EXPERIENCES OF DISENGAGEMENT FROM MENTAL HEALTH SERVICES: AN INTERPRETATIVE STUDY

by

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ABSTRACT

Whilst there is evidence of a range of effective treatments available for people with severe mental health problems (SMHP), people frequently disengage from mental health services (MHS). This thesis investigates experiences of disengagement of people with SMHP and comprises two studies: 1) semi-structured interviews to elicit the experiences of people with SMHP and a history of disengagement from MHS; and 2) building on those findings, focus groups with staff from assertive outreach teams (specialising in providing care for people with SMHP and a history of disengagement).

The participants were those perceived as the most disengaged from MHS yet they were willing to engage with the research. Interpretative phenomenological analysis was used to develop themes for individual participants and then across the participants. Disengagement from MHS was part of a wider experience of a limited connection to social structures, including an ambivalent and complex relationship with MHS. There was a sense of sadness in all aspects of the participants' experience but they had developed strategies to reinforce personal resilience and to reassert personal identity.

The findings of this thesis can be employed to better understand the context of disengagement from MHS and consequently better inform future engagement with this client group

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OVERVIEW

The following thesis aims to investigate the experiences of disengagement from mental health services for people who have severe mental health problems. The thesis comprises two studies that sought to address these aims: How the research participants understood their own health, well-being and illness; How did the research participants perceive their needs in relation to statutory mental health services?; How did the research participants understand the role of drugs and alcohol within their lived experience?; Related to study 2, what were the perspectives of assertive outreach team (AOT) staff on the experiences of disengagement from mental health services for people (in particular for 'black' men) with severe mental health problems? There are two studies within the thesis, individual interviews with service user participants (n=7) (study 1) followed by focus groups with clinical staff from AOTs (n=12) (study 2).

Whilst there is evidence that there are a range of effective treatments available for people with severe mental health problems (SMHP), engagement with services and treatments is often poor. There are a myriad of sociological, psychological and idiosyncratic reasons why people with SMHP engage or disengage from mental health services and these remain poorly understood (Chase et al., 2010). Research into the consequences of disengagement demonstrates that disengagement from mental health services can have devastating consequences including more unmet needs, a greater risk of non-compliance with medication, dual diagnosis, less control over symptoms, social impairment, housing instability, contact with the police and judiciary and psychiatric in-patient services, self-harm, severe self-neglect and even suicide (Fenton et al., 1997; Mueser et al., 1998; SMCH, 1998; Kreyenbuhl et al., 2009; Davies et al., 2014). These difficulties are in addition to living with the symptoms of their SMHP, social difficulties and on-going stigma in society which are present for many people with SMