructed in routine interactions between service users and professionals. This may have increased the validity of the findings, however, ensuring service users' stories were heard was a priority in the current study. This aimed to address a gap in the literature and ensure these perspectives were not presented in anyway subservient to more powerful professional constructions; a critique of much mainstream research (Beresford & Carr, 2012; Pilgrim & Rogers, 1999).

In keeping with much narrative research, the analysis explored participants' retrospective accounts. A longitudinal design would not have been feasible due to the methodological problems in identifying young people prior to their referral to an EIP service. However, for some participants this meant talking about how they made sense of their experiences a number of years ago, often at a time of much distress and confusion. Nevertheless, it has also been argued that traumatic experiences are particularly memorable, and people can provide relatively precise estimates of their first experiences of psychosis (Howe, Toth & Cichetti, 2006; Yung & McGorry, 1996). Whilst the methodological difficulties with this design are acknowledged, they are less of a concern for the aims of the current study and the assumptions of positionality and subjectivity (Riessman, 2000). Rather, the research was interested in how young people constructed their experiences through language, which may offer some insights into how young the participants' constructions had changed over time.

The ability of the current research to claim participant equity or empowerment is minimised by the limited service user involvement in its planning and execution. While consultation was carried out with clinical psychologists working within EIP services, service user participation would have offered a valuable contribution to ensuring the relevance of the research. This was restricted by the academic requirements and time scale for this study.

#### 4.3.2. Analytic Issues

The benefits and suitability of using NA in the context of the current study are outlined in section 2.2.2. However, NA can be critiqued on the grounds that it lacks a particular framework or definition (Riessman, 2008). Whilst, this offers a flexible approach, it poses challenges for quality assurance (Riessman, 2008). Standards for 'good enough' narrative inquiry have been proposed by Riessman and Quinney (2005), who argue that research should pay attention to language, sequence, consequence and context. The choice of an integrated framework, drawing upon a range of narrative approaches, facilitated consideration of each of these factors to different extents across each level of analysis (Stephens & Breheny, 2013). Attending to the broader context, as well as the interview

setting, can be viewed as a particular strength of such an approach (Riessman, 2008), however, it also raised a number of challenges.

Carrying out a multi-levelled analysis restricted the possibility of presenting more in-depth findings attending to content, performance and context. Indeed, any one of these levels would have generated enough material to pose challenges for the presentation of results, which also aimed to include as much of the participant's own voice as possible. As such, decisions about how to narrow the focus of the analysis were made. At the personal level, participants sometimes spoke about other aspects of their lives or their experiences of other mental health services. While subtler narratives were attended to, those directly connected to the study were prioritised. At the interpersonal level, the specifics of each participant's dialogue and interview context were prioritised, therefore, I have attempted to reflect on the impact of the researcher's own lens across interviews in section 4.4.1. and 2.3. Furthermore, at the ideological level, while a range of wider narratives were indicated in participants' accounts (e.g. those highlighting gender or neo-liberal ideals), these could not be explored in any detail. Instead, the analysis focused on master and counter narratives deemed most salient to the aims of this study.

The integrated analysis also proved challenging when presenting the narratives. At the personal level, attempts were made to move away from a purely descriptive account by attending to language and context. However, at times this overlapped significantly with the other levels, supporting Murray's (2000) assertion that the different levels are not easily separated. An integrative presentation of the analysis may have been more intuitive, however, the chosen method enabled each participant's key narratives to be attended to more closely and ensured adequate attention was paid to each analytic level.

With the above issues in mind, it could be argued that the research may have benefited from focusing more comprehensively upon one analytic level. However, the trade-off between width and depth appears justified. The failure to attend to any one of these levels would have risked minimising the importance of individuals' stories, or the social location of the narrators (Plummer, 1995); it

is unlikely this would have addressed the research questions in a meaningful way, and it would have reduced the ability to claim any wider relevance. The further ways in which the quality and 'trustworthiness' of this approach has been considered will now be discussed.

#### 4.3.3. Evaluating the Quality of the Study

##### 4.3.3.1. *Rigorousness of Procedures*

The analytic procedure ensured the research was based on systematic observations (Riessman & Quinney, 2005). Within this research, each interview was analysed in the same way. The tone and form of the overall story was noted in the initial reading (Murray, 2007) and separate readings were then carried out to consider each of the three levels of analysis as outlined in section 2.11. Observations and interpretations for each level of analysis were colour coded and recorded on each transcript (see Appendix K).

##### 4.3.3.2. *Transparency*

In an attempt to ensure the transparency and accountability of the analytic procedure, examples of extracts detailing each level of the analysis are included in Appendix K. Furthermore, potential sources of bias have been highlighted, both through personal reflexivity and considerations of the researcher's positionality (see section 2.3.) and by attending to the co-construction and context of each interview, as a key part of the analysis.

##### 4.3.3.3. *Validity*

Narratives are open to different interpretations, posing a challenge for validity claims. Riessman (2008, pg. 219) emphasises the co-constructed nature of narratives, suggesting the researcher "does not find narratives but instead participates in their creation". Furthermore, the retrospective narrative analysis employed in the current study must acknowledge selective reconstruction, possibly influenced by memory bias and the exclusion of experiences that undermine current identity claims (Herman, 1992; Riessman, 1993). Uncovering an 'absolute truth' was not viewed as either an aim or a possibility within this research, instead the hope was to ensure more marginalised stories were

heard. Nevertheless, paradoxically when interpreting and re-telling the participants' stories there is a risk of continuing to privilege professional views. With this in mind, steps were taken with the aim to ensure 'trustworthiness' of the interpretations made. Riessman (1993) suggests four ways of approaching validation in narrative inquiry; I will outline how I have attempted to address each of these in turn.

#### *4.3.3.4. Persuasiveness and plausibility*

Riessman (1993) argues that persuasiveness is greatest when theoretical claims are supported with evidence from the participant's account and alternative interpretations are considered. Throughout the results, direct quotes from participants have been included and extended interview extracts are provided in Appendix L. During the analytic procedure, multiple interpretations were considered, holding in mind issues of reflexivity such as those raised in section 2.3. The interpretations presented are those deemed most sound by the researcher in the context of each entire narrative. Where multiple interpretations were viewed as particularly salient, these have been presented to the reader to increase transparency (see for example section 3.1.3.)

The plausibility and credibility of my interpretations were also considered through seeking consensual validity (Lieblich, Tuval-Mashiach & Zilber, 1998). Findings were reviewed by the research supervisor, and discussed with clinicians with experience of working in EIP services, to ensure consideration of alternative perspectives and consensus amongst informed others. Feedback was positive in that findings resonated with professionals and were deemed clinically useful when thinking about everyday interactions with service users.

#### *4.3.3.5. Correspondence*

Checking the resonance of interpretations with the individuals who participated in the study offers further opportunities to consider validity claims and helps to address the power imbalance inherent in re-telling participants narratives. This seeks to triangulate multiple interpretations rather than reify a 'truth' (Riessman, 2008). The dynamic quality of participants' stories needs to be acknowledged when affirming validity through correspondence, however, such feedback can

provide additional theoretical insights (Riessman, 1993). Whilst gaining feedback from participants is planned, this has not yet been collated at the time of writing, due to time restrictions.

The aim of correspondence was held in mind when presenting the narrative analysis of each participant's account. Attempts were made to clarify the researcher's interpretations and distinguish these from the participant's own view of their experiences. While attempts were also made to use accessible language, this presented challenges when describing theoretical concepts integral to the analysis, such as those associated with positioning theory (Harré et al., 2009). This will be held in mind when seeking feedback from participants and when preparing findings for further dissemination.

#### *4.3.3.6. Coherence*

Agar and Hobbs (1982) suggest three types of coherence criteria by which to evaluate the validity of narrative research; global, local and themal:

- **Global coherence** refers to a narrator's overall goal in telling their account, for example, recalling past events, facilitating impression management or justifying actions. Global coherence was attended to by considering the content and the dialogical aspects of each narrative. The analysis also focused on acts of positioning exploring how participants might be constructing identities and assigning rights and duties to themselves or others (Harré et al., 2009).
- **Local coherence** speaks to what a narrator is trying to achieve within the narrative through the use of linguistic devices. This was achieved through identifying 'small stories' (Baldwin, 2006) and performative aspects of each narrative, such as expressive sounds and asides (Riessman, 2008).
- **Themal coherence** relates to the content of each narrative, highlighting important and repeating themes. This was attended to by identifying key

narratives for each participant, incorporating pivotal events and re-occurring stories (Phoenix, 2008).

Agar and Hobbs (1982) suggest that interpretations are strengthened when they can be understood within each type of coherence. Whilst the interactional nature of each narrative placed some constraints upon this, throughout the analytic process, initial hypotheses were considered and modified in light of the above criteria.

#### *4.3.3.7. Pragmatic use*

Riessman (2008) asserts that the validity of narrative research lies in its ability to inform future studies and to contribute to social change. Whilst the current study does not seek to make generalisability claims, White and Epston (1992) argue that individual narratives reflect culturally available and appropriate stories shaped by historical, social and institutional structures and, thus, can provide an insight into wider perspectives. Therefore, this study offers valuable findings for informing policy, research and practice with young people experiencing a FEP (discussed further in section 4.5). These findings may have an impact through dissemination to participants, EIP services and any resulting publications or presentations. A pivotal aim of narrative research is 'to enable voices to be heard that are usually silent' (Plummer, 2001, p. 248). The first-person narratives presented in this research highlight the importance of having access to multiple and alternative narratives to construct their experiences. Therefore, these narratives can in themselves offer a tool of resistance, enhancing the social position of more marginalised voices (Schneider, 2012). Readers may identify with participants' narratives or find new ways of making sense of their own experiences (Chase, 2005).

#### *4.3.3.8. Epistemology*

Consistent with a social constructionist epistemology, this study aimed to identify how experiences of a FEP are constructed through language (Willig, 2008) and how subject positions are offered, accepted or resisted in interpersonal talk (Burr, 1995). This approach also aimed to ascertain wider discourses shaping narratives and the associated power implications for

individual subjectivities. This acknowledged the implications for material realities, including being labelled, forcibly medicated, discriminated against and silenced. Such findings offer real implications for informing institutional and social practices.

#### **4.4. Reflexive Review**

A process of ongoing reflexivity was viewed as central to this study, in light of the subjective nature of NA and sources of bias inherent in any qualitative research (Plummer, 2001). My motivation to carry out the research is further attended to in Appendix B. This invites the reader to appraise the findings in light of the researcher's potential contribution to the construction of meanings, and acknowledges the impossibility of taking a position of objectivity on the subject matter (Willig, 2013). Ricoeur (1897) argues that narrative interpretation is impacted on by both the researcher bringing their ideas to the narrative but also through narrator trying to convince the audience of their story. These issues have been attended to as an integral part of analysis and by keeping a reflective diary throughout the research process (Appendix C).

##### **4.4.1. Power and Difference**

Power relations will inherently come into play in the process of conducting and representing research, raising ethical and moral decisions and dilemmas (Bhopal & Deucha, 2015). Power differentials are explicit in the current study, where I carried out research with mental health service users who may typically be afforded less of a voice than professionals. Gergen and Gergen (2003) warn that researchers risk further subjugation of researched groups through the dissemination of their findings. Consequently, there is a responsibility to reflect on the moral dimension of telling someone else's narrative that involves choices made by the researcher (Hunter, 2010; Liamputtong & Ezzy, 2005). Throughout the analytic process, I questioned in whose interest my interpretations were made and attempted to present participants' stories in a credible and trustworthy manner whilst avoiding 'romanticising' their narratives (Fine, 2003).

My own lens as a White-British female in clinical psychology training will also be inherent in my worldview and my assumptions about what defines 'normality'. As such, my experiences, beliefs and epistemologies influence what I might consider to be a 'better' or more helpful story or identity. For example, the privileging of agentic identities may reflect the dominance of Western individualistic values in the narratives I draw upon. My positionality, as well as my critical stance, will have to some extent shaped the translation of the participants' stories, and other possible readings of the data are acknowledged.

While it is not possible to reflect on all aspects of power and difference, the following sections consider issues felt to be particularly salient to this study.

#### *4.4.1.1. Race and Culture*

My identity as a White British female, may have a particular relevance for the findings of this study as I interviewed participants from different ethnic and cultural backgrounds to myself. When considering the demography of EIP services (Fisher et al., 2008), and the participants who took part in the research, it is important to acknowledge that issues of race, ethnicity and culture featured minimally in the narratives told. This is also striking in light of the existing research that highlights how these factors can impact upon peoples' experiences of accessing mental health services (Mann et al., 2014; Rabiee & Smith, 2014).

The rationale to not ask about these issues explicitly was based on a wish to avoid asking leading questions that might shape the narratives around particular topics (Kim, 2016). Furthermore, I wished to avoid the criticisms of much research that people from BME backgrounds can be portrayed as the 'problematic other' when referring to beliefs about distress that contrast with dominant views in Western mental health services, and to acknowledge that alternative views are often held by people from diverse backgrounds and are not specific to minority or migrant cultures (Kalathil & Faulkner, 2015).

Nevertheless, on reflection it is acknowledged that without a clear sign that the researcher was open to hearing about cultural difference or racism, participants'

may not have felt able to discuss personal experiences related to this. Without the opportunity to name and explore these issues, participants may not have had the chance to reflect on how such experiences might relate to their FEP or accessing EIP services. Furthermore, it could be assumed that partly due to my identity as a White British female, it is possible I have had very different lived experiences to those of my participants. As such, it is possible that I was less perceptive about specific issues of ethnicity and culture that did arise as the participants narrated their experiences, and consequently these discussions were not expanded upon during the interviews.

#### *4.4.1.2. Class, Gender and Religion*

It should also be highlighted that three out of five of the participants who took part in this study were female. This is despite research suggesting that EIP service users are predominantly male (Fisher et al., 2008). It is possible that female participants perceived it to be easier to share their experiences with a researcher who also identified as female, but not necessarily so. However, it is acknowledged that similarities and differences between the researcher and participants in terms of gender may have shaped or restricted the co-construction of individual narratives and the issues participants felt able to share. Furthermore, other issues likely to be pertinent to the participants' lives, such as religious background and class, were not explored at any length during the research process. Both religious affiliation and class have previously been suggested to play an important role in the experiences of distress and access to mental health services (Islam et al., 2015; World Health Organisation, 2014). Again, perceived differences between the researcher and participants may have silenced narratives around these issues.

Given the reflections highlighted in sections 4.4.1.1. and 4.4.1.2., if I were to carry out this research again, I would aim to consider issues of power and difference more carefully during the research design, data collection and analysis. I would reflect more carefully on the visible and invisible differences between myself and participants and how this might influence the information shared or the questions I asked. I would consider more carefully how I could ensure participants felt able to talk about issues of difference, perhaps by

asking explicit questions, providing examples or using self-disclosure during the interviews (Abell et al., 2006; Reinhartz & Chase, 2003). Additionally, seeking relevant stakeholder involvement, including service user perspectives, in the development of interviews may have been beneficial. Reflecting on these limitations has been a valuable learning experience and will shape how I attend to similar issues in future research and clinical work.

#### 4.4.2. Interview Process

Issues specific to each interview have been discussed as part of the analysis and in section 2.3. Nevertheless, a common reflection across interviews was the challenge in attempting to speak outside of dominant narratives. On reviewing my transcriptions, I had refrained from using words such as 'psychosis' unless first brought up by the participants. However, at times this appeared to complicate questioning and perhaps influenced participants' own choice of language. Furthermore, semi-structured interviews were used to facilitate conversations around topics relevant to the research. However, I was aware that my fears about going 'off topic' meant at times I asked a question, rather than followed up on themes arising from the participants' speech. Finding a balance in managing 'digressions' is acknowledged as a challenge of NA and a different approach such as an unstructured interview may have uncovered alternative stories (Riessman, 2000).

#### 4.4.3. Language

The use of terms such as 'psychosis' and 'FEP' within this study could easily be critiqued for reifying dominant constructions of 'unusual experiences'. This was carefully considered in the design and write up of this research. However, the research title and questions were constructed with the aim of achieving resonance and accessibility across a wide audience with various perspectives, particularly those where such dominant conceptualisations may be commonplace. Corstens et al. (2013) make suggestions for research and practice based on emerging perspectives from the Hearing Voice Movement. They recognise the challenge of finding neutral language that is not rooted in the assumptions of the biomedical model and suggest using descriptive phrases such as

'unusual beliefs' as opposed to 'symptoms' and 'delusions', within the current study I have attempted to be mindful of this as much as possible.

#### 4.4.4. Epistemological Reflexivity

It is important to acknowledge that the findings presented are not only shaped by the researcher's values, experiences and interests, but also by the methodological and epistemological assumptions of the research (Willig, 2001). NA, underpinned by a social constructionist epistemological position, offered an approach that attended to language and discourse, and how participants constructed their experiences of a FEP within a particular context. Social constructionist approaches have been critiqued for failing to attend to materiality and power (Nightingale & Cromby, 1999; Hollway & Jefferson, 2000). As discussed in section 2.1, the current study adopted an epistemologically relativist and ontologically realist position, with the aim of acknowledging material practices and subjectivity in the construction of participants' narratives. While this approach has been critiqued for leading to inconsistencies by only selectively challenging knowledge claims (Harper, 2011; Woolgar & Pawluch, 1985), Elder-Vass (2012) argues that it can offer a coherent approach that enables us to make connections between individual human agents with causal powers and the discursive pressures that might influence them.

Nevertheless, taking this approach to the research will still have illuminated certain aspects of the data, while obscuring others. For example, by giving precedence to the role of language in the construction of reality, it could also be argued that this approach has limited utility for highlighting non-discursive forms of meaning-making and communication (Riessman, 2008). Furthermore, the approach limits any generalisability or 'truth' claims, which positivist research methods may attempt to address (Willig, 2001).

Taking a different approach to address the aims of the current study is likely to have brought different aspects of the data to the forefront. For example, an IPA approach assumes there is some correspondence between what a person says and their subjective experience, with the role of the researcher to interpret participants' accounts to offer an 'insider perspective', rather than participating

in the co-construction of a particular narrative (Harper, 2011; Willig, 2001). Therefore, taking a phenomenological approach, using a method such as IPA, may have better addressed questions about the participants' lived experience of a FEP, by exploring, the participants' 'inner worlds', including their thoughts and feelings and the quality and texture of their experiences of a FEP (Willig, 2008).

## **4.5. Implications and Recommendations**

### 4.5.1. Clinicians Working with Young People During First Episode of Psychosis

In support of previous research (e.g. Harris et al., 2012), this study suggests that mental health professionals play a key role in shaping how young people construct their FEP. Furthermore, providing purely biological explanations may limit the extent to which young people can maintain a sense of hope or agency (Perry et al., 2007). In acknowledging this responsibility, clinicians can support service users in accessing a range of diverse perspectives. This may be through the formal explanations they provide via psychoeducation, but also by attending to the discourses they draw upon in their everyday interactions with young people and their families. Specifically, clinicians could refrain from emphasising one particular view to clients and instead attempt to introduce multiple perspectives by sharing first-person accounts of psychosis, for example those published by Romme et al. (2009) in 'Living with Voices: 50 Stories of Recovery'. Clinicians might be supported to do this if the standardised information provided to service users and their families, for example via service websites and leaflets, also presented multiple theories about the causes of psychosis, highlighting that it is a contested area.

The value young people place on making sense of their 'unusual experiences' is also highlighted by this study. There are numerous ways in which service users can be exposed to a plurality of explanations and positive role models to aid this process. These might include, peer support, perhaps in the context of user-led support groups such as those offered by the HVN (Corstens, 2014). Such groups can also promote the development of peer relationships, deemed to be an important aspect of development in young adulthood (McGoldrick et al., 2015).

In line with published guidelines for psychosis (NICE, 2014) psychological therapy should be routinely offered to young people experiencing a FEP and where possible as a 'first line treatment'. This can facilitate an exploration of the impact of psychosocial experiences otherwise obscured by the effects of prematurely prescribed anti-psychotic medication (Johnstone, 2011). Psychological therapy could be discussed and offered at first assessment and subsequent review meetings. An obvious barrier to this suggestion may be the limited resources available to offer psychological therapy to all service users. Thus, commissioners should aim to prioritise the recruitment and training of staff to offer skills in delivering psychological therapy.

Opportunities for meaning-making for people who do not wish to engage in therapy can also be provided during routine conversations with care-coordinators by creating a space for service users to co-construct both positive and negative aspects of their FEP using their own words and theories (Dillon & May, 2002; Thornhill et al., 2004). A positive and trusting relationship is likely to be key in enabling service users to speak openly about their personal understanding of psychosis to professionals, as a fear of these views being pathologised or invalidated may potentially lead to resistance through disengagement (Terkelsen, 2009). Clinicians might facilitate these relationships through offering a collaborative, non-judgemental approach and demonstrating respect and empathy by listening to service users' views and offering information and explanations in a tentative manner (BPS, 2014). Time to build these relationships and offer service users' space to narrate their experiences will need to be reflected in clinicians' job plans and supported via supervision and training.

To further promote the collaborative approach to care-planning as valued by participants, clinicians might share the ambiguity and gaps in knowledge around diagnosis, causality theories and treatment for psychosis to enable young people and their social networks to make informed choices about their support and avoid being positioned as a 'passive patient'. Specifically, service users should be supported to make decisions about the types of 'treatment' they wish

to receive and be provided with information addressing the potential benefits and risks of different options, including side effects of medications.

#### 4.5.2. Clinical Psychology and First Episode Psychosis

Clinical Psychologists (CPs) are in a privileged position to support the implementation of the above suggestions through training, consultation, supervision and co-working with other professionals (BPS, 2007). In particular, facilitating reflective practice groups within teams may support the deconstruction of taken for granted language in interactions with service users (Finlay, 2008). Within CP's practice the concept of 'relational reflexivity' (Burnham, 2005) may be of benefit to encourage responsive listening to service users' talk and create a space that offers a polyphony of viewpoints in both individual and family therapies.

The role of social constructionist informed interventions may support young people to gain 'outsight' as opposed to 'insight' into their experiences (Smail, 2005). For example, Narrative Therapy (NT; White & Epston, 1990) aims to externalise and resist dominant social discourses that facilitate pathologised identities and construct alternative and preferred stories (Morgan, 2000; White, 1995). Alternative narratives can also be 'thickened' and elaborated on by outsider witnesses, such as other young people who have experienced a FEP or service user' friends and family. Such approaches might support the co-construction of a contextualised and meaningful narratives that acknowledge the trauma of a FEP, yet offer agency over 'unusual experiences' and potentially opportunities for personal growth (Pietruch & Jobson., 2012).

As highlighted by this study, EIP services may not be the first services accessed by young people experiencing a FEP. As such, CPs could offer consultation and training to health professionals across a range of services, including Primary Care (PC), acute services and third sector organisations This might aim to increase awareness around FEP and the ways in which professionals might share information about psychosis, for example using the BPS (2014) report to highlight diverse perspectives.

CPs are also well positioned to ensure a multiplicity of perspectives of a FEP are heard using a variety of different platforms. For example, by contributing to practice-based research, anti-stigma campaigns, and when raising awareness of FEP among young people, for example providing psychoeducation in schools (Malla et al., 2015).

#### 4.5.3. Early Intervention in Psychosis Policy

Currently, the majority of mental health services in the UK are underpinned by the medical model. Consequently, huge shifts are warranted to bring about long-term change and enable an approach where service users can access a range of constructions of unusual experiences. There are numerous barriers and challenges faced when working towards these changes. For example, the training programmes for mental health professionals may be more or less closely aligned to the medical model. Furthermore, services may have a culture of offering 'paternalistic' rather than 'collaborative' support, with a perceived 'duty of care' to offer medical treatment (BPS, 2014).

Steps towards effecting wider change will need to involve facilitating a collaborative approach in services and should include 'Experts by Experience' in all aspects of service development and policy (Miller, Chambers & Giles, 2015). 'Experts by Experience' can take a lead or participate in research, recruitment, facilitating service user involvement groups and planning care. Furthermore, lived experience of accessing mental health services should be viewed as an important source of knowledge when training mental health professionals (Repper & Breeze, 2007). Offering support for people experiencing a FEP in less medicalised contexts may also be important, especially for people who do not subscribe to an illness model. This might be done by offering flexibility around appointments in community and culturally sensitive locations, offering self-referral pathways and accepting service users may choose to receive part or all of their support outside of the mental health system (BPS, 2014).

The 'Understanding Psychosis and Schizophrenia' report (BPS, 2014) is an example of an attempt to move towards wider change in how psychosis is

viewed and supported in services. Additional mainstream publications such as this are warranted, with further acknowledgement of specific issues affecting people from BME backgrounds (Kalathil & Faulkner, 2015). The young people from BME backgrounds in this research often constructed their experience within a spiritual framework. Furthermore, they highlighted cultural beliefs that led to a mistrust of mental health services as a barrier to help-seeking. As such, supporting the development of cultural awareness in EIP teams and increasing partnership working with religious leaders and organisations in the local community is likely to be beneficial (Majumdar et al., 2004).

Despite the drive for practising with 'diagnostic uncertainty' (Singh & Fischer, 2005), the young people were aware of being given a diagnosis, which often increased distress and perceived stigma. As such the rationale for the requirement of diagnostic labels and the way in which this is decided and communicated needs to be carefully considered. Furthermore, the young people in this study raised a range of side effects from their medication that at times hindered recovery. In light of this it can be suggested that within EIP services, prescription of neuroleptics should be cautious and postponed where possible (Bola, Lehtinen, Cullberg & Ciompi, 2009). An alternative approach to service provision in FEP that promotes a short-term role for medication, as well as facilitating social connections and multiple perspectives, is the Open Dialogue approach, which is increasingly recognised across a range of countries and addresses many of the potential barriers to recovery highlighted in the current study (Seikkula, 2011).

Currently, the majority of research exploring psychosis and FEP continues to be based on the assumption that psychosis is predominantly a result of a biological illness. It has been suggested that this is strongly influenced by pharmaceutical companies, who have funded the majority of research into 'schizophrenia', and have a vested interest in publishing data supporting the efficacy of medical interventions (Mosher, Gosden & Beder, 2013). Therefore, to enable other perspectives to be equally valued within services and heard by service users, there is an urgent need for research funding that further explores social, psychological and cultural influences on experiences of psychosis. Furthermore,

this research supports the assertion that ‘unusual experiences’ are often meaningfully linked to adverse past experiences. Thus, policy guidelines should aim to facilitate interventions that are truly preventative by addressing the known psychological and social factors that contribute to distress, such as poverty and abuse, and reducing inequalities across society (Wilkinson & Pickett, 2010).

#### 4.5.4. Suggestions for Future Research

Additional qualitative research exploring first-person accounts of accessing EIP services from services users from a range of diverse social and cultural backgrounds is required (Chase, 2005). While these might include ‘recovery narratives’, less positive narratives of FEP that validate the level of distress experienced by many young people should not be neglected (Roussi & Avdi, 2008). This should also encourage more service user-led projects to ensure participant’s authorship is prioritised (e.g. Pitt et al., 2007).

Whilst acknowledging the methodological challenges, future research could explore how young people outside of mental health services construct a FEP offering valuable comparisons and contributing to a more comprehensive literature base. In further support of the EIP agenda, future research might also ask young people what they feel might have prevented their FEP.

#### **4.6. Conclusion**

This research suggests discourses available with EIP services can play a key role in shaping how young people construct their FEP. Despite the young people in this study drawing upon a range of narratives to explain their ‘unusual experiences’ the power of the biomedical model was implicit in their accounts. This appeared to threaten their attempts at personal meaning-making and risk positioning them within stigmatised identities. While these findings are based on a small number of accounts, they highlight the benefit of mental health professionals attending to language when scaffolding young people’s sense-making, and the importance of privileging multiple perspectives to facilitate a sense of agency and hope.

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## **5. APPENDICES**

### **Appendix A: Literature Search Strategy**

#### **Search Terms**

A range of search terms were used in an attempt to identify relevant literature relating to how young people construct their experiences of FEP. The key search terms, combined search terms, (filters) and Boolean operators 'AND' and 'OR' are detailed below:

**S1** Psychosis (qualitative methodology)

**S2** First Episode Psychosis (age range 14-35)

**S3** Early Intervention in Psychosis (qualitative)

**S4** Psychosis AND Explanation\* OR Belief\* OR Construction\* OR Meaning\* OR Narrative\* OR Discourse\*

**S5** First Episode Psychosis AND Explanation\* OR Belief\* OR Construction\* OR Meaning\* OR Narrative\* OR Discourse\*

**S6** Early Intervention in Psychosis AND Explanation\* OR Belief\* OR Construction\* OR Meaning\* OR Narrative\* OR Discourse\*

#### **Inclusion and Exclusion Criteria**

First Episode of Psychosis articles were included if they focused on the experiences of people aged 14 -35 (typical age range associated with EIP services) and explored individual's subjective experiences of first episode psychosis, as opposed to family members' or health professionals' views. Studies were included from after 2001 as this date reflects the EIP service policy implementation guidelines and the wider introduction of EIP service in the United Kingdom (Department of Health, 2001). Qualitative methodology was prioritised due to the nature of this topic and articles not written in English were excluded.

## **Search Strategy**

The literature search began with the broad search terms of 'Psychosis' and 'First episode of psychosis' returning a total of 99,161 and 3,081 articles respectively. Therefore, a systematic search based on the terms and inclusion criteria listed above was carried out to refine the results. Titles were checked initially to ensure relevance to psychosis, FEP or Early intervention in Psychosis. Abstracts were then scanned to ensure relevance to the topic. The reference lists of relevant papers were hand-searched and Google scholar was searched (based on the above search terms) to locate additional grey literature (e.g. unpublished doctoral theses), policy and guidelines related to mental health services and psychosis.

## **Appendix B: Reflections on Choice of Topic**

My interest in this topic was fostered both by the values underpinning my clinical psychology training but also my experiences of working clinically with people having experiences of psychosis. It is important to reflect on these personal and professional experiences as they will have informed the design, analysis and presentation of this research, over other possible readings.

Whilst I often find myself taking medical terminology and diagnostic labels for granted, I have increasingly questioned the use of psychiatric labels and the power these can have over how people talk about themselves and are perceived by professionals and wider society. Nevertheless, my clinical work has introduced me to many individuals who have reported diagnosis and medical interventions to be extremely beneficial, if not potentially lifesaving. Furthermore, I have witnessed the difficulties faced by clinicians working with minimal resources in acute mental health settings with people in a high state of distress. As such I hoped to avoid being in anyway blaming of individuals, in taking a somewhat critical stance to the dominance of the medical model. However, my enthusiasm for this topic has been shaped by those people who I have worked with, for whom in my eyes, the iatrogenic effects of medicalised approaches have been more salient. As such, I feel strongly about the need for clinical practice to be shaped by people who have first-hand experience of psychosis.

My interest in the topic was particularly nurtured by my past experience of working with a young person who was experiencing unusual beliefs and hearing voices in the context of a traumatic history, their meaning-making influenced strongly by their cultural and religious beliefs. They had been given a diagnosis of 'treatment resistant schizophrenia', which was reiterated to them repeatedly during medical reviews. I was struck by the power of the medical model in relocating blame for ineffective medication to an incurable disease and the profound impact that this labelling appeared to have for shaping this young person's sense of hope. The paradoxical effect this approach had by hindering engagement and meaning-making, and the sense of powerlessness faced in

any attempt to challenge its legitimacy, is still something I think about regularly. This experience had a profound effect on my view of the power associated with 'expert knowledge' and the threat this poses to overshadow service user's identities and subjectivity. Thus I hoped my research would at the least enable other perspectives to be heard. However, my diverse experiences of working clinically also meant I wished to refrain from privileging 'one truth', rather promote the equal acknowledgement of multiple perspectives. Throughout the research process it has helped to keep this in mind when questioning my assumptions during the analytic process. It also appears important to acknowledge at the time of the analysis I did not have experience of working in an EIP service, thus came to this research with a somewhat naive view of the assumptions underpinning services, based on the literature rather than clinical experience. While I am supportive of the concept of early intervention and the aim to offer a more youth-centred approach, I feel this lack of direct experience of working in a service was beneficial in facilitating a more curious stance.

## **Appendix C: Reflective Diary Extracts**

Bold (2011) argues that keeping a reflective diary during the process of narrative research is invaluable for engaging reflexively with the data. I found this process most beneficial during the data collection, analysis and write up stage of the research to reflect on the personal assumptions I was bringing to the reading of the data and also the co-construction of the narratives. Brief examples of extracts from the reflective diary are presented here:

### Interviews: Day One

Interviewed Leo and Shoma, unfortunately this was straight after each other, would have been good to have some extra time to reflect on the first interview and thought about how I set it up and how the questions were received. Leo was very talkative; I was worried that the participants may find it hard to talk in the interview context but this did not seem the case with either interview. Hopefully this means that I was able to create a relaxed atmosphere to some extent or perhaps that the chance to further share their past experiences was welcomed. I noticed for both interviews I was very conscious of the language I was using, trying not to ask any leading questions, but also worried this led to some clumsy questioning, as I was overthinking and I probably missed some opportunities to follow up on things and make it feel like more of a conversation.

Leo's story was very positive, while being very open during the interview I got the impression that she was a little guarded, almost expecting me to challenge this is somehow maybe? It felt like she was working hard to protect her identity as separate from a 'service user', as she talked about her outside interests a lot and her plans for the future. Shoma talked about some very difficult past experiences and I was trying to balance not being leading but also making sure she did not feel invalidated with neutral responses. Her story was very moving and I got the impression that she really values her voices, and there was something very sad about the loss of these in the face of 'getting better'. I was really struck about how meaningful these were in the context of her past history, but also how distressing they were at the same time and the ambivalence this seemed to cause. I wondered how able she felt to share this with me because

she seemed to tread carefully around this subject even though she had been so open about other aspects of her experience.

### Write up of the Analysis

I am really struggling to make a decision about how to best present each participant's narrative. Feel I am under a lot of pressure to get this 'right' for them. I have a lot of rich data and it feels impossible to convey this within the limited space, I have to sacrifice a lot of their speech which seems very meaningful and it is a hard process. In hindsight maybe recruiting less participants would have been more appropriate for this type of analysis, but each participant's narrative is so different I think that would have been a great loss. It is also difficult to separate the three levels of analysis out, they are all connected and hard to define, but I think it is helping to ensure I look at it through different lenses and I feel it adds a lot to the analysis, so I am happy I chose this method. I am also aware of the language I am using, some of the jargon relevant to positioning theory may not be that reader friendly and I am aware of asking for feedback from the participants, so trying to get a balance with this.

## Appendix D: Interview Guide

### Overview

The semi-structured Interview offers a number of flexible questions aimed at gathering participants' narratives about the time prior to and during their engagement with the EIP service. The order and wording of question will be adjusted in light of the participant's answers and the flow of the conversation. Prompts may also be used flexibly to enable clarification of questions or facilitate more detailed responses.

### Introduction

- Explain confidentiality and right to withdraw
- Request Consent
- Explain aims and topic of discussion
- Demographic details including name, age, ethnicity and amount of time accessing EIP will be gathered verbally.

### Interview Questions

1. What kind of experiences led up to you accessing the (EIP) service?
2. Before you came into contact with the service, what did you make of these experiences?
3. What did the people around you make of these experiences?
4. How did you feel about accessing an EIP service?

*Prompt: Did you try to get support anywhere else before accessing the EIP service?*

5. How would you currently explain some of the things you have/ are experiencing?
6. Has your understanding of these experiences changed since being in contact with the EIP service?

*Prompt: Why do you think this is?*

7. What explanations have been given to you by different people in the EIP service?

*Prompts- How do these explanations fit for you / how useful are they?*

8. Has anything/anyone else helped you make sense of your experiences?

*Prompt – are there particular conversations you have had / any information you have been given? E.g. family / friends / peers*

9. How relevant does the support offered by the EIPs feel for you?

*Prompt – What do you do if you do not agree with this?*

*Is there anything else that would be helpful?*

## **Closing**

- Review consent
- Debrief, including concerns regarding information shared. Discuss how participant experienced the interview, how they are feeling and whether they would like additional support.
- Ensure participant has researcher's contact details and answer any remaining questions.

## Appendix E: Participant Information Sheet



### Participant Information Sheet

**Version: 2**

**Date: 02.10.2015**

### UNIVERSITY OF EAST LONDON

School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

### **The Principal Investigator**

Samantha Harris

### **Contact Details:**

E-mail: [u1331794@uel.ac.uk](mailto:u1331794@uel.ac.uk)

### **Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need to consider in deciding whether you would like to participate in a research study.

The study is being conducted as part of a Doctorate degree in Clinical Psychology at the University of East London.

### **Project title**

Exploring Young Peoples' Constructions of a First Episode of Psychosis

### **Purpose of the research**

This research aims to explore the experiences of young people who receive

support from an Early Intervention for Psychosis Service.

People may have lots of different experiences that mean they might seek support from an Early Intervention in Psychosis service.

Some examples include:

- Hearing voices or sensing things that other do not
- Holding strong beliefs that many others do not share
- Difficulties with thinking and concentrating
- Changes to behaviour such as lacking motivation or interest in things

This study is interested in how young people make sense of these types of experiences and if this has changed since receiving input from an Early Intervention Service.

Research has suggested that how people understand these types of experiences can affect how distressing or upsetting they are. It is hoped that this research will increase understandings of how Early Intervention Services and mental health professionals can offer the most relevant information and support for young people.

### **What do I need to know before deciding to take part?**

Before deciding to take part in this research, please feel free to contact the researcher using the details provided if you have any further questions or concerns. Before taking part you will be asked to sign a consent form. This also explains that you are able to withdraw from the study at any time during the research without giving a reason (up until the point where your interview has been transcribed and anonymised). If you do decide to withdraw from the study this will not have any impact on the support provided by the Early Intervention Service.

### **Who will be informed that I am taking part?**

A member of staff involved in your care at the Early Intervention Service will be aware of your involvement in the research. Your G.P will also be informed that you are taking part. A member of the Early Intervention Team or an appropriate

service may also have to be informed of your involvement in the study if the researcher has serious concerns about your safety or the safety of others. This would be discussed with you in the first instance wherever possible.

### **What happens if I decide to take part?**

If you decide that you would like to take part in this study you will be invited to talk to the researcher about how you make sense of some of your experiences and the reasons you are in contact with the Early Intervention Service. During the interview you might also be asked about explanations, or conversations you have had, that may or may not have helped to explain some of your experiences. The interview will last approximately 60 minutes and will be carried out by myself in a private space where you can talk confidentially. The interview will be recorded for the purposes of the research. You may bring a family member, friend or carer with you.

### **What happens to the information I provide?**

The information you provide during the interview may be used for the purposes of the study but will be kept confidential. You will remain anonymous in any reports or resulting publications and any names or identifying information will be changed in the write up. Some extracts from the interviews will be used within the final report. There is a small possibility that an extract may be identifiable by someone known to you such as a family member or a member of the Early Intervention Service, however the quotations used will be chosen carefully to reduce any risk of this. I will be responsible for transcribing the interviews. The information from interviews and signed consent forms will be stored safely in a locked space to ensure they are not accessed by anyone other than me and my supervisors. The information you provide during the interview may be kept securely for 3 years after the completion of the study.

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

The study results will be written up as part of a doctoral thesis and submitted to the University of East London. There may also be the opportunity for the thesis to be published in an academic journal. Participants taking part in the study will also be provided with a summary of the findings.

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

Taking part in this research will offer a space to talk openly about your experiences, which some participants may find beneficial. It is also hoped that sharing how you make sense of your experiences, and how this has impacted upon you, will provide important information on how mental health services can better meet the needs of service users and help people to explore their experiences in helpful and empowering ways.

**What are the potential risks of taking part?**

If you decide to take part in this research, your safety and health will be prioritised. However, due to the nature of the research topic there is a risk that people may become upset when speaking or thinking about past or present experiences. With this in mind, the interview will be carried out as sensitively as possible and you will not have to talk about any topics that you do not feel comfortable to discuss.

If you were to become very upset or distressed during the interview, the interview will be stopped and the researcher will speak to you to ensure you are feeling safe and to check whether or not you wish to continue the interview. The researcher will also ensure you have access to an appropriate source of support. If in the event you the researcher becomes very concerned about your well-being this information will be shared with a member of the Early Intervention Team involved in your care.

While all information collected during the interview is confidential and anonymous, any serious concerns about your safety, or someone else's safety, raised within the interview may need to be shared with a member of the Early Intervention Team or the appropriate service. This would only be done with the aim of protecting your well-being and would be discussed with you first wherever possible.

**Who can I contact about this research?**

Please feel free to ask any further questions you might have about this research.

You are able to contact:

Samantha Harris (Trainee Clinical Psychologist at the University of East London)

Dr Maria Castro Romero (Academic tutor at the University of East London).

Thank you in anticipation.

Yours sincerely,

Samantha Harris

## Appendix F: Participant Consent Form



### Participant Consent Form

**Version: 2**

**Date: 02.10.2015**

Participant Identification Number:

#### UNIVERSITY OF EAST LONDON

#### Consent to participate in a research study

Title of Project: 'Exploring Young Peoples' Constructions of a First Episode of Psychosis'

Name of Researcher: Samantha Harris

Please initial box

1. I confirm that I have read the information sheet dated 02.10.2015 (version 2) for the above study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained.
  
2. I understand that my participation is voluntary and that I am free to withdraw from the study (up until the point that the interview has been transcribed and anonymised) without giving any reason. If I choose to withdraw I understand that my medical care or legal rights will not be affected.
  
3. I agree to my General Practitioner being informed of my participation in the study.
  
4. I understand that with the exception of my G.P and a key worker in the Early Intervention Team, my involvement in this study will remain confidential. Any data gathered from interview will remain anonymous and confidential and only the researchers involved in the study will have access to identifying data.
  
5. I understand that there are limits to confidentiality if any serious concerns arise about my safety or the safety of another person during the interview. Under these circumstances information I have provided may be shared with the Early Interview Team or a relevant service to ensure my safety

and/or the safety of others. I understand this would be discussed with me in first instance wherever possible.

6. I agree to take part in the above study.



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

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

# Appendix G: University of East London (UEL) School of Psychology Research Ethics Approval

## EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES

[uel.ac.uk/qa](http://uel.ac.uk/qa)

Quality Assurance and Enhancement



27<sup>th</sup> October 2015

Dear Samantha,

<b>Project Title:</b>	<b>Exploring Young Peoples' Constructions of a First Episode of Psychosis</b>
<b>Researcher(s):</b>	<b>Samantha Harris</b>
<b>Principal Investigator:</b>	<b>Samantha Harris</b>

I am writing to confirm that the application for the aforementioned NHS research study reference **15/LO/1445** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **27<sup>th</sup> October 2019**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk).

**Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.**

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

Yours sincerely,

**Catherine Fieulleateau**  
**Research Integrity and Ethics Manager**

**For and on behalf of**  
Professor Neville Punchard

University Research Ethics Committee (UREC)

Docklands Campus, University Way, London E16 2RD  
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3394 MINICOM 020 8223 2853  
Email: [r.carter@uel.ac.uk](mailto:r.carter@uel.ac.uk)



Research Ethics

Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

## NOTICE OF ETHICS REVIEW DECISION

### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**SUPERVISOR:** Maria Castro    **REVIEWER:** Elizabeth Attree

**STUDENT:** Samantha Harris

**Title of proposed study:** Exploring Young Peoples' Constructions of a First Episode of Psychosis

**Course:** Professional Doctorate in Clinical Psychology

**DECISION** (*Delete as necessary*):

**\*APPROVED**

**APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

**NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must

be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**Minor amendments required** *(for reviewer):*

**Major amendments required** *(for reviewer):*

**Confirmation of making the above minor amendments** *(for students):*

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*

Student number:

Date:

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

MEDIUM

LOW

*Reviewer comments in relation to researcher risk (if any):*

**Reviewer** (*Typed name to act as signature*): Elizabeth Attree

**Date:** 06/03/2015

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)*

**PLEASE NOTE:**

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here:

<http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

## Appendix H: NHS Research Ethics Committee Approval



### **Health Research Authority** London - London Bridge Research Ethics Committee

Skipton House  
80 London Road  
London  
SE1 6LH  
Telephone: 020 7972 2580

26 October 2015

Miss Samantha Harris  
Camden and Islington Primary Care Trust, 4th Floor East Wing  
St. Pancras Hospital, St. Pancras Way  
NW1 0PE

Dear Miss Harris

**Study title:** Exploring Young Peoples' Constructions of a First Episode of Psychosis  
**REC reference:** 15/LO/1445  
**Protocol number:** n/a  
**IRAS project ID:** 174957

Thank you for your letter of 23 October 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Kirstie Shearman, [nrescommittee.london-londonbridge@nhs.net](mailto:nrescommittee.london-londonbridge@nhs.net).

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified 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 <http://www.rdforum.nhs.uk>.

*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*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**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).**

#### **Ethical review of research sites**

##### NHS 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).

##### Non-NHS sites

#### **Approved documents**

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
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Covering letter on headed paper [Cover Letter]	1	02 October 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Certificate]	1	01 August 2014
GP/consultant information sheets or letters [GP Cover letter]	1	02 October 2015
Interview schedules or topic guides for participants [Interview Guide]	1	09 July 2015
IRAS Checklist XML [Checklist_03082015]		03 August 2015
Participant consent form [Consent Form]	2	02 October 2015
Participant information sheet (PIS) [Participant Information Sheet]	2	02 October 2015
REC Application Form [REC_Form_03082015]		03 August 2015
Referee's report or other scientific critique report [Review]	1	26 January 2015
Research protocol or project proposal [Protocol]	2	02 October 2015
Summary CV for Chief Investigator (CI) [S.Harris CV]	1	09 July 2015
Summary CV for supervisor (student research) [DoS CV]	1	09 July 2015

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

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

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

<b>15/LO/1445</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

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

Yours sincerely

pp. 

**Mr Brady Pohle**  
**Vice Chair**

Email: nrescommittee.london-londonbridge@nhs.net

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*  
*"After ethical review – guidance for researchers"*

*Copy to: Mr Neville Punchard*  
*Ms Anna Golab Mirepoix, Camden and Islington NHS Foundation Trust*

### London - London Bridge Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 30 October 2015

#### Committee Members:

Name	Profession	Present
Mr Brady Pohle	Vice Chair	Yes
Ms Jane Smith	Lay Member	Yes
Dr Ralph White	Pharmacist	Yes

#### Also in attendance:

Name	Position (or reason for attending)
Miss Kirstie Shearman	REC Manager

## Appendix I: NHS Research and Development Approval



1st Floor, Bloomsbury Building  
St Pancras Hospital  
4 St Pancras Way  
NW1 0PE

Tel: 020 3317 3045  
Fax: 020 7685 5830/5788  
www.noclor.nhs.uk  
23 December 2015

Miss Samantha Harris  
School of Psychology  
University of East London  
Water lane  
E15 4LZ

Dear Samantha Harris,

This NHS Permission is based on the REC favourable opinion given on 26 October 2015.

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in **the trust(s) identified below**:

<b>Study Title:</b> Exploring Young Peoples' Constructions of a First Episode of Psychosis		
<b>R&amp;D reference:</b> 174957		
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Yours sincerely,

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## Appendix J: Transcription Conventions

The following transcription conventions were used based on the framework proposed by Banister et al. (2011):

**(1)** Length of pause in seconds

**[laughing/coughing]** Non – speech sounds such as laughing or coughing.

**[inaudible]** Inaudible section of transcript

**[name/place]** Confidential information changed with description.

**<l: text>** Overlapping speech or brief interjection.

**/** Interruption

For extracts presented within the Analysis chapter, short utterances and overlapping speech such as ‘Yeah’ or ‘Hmm’ have been removed and replaced by ‘....’ for continuity and coherence.

## Appendix K: Example of Analytic Procedure

An extract of the analytic procedure is provided for each level of analysis. Acts of positioning were attended to at each level, these are highlighted in green.

### Sample Extract Detailing the Analysis at the Personal Level

1 I: How would you say, what kind of experiences did you have that led up to you  
2 coming into the Early Intervention service?  
3 L: Um, er (.) well right from the beginning?  
4 I: Yeah.  
5 L: Okay [deep breath] (2) I was going through (2). I'm going to keep it brutally honest  
6 with you <!:Yeah> because I'm not ashamed of it no more. I can like just get it off my  
7 chest, but I was (2) **I just got promoted and I was also acting because that's what I**  
8 **do.** I had a Youtube Channel and I was doing [my job], running my own little  
9 business. Erm, so I like, money wasn't an issue, I was doing my thing (1) but the  
10 people around me had a lot of issues that I got involved in. Like I've always been the  
11 type of person that like, everyone feels comfortable and to tell me their secrets, and  
12 their problems and everything and with the heart that I have I would naturally just be  
13 like yeah okay I've got you, I've got you, and get distracted and be, and everyone's,  
14 everyone's drama including my own (2) So I had my cousin, who, whose on the  
15 roads and I was with him (2) just to make sure he's safe, erm, and he had kids as  
16 well, so I would look after his kids and I had a relationship with his, with his baby  
17 mother and then we got into the like problems, and then like the whole family  
18 problem happened (1) where I felt like the whole family turn against me (3) and then  
19 I had a friend who was going through issues with her boyfriend smoking (1) I was  
20 smoking weed with her, but it wasn't any weed it was like skunk like this mix with a  
21 chemical, but I, I, I don't, I'm not a smoker but I was only doing it to like confide with  
22 her (1) So I had, I was doing that, plus I had, I had so much on my head that I was  
23 really overthinking things, and I started to picture things and hear voices (1) and then  
24 I just, I tried to explain myself, I tried to explain myself to a lot of people, but no one  
25 was really understanding it themselves, because I was confused and I was just (1) I  
26 had so much data, information in my head that I like, when I smoked I could see like  
27 numbers like yeah, like the matrix I was seeing stuff like that (2) yeah it was very, it  
28 was very weird and scary and I could hear like voice of people that didn't really like  
29 me, <!:Mmm> I could just feel this energy around me that wasn't comfortable, and  
30 then my mom started to notice something was wrong (1) I used to get phone calls  
31 but on the phone, when I used to pick up the phone, it didn't sound like the person  
32 that was calling (1) and it sounded like, like a devil, like a Satan, like I just (2) It was  
33 weird like it was all random things kept on happening and then I kept on looking at  
34 cars and seeing evil I wasn't (2) looking at the world I was looking at the future.  
35 That's how I felt, I thought I was in a future (3) So then my mom brought me to  
36 hospital the first time.

**Commented [SH1]:** Preferred identity – positioning herself as successful / has maintained this identity. Highlighting her prior success / normality.

**Commented [SH2]:** Reducing sense of personal blame.

**Commented [SH3]:** Social stress, sharing responsibility, normalising

**Commented [SH4]:** Relationship difficulties, felt betrayed and isolated? Sense of blame / shame?

**Commented [SH5]:** Aware of publicised link between skunk and psychosis – seen as the trigger? May promote essentialist thinking or attribute cause to external factor.

**Commented [SH6]:** Psychological explanation, build-up of stress / thinking changes.

**Commented [SH7]:** Not seen as a medical problem by self or others, lack of knowledge about psychosis / different meaning assumed? Perhaps highlights difficulty in explaining what is happening in words.

Difficulties in help-seeking

**Commented [SH8]:** Meaning-making – linking to relationships / past experiences?

**Commented [SH9]:** When unnoticed by others initially

**Commented [SH10]:** Very frightening experiences / making sense in a spiritual /supernatural framework?

## Sample Extract Detailing the Analysis at the Interpersonal Level

1 I: How would you say, what kind of experiences did you have that led up to you  
2 coming into the Early Intervention service?

3 L: Um, er (.) well right from the beginning?

4 I: Yeah.

5 L: Okay [deep breath] (2) I was going through (2). I'm going to keep it brutally honest  
6 with you <I:Yeah> because I'm not ashamed of it no more. I can like just get it off my  
7 chest, but I was (2) I just got promoted and I was also acting because that's what I  
8 do. I had a Youtube Channel and I was doing [my job], running my own little  
9 business. Erm, so I like, money wasn't an issue, I was doing my thing (1) but the  
10 people around me had a lot of issues that I got involved in. Like I've always been the  
11 type of person that like, everyone feels comfortable and to tell me their secrets, and  
12 their problems and everything and with the heart that I have I would naturally just be  
13 like yeah okay I've got you, I've got you, and get distracted and be, and everyone's,  
14 everyone's drama including my own (2) So I had my cousin, who, whose on the  
15 roads and I was with him (2) just to make sure he's safe, erm, and he had kids as  
16 well, so I would look after his kids and I had a relationship with his, with his baby  
17 mother and then we got into the like problems, and then like the whole family  
18 problem happened (1) where I felt like the whole family turn against me (3) and then  
19 I had a friend who was going through issues with her boyfriend smoking (1) I was  
20 smoking weed with her, but it wasn't any weed it was like skunk like this mix with a  
21 chemical, but I, I, I don't, I'm not a smoker but I was only doing it to like confide with  
22 her (1) So I had, I was doing that, plus I had, I had so much on my head that I was  
23 really overthinking things, and I started to picture things and hear voices (1) and then  
24 I just, I tried to explain myself, I tried to explain myself to a lot of people, but no one  
25 was really understanding it themselves, because I was confused and I was just (1) I  
26 had so much data, information in my head that I like, when I smoked I could see like  
27 numbers like yeah, like the matrix I was seeing stuff like that (2) yeah it was very,  
28 it was very weird and scary and I could hear like voice of people that didn't really like  
29 me, <I:Mmm> I could just feel this energy around me that wasn't comfortable, and  
30 then my mom started to notice something was wrong (1) I used to get phone calls  
31 but on the phone, when I used to pick up the phone, it didn't sound like the person  
32 that was calling (1) and it sounded like, like a devil, like a Satan, like I just (2) It was  
33 weird like it was all random things kept on happening and then I kept on looking at  
34 cars and seeing evil I wasn't (2) looking at the world I was looking at the future.  
35 That's how I felt, I thought I was in the future (3) So then my mom brought me to  
36 hospital the first time.

**Commented [SH11]:** Referring directly to me, aware of interview, Checking how to answer in the 'right' way.

**Commented [SH12]:** About to begin the story – dramatizing, signalling it is going to be hard to hear? Taking audience on a journey

**Commented [SH13]:** Suggesting experience was 'brutal' / addressing the audience - Ensuring she is believed?

**Commented [SH14]:** Further contextualises dramatization of story,.

**Commented [SH15]:** Comparison to a therapist role?

**Commented [SH16]:** Positioning herself as trustworthy / reliable – adding credibility to story?

**Commented [SH17]:** Continues to position self as helpful / taking on too much

**Commented [SH18]:** Vague? Self-censoring / difficult to talk about?

**Commented [SH19]:** Perceived blame? An aside justifying and reducing blame / protecting 'good' identity

**Commented [SH20]:** Repeating / emphasising the extent of stress – resisting being positioned seen as vulnerable?

**Commented [SH21]:** Emphasising out of the ordinary for her, perhaps also in the past, distancing self.

**Commented [SH22]:** Dramatizing / repeating - emphasising how differently she was seeing things.

## Sample Extract Detailing the Analysis at the Ideological Level

1 I: How would you say, what kind of experiences did you have that led up to you  
 2 coming into the Early Intervention service?  
 3 L: Um, er (.) well right from the beginning?  
 4 I: Yeah.  
 5 L: Okay [deep breath] (2) I was going through (2). I'm going to keep it brutally honest  
 6 with you <I:Yeah> because I'm not ashamed of it no more. I can like just get it off my  
 7 chest, but I was (2) I just got promoted and I was also acting because that's what I  
 8 do. I had a Youtube Channel and I was doing [my job], running my own little  
 9 business. Erm, so I like, money wasn't an issue, I was doing my thing (1) but the  
 10 people around me had a lot of issues that I got involved in. Like I've always been the  
 11 type of person that like, everyone feels comfortable and to tell me their secrets, and  
 12 their problems and everything and with the heart that I have I would naturally just be  
 13 like yeah okay I've got you, I've got you, and get distracted and be, and everyone's,  
 14 everyone's drama including my own (2) So I had my cousin, who, whose on the  
 15 roads and I was with him (2) just to make sure he's safe, erm, and he had kids as  
 16 well, so I would look after his kids and I had a relationship with his, with his baby  
 17 mother and then we got into the like problems, and then like the whole family  
 18 problem happened (1) where I felt like the whole family turn against me (3) and then  
 19 I had a friend who was going through issues with her boyfriend smoking (1) I was  
 20 smoking weed with her, but it wasn't any weed it was like skunk like this mix with a  
 21 chemical, but I, I, I don't, I'm not a smoker but I was only doing it to like confide with  
 22 her (1) So I had, I was doing that, plus I had, I had so much on my head that I was  
 23 really overthinking things, and I started to picture things and hear voices (1) and then  
 24 I just, I tried to explain myself, I tried to explain myself to a lot of people, but no one  
 25 was really understanding it themselves, because I was confused and I was just (1) I  
 26 had so much data, information in my head that I like, when I smoked I could see like  
 27 numbers like yeah, like the matrix I was seeing stuff like that (2) yeah it was very, it  
 28 was very weird and scary and I could hear like voice of people that didn't really like  
 29 me, <I:Mmm> I could just feel this energy around me that wasn't comfortable, and  
 30 then my mom started to notice something was wrong (1) I used to get phone calls  
 31 but on the phone, when I used to pick up the phone, it didn't sound like the person  
 32 that was calling (1) and it sounded like, like a devil, like a Satan, like I just (2) It was  
 33 weird like it was all random things kept on happening and then I kept on looking at  
 34 cars and seeing evil I wasn't (2) looking at the world I was looking at the future.  
 35 That's how I felt, I thought I was in a future (3) So then my mom brought me to  
 36 hospital the first time.

Commented [SH23]: Alluding to shame in the past / aware of stigma associated with psychosis.

Commented [SH24]: Resisting being positioned as a service user / client  
Giver of support rather than in need.

Commented [SH25]: Drawing on social narratives but possibly triggered by cannabis – perhaps discourses of stress vulnerability / drugs.

Commented [SH26]: Aware of blaming / stigmatising narratives – attempts to resist

Commented [SH27]: Normalising onset – perhaps continuum model?  
Individualism – problem was her thinking?

Commented [SH28]: Drawing on Sci-fi / popular culture narratives

Commented [SH29]: Spiritual / supernatural

Commented [SH30]: No mention of medical language / mental health terminology

Commented [SH31]: Religious/Spiritual references

## Appendix L: Extended Interview Extracts

### Extended Extracts of Leo's Interview

212 *I: So what kind, what kind of explanations did the early intervention service give*  
213 *to you about what had happened?*

214 L: Well, they didn't really give me, like an explanation, they allowed me to  
215 explain. So they just they kind of like, I said what I had to say and they  
216 transferred it back, just what I said in another content, <I: Yeah> yeah so that I  
217 could understand it, but erm what I got from it was that everything that I've been  
218 through was a pattern from like something I've held in from the past from people  
219 and [my psychologist] allowed me to reflect on certain experiences in my life  
220 that I held on, or certain traumas and stuff like that that made me understand a  
221 bit more. Yeah (1) because when I was in the van and I could hear that voice  
222 get her get her, that voice was from one of my, one of my (1) well (1) it's kind of  
223 complicated but a friend that I grew up with in school from year eight <I: Yeah>  
224 and before I went into hospital I came to her and said like I'm going through  
225 something and I couldn't really express myself properly, and I felt like she didn't  
226 really have my back so I cut her off <I: Mmm> for a year and a half I like cut her  
227 off to the core (2) and I've never ever done that to no one, especially someone I  
228 thought I classed as a friend. I could hear her voice but when I came to early  
229 intervention and explained that, she explained what relationship did you have  
230 and it was me that held on to certain things that she did that I didn't like and I  
231 should have said I should have spoken in my, in like the moment of time when  
232 she did certain things, but I didn't I let it go and I held on to it. So I think I could  
233 probably hear her voice and certain things like that and I met up with her  
234 recently and she explained her side of the story, I explained mine and we came  
235 to some mutual ground so yeah (1) its (2) I don't regret, I don't regret it at all.

236 *I: So its sounds like before you felt like it was something spiritual <L: Mmm>*  
237 *and you had some of those understandings, did that change at all?*

238 L: No I still believe that it is a spiritual thing, erm, I do believe that I went through  
239 this for a reason. I didn't go through it for no reason. I didn't, it's for a purpose,  
240 God's purpose I believe. I believe it's my testimony it's my story to know that  
241 like (2) where I come from, what I went through and where I am now and the

242 fact I can be a voice for a lot of people I can tell my story, because what I went  
243 through was real for me and no one can ever take that away from me <I: Mmm>  
244 and I pray and I, I still believe it's a spiritual thing.

245 *I: And do you, is that explanation for you, would you say it was helpful or*  
246 *unhelpful or?*

247 L: Yeah, yeah it was very, it was hard, it was tough but, its it, its outcomes very,  
248 yeah cause I think if I didn't go through all of this I wonder where I would be  
249 now <I: Yeah> but I'm so happy (2) where I am now, I'm very very happy.

.....

315 *I: Do you know erm, like where those ideas about being a bad word might have*  
316 *come from?*

317 L: I think the way how, I see other people in the hospital and I, I, I used to reflect  
318 myself to their character and be like I don't I don't act like that. I think I'm I'm  
319 more sane than everyone in here. So I, I personally don't think I have mental  
320 health like that [laughing] <I: Yeah> I know it sounds messed up but that's how I  
321 thought in my head I felt (1) no I'm not like no I'm not I'm not crazy, I'm not  
322 crazy, I'm not mad, I'm not taking that, nope, not having it, you're lying, nope,  
323 not mad (2) yeah.

324 *I: So how did that feel then accessing a mental health service?*

325 L: Yeah I feel erm, I was on the defence <I: Yeah> yeah (1) I was definitely on  
326 the defence (1) I was open-minded but deep down I was on the defence (1) but  
327 its its taught me a lot, so I can't knock it, it's taught me a lot.

Extended Extracts of Shoma's Interview

1 *I: What kind of experiences did you have that led up to you coming to the early*  
2 *intervention <S: Okay erm> service?*  
3 *S: Was back In twenty, twenty fourteen, September <I: Yeah> even before that,*  
4 *I used to feel like someone is following me, even night time I'd feel like*  
5 *someone was there (1) I didn't pay that much attention to it and then (2) back in*  
6 *twenty fourteen September I started erm (1) hearing voices in my head <I:*  
7 *Yeah> and I started seeing two people and also erm (1) the voices I heard most*  
8 *of the time, there's two people I can hear them (1) clearly (1) they say that I'm*  
9 *not worth in this world, I shouldn't live in this world, I should do something to*  
10 *myself (1) I should, I should die and they used to give me options. Like what I*  
11 *can do to kill myself (2) and er also er I still feel like someone's like touching me*  
12 *properly (1) I can't see them (1) I can see that I can feel that someone's*  
13 *touching m- all on my body and also at night time I couldn't sleep at all and er*  
14 *and still feeling like someone is sitting on top of my head board (1) and reading*  
15 *really loudly <I: Mmm> and erm I still stay with erm my sister in the same bed*  
16 *(1) so even she is er sleeping next to me I feel like in the gap between us some*  
17 *sleeping next to me (1) but when I look there's no one there <I: Okay> So those*  
18 *things freaks me out <I: Yeah> and cause er and ah I couldn't, I didn't know*  
19 *what to do (1) So only option I had, I went to the GP <I: Mmm> and I explained*  
20 *GP about it and GP sent me to the community mental health team and that time*  
21 *erm I was going to see them every month but they're not doing anything (1)*  
22 *and by December (1) erm, I couldn't control myself I feel like to cut myself or*  
23 *harm myself <I: Mmm> and I was scared. I been calling them, I went to the GP*  
24 *and er (2) they're not doing anything and er the GP er (2) called them and told*  
25 *them but then they weren't doing much and then I went to er A and E. One, One*  
26 *of the night, really scared, I went to A and E and from A and E they er they er*  
27 *saw me and they booked me with er day centre in (Hospital) and fo- there I was*  
28 *two months there, every day I used to go nine to five <I: Mmm> and from er day*  
29 *centre they put me here.*

.....

192 *I: So, how did you feel in general about accessing mental health services?*

193 S: Er yeah its, its good, mental services are okay, but then I'm not happy with it  
194 everything, because what I want to achieve I achieve because before I couldn't  
195 go outside because I was scared <I: Yeah> I didn't know why people wanted to  
196 harm me, they really freaky looking, they looking at me really angry but then  
197 from here they put me with erm one of the erm psychologists and er (the  
198 psychologist) erm she (1) was taking me outside she was explaining me what  
199 is real, what is not so now I , even though when I go outside I see those people,  
200 but now I know the people look angry (1) they don't really exist (1) the people  
201 who look normal and happy and not saying, those are the real (1) so now I  
202 know the difference between who to avoid and who not to avoid <I: Mmm> and  
203 so now I'm using bus, going outside, I'm not that scared, I used to anxiety  
204 attacks as well (1) but now I'm okay with that so yeah.

205 *I: And so, so when you came to early intervention do you think how you  
206 understood or explained those experiences changed?*

207 S: Yeah it did (1) a lot because I used to think oh like they might be ghosts and  
208 this and that, I used to make things up and erm I used to think I should keep  
209 those people around me like those people I see and the voices but they  
210 explained to me that I er, I shouldn't because they're not doing anything  
211 because, er when I talk to them (1) I'm telling them like they're doing good for  
212 me <I: Hmm> But they explained look (1) you said this but they're not actually  
213 doing good, they're trying to erm mislead your brain and d – do, but now I  
214 realised they're they're trying to, not make me do but trying to make it worse so  
215 now I'm trying, I'm saying okay I can let them go, I don't want to let them fully  
216 go because I still get the feeling, somehow they can (1) protect me, but not like  
217 fully so yeah.

218 *I: Yeah so what er what explanations did they give you in early intervention?*

219 S: Erm they told me er this is er (1) psychosis, people experience this (1) I  
220 might think it's real, but its semi-conscious, it's not real so it just that er I need to  
221 understand (1) and (1) keep trying more about erm working on taking my  
222 medication and get better. I can see that when I take medication by the time  
223 they, they started from five milligrams and gradually decrease, and now it  
224 decreased to a level it doesn't bother me any more <I: Right> so yeah.

Extended Extracts of Frank's Interview

29 *I: So what do you mean downhill what kind of things happened?*

30 F: Oh erm (3) I was, I was involved in criminal activity at the time so I was doing  
31 a lot of dodgy things. So then I got really paranoid that people were following  
32 me that police were following me <l: mm> that erm police were watching me  
33 from erm my TV. Police were (2) just anything (1) that I saw for like er (1) how  
34 can I describe for like er proper, someone who is really in to the high end of  
35 drugs <l: Mmm> and business like that. I deflected it on myself. Anything I saw  
36 on the TV, any new technology (1) that I saw <l: Yeah>, that they was doing I  
37 used to deflect it, it happening to me <l: Yeah> and that kind of progressed on  
38 to erm to (1) to music (1) like I used to think the music is like have a message to  
39 me. I'd forget my words at my worst stage.

40 *I: Did you erm did you notice anything else like erm seeing or hearing things?*

41 F: No that wasn't really affecting me, that didn't really affect me. I never used to  
42 hear stuff or hear voices or anything <l: Yeah> it was just erm (2) just over (1)  
43 paranoia really.

.....

212 *I: Do you know when you first got referred to early intervention how did you feel*  
213 *about accessing the service?*

214 F: I was embarrassed I was I felt like I don't need it, I felt embarrassed in a  
215 sense that people are degrading me because I'm a grown man and I've got to  
216 come see a lady and talk to her and everything (1) but the more time that they  
217 don't give up on you (1) if that makes any sense, the more times that they stay  
218 there and when you do your stupidity they kind of don't react to it, it kind of  
219 makes you realise that you do need a service.

220 *I: Okay so what was it that was embarrassing about it?*

221 F: Just the questions they ask. They ask you questions like erm are you are you  
222 alright, do you hear voices [laughing]? To me that sounds a bit silly but to  
223 someone else that's a serious question <l: Yeah> but erm just the question they  
224 ask you sometimes it sounds silly but er I had that boss mentality. Like I'm my  
225 own man I'm my own this, I'm my own whatever and like coming to somewhere

226 where they ask you this and where you're not really in control of your own life  
227 because you've got to go see them every week and they are giving you  
228 appointments that you have got to go to they giving you, doctors follow ups to  
229 go see your own doctor and it was just this ain't my life anymore <I: Yeah> and  
230 I'm one of those people that when you put a lease around me I go the opposite  
231 way <I: Yeah> so yeah that was that was the main issue at first .  
232 *I: So since you have been in early intervention, this time are you (2) how are*  
233 *things at the minute are you still having any of those experiences?*

.....

247 *I: So did the, when you came to early intervention did they give you kind of any*  
248 *explanations or did you have any conversations?*  
249 F: They tried to, but it didn't really make sense, if you get what I mean <I:Mmm>  
250 because they was more I don't know (2) [care co-ordinator]'s alright because  
251 like, but I've been with a lot of people (1) but the only thing that the downhill side  
252 to it was they they they generalise too much. So if you take weed you've got  
253 psychosis that's that's all they understand. So then when you haven't got  
254 psychosis it's hard for them to talk to you and to understand where your coming  
255 from <I: Yeah> if this, if that makes any sense, but erm  
256 *I: So what kind of things did they say?*  
257 F: I can't really remember the specifics but erm it was more about hearing  
258 voices erm it was, er just more about hearing voices, am I gonna harm myself it  
259 was just away from the point if you get what I mean to my needs <I: Yeah> it  
260 was more general not specific

Extended Extracts of Jade's Interview

34 *I: Do you remember how you understood what was happening?*

35 J: I didn't, I simply didn't until I got better at the end of like November <I: Yeah>  
36 and then it's like okay so I had a mental health issue did I? Oh right now you tell  
37 me I literally thought I was just getting locked up somewhere not being able to  
38 go out, because I had to be supervised every time I went out, even to go for a  
39 cigarette I had to be supervised so I just thought this is ridiculous, and even  
40 some of their rules and regulations just made me think even more psychotic  
41 thoughts because you got told you couldn't go for a cigarette and then it's got a  
42 notice up on the board at one fifteen pm, at two forty five pm [laughing] at three  
43 sixteen pm, it's like who goes for cigarettes at a specific time? Unless it's during  
44 your lunch break so I just really didn't get it I just thought (2) I was well  
45 confused. I didn't understand what was going It was my first episode, it was the  
46 build up to my first episode so I didn't know what was happening I just thought I  
47 was a bit sad and depressed. I didn't think it was post-natal depression because  
48 I was fine with my baby, so I just thought (1) I don't know I felt a bit deserted by  
49 friends because I'd just had a baby and they were not inviting me out as much  
50 and (1) stuff like that <I: Yeah> So I thought it was just getting to me a bit.

.....

65 *I: And when you were in hospital did you get any explanations <J: No> from*  
66 *staff or the other people in the hospital?*

67 J: No they said you're in hospital but I said what kind of hospital, a hospital is  
68 people in beds sick on ventilators coughing, ill, crutches, wheelchairs. This isn't  
69 a hospital; I don't know what it is but it's not a hospital. But they didn't explain it  
70 for my mental health and they (1) all I got told was just take your medication and  
71 if you don't were going to inject you.

72 *I: How did you feel about taking the medication.*

73 J: Well I didn't even know what I was taking the medication for so some of it I  
74 was spitting out and not taking and they would just hold you down and inject  
75 you which was unpleasant

.....

169 *I: I see, have you had any other conversations here that have help you make*  
170 *sense of why this might have happened?*

171 J: It all just links back to having my baby, the chemical imbalance. That is what  
172 what they said as well a hormone imbalance erm but they said the chemical  
173 balance changed in my brain which can be triggered through pregnancy <I: I  
174 see> and erm yeah (1) as a result your one of the unlucky ones [laughing].

175 *I: Would you say how you have explained it has changed from coming in the*  
176 *service?*

177 J: Sorry?

178 *I: So coming to the service and having those sorts of conversations has it*  
179 *changed how you make sense of it?*

180 J: Erm I guess so, I guess so I've changed my care-coordinator twice <I: Yeah>  
181 so both of them, they are very different ladies, but they are both amazing. Like  
182 the old one she was more (3) I'll fight for you to get employment, I'll give you  
183 references for this, I'll help you with that and this new one more like okay so  
184 what do you want to do? Let me know what you want to do, let's do it your way.  
185 Don't worry about the doctor we will do it your way do you know they are both  
186 like you know, yeah the thing is I've met some really nice people along the way  
187 and (1) first and foremost they are doctors and stuff but around that they  
188 actually care about our conversations. I saw one of the doctors on the bus and  
189 we were having a conversation about my libido and whether it's changed since  
190 being on the medication [laughing] so (1) we can have some funny times as well  
191 they are good, they are.

Extended Extracts: Joesph's Interview

61 *I: Do you remember back then, how, did you have any ideas about what was*  
62 *happening or how was you making sense of what was happening?*

63 J: Erm basically (1) I I I just (1) because I'm not I'm not, I'm not a religious  
64 person but you know, I thought I had all these thoughts of like, you know,  
65 someone's probably done some curse on me or someone's done something to  
66 like, you know, I just, maybe there are ghosts or something like that, I don't  
67 know, I was going through all of these things in my head <I: Yeah> at the time it  
68 was just very traumatic you know.

69 *I: Do you know where that explanation might have come from?*

70 J: Erm [coughing] erm basically I erm do you mean, I've actually erm, what's the  
71 word, you know I've I've studied in like sort of like cultures and different beliefs,  
72 and everyone has different belief systems, erm religious beliefs and erm (1) I  
73 found that basically with every mental illness there's always some sort of erm  
74 what's the word, there's always erm you know (1) anything that happens to you  
75 I don't believe it's just some mere (1) you know something happens to you  
76 because there's something in your life that you need to either deal with (1) or  
77 something that you need to erm (1) address and I think that's the er (1) with all  
78 the stress and the tension that I was experiencing at the time erm (1) as well as  
79 everything else my thoughts were on erm , what what what I was going to do in  
80 my life and stuff I think you know erm the denial and all those sorts of things  
81 just came up basically kind of came up and affected me that's basically how felt  
82 <I: Mmm> at at that term <I: Yeah> yeah.

.....

158 *I: So erm, so when you came into this service did you er did any of the staff give*  
159 *you explanations about what had happened or did you have conversations*  
160 *about? <J: Erm>*

161 J: Basically erm (1) what was it (2) basically they talked very much about the  
162 symptoms, they talked more and they emphasised on the symptoms, you know,  
163 do you see here what it says, and do you (1) you know <I: Hmm> They said this  
164 is something to do with, you know, there's no normal, you know, they're still

165 their still trying to understand mental disease basically they don't understand  
166 what triggers it, what so there's always this study you know trying to understand  
167 so yeah they were just talking to me about the symptoms and this and that and  
168 then before I got my medi-, before I got my medication, which is ami- ami-  
169 amipiprazole basically and erm (1) I (2) had a heavy dose and er when I first  
170 had a heavy dose I was always sleeping, drowsy, weak, tired just (1) out of  
171 sorts and but, you know, I kind of needed that at that, at the same time, just to  
172 calm, you know, you don't know if it going to work but it's the erm, it was the er  
173 er lightest sort of, the best sort of erm medication apparently they say,  
174 that's what they said so I took it and then yeah you know.

.....

189 *I: How did you feel about going on medication?*

190 J: Woah, no one wants to go on medication really, you know, any any human  
191 they feel like you know they feel (1) it's sort of like to know that you depend on  
192 something to keep you, you know you don't feel human, you don't feel like erm  
193 (1) you know you can you know, you feel like, you know (1) there's there's  
194 always this stigma about mental illness you know, how everyone's always very  
195 like oh he's you know (1) people have these views about mental illness and  
196 stuff like that but you don't think your, you don't think it's going to happen to  
197 you, and then it happens to you and you have a different perspective on it, you  
198 know, that's what I think you know (1) the more people erm (1) see like (1) erm  
199 the more other people are able to be in another's person's shoes and erm  
200 experience it first-hand they can be more understanding and stuff like that (1) so  
201 for me erm, I just believe the whole erm (1) you know the whole medication  
202 thing is just like erm (1) and that's what causes people to feel (1) erm what's the  
203 word (1) it causes people to erm feel (1) oh whats the word (1) reticent not  
204 reticent is it? Not reticent (1) what's the word (2) less inclined to er take the erm  
205 medication you know because they know that when people look at you they you  
206 know feel like oh are they looking at me weird or you know they can see that  
207 you're slightly tired or weak or, so that had a strong impact on me as well.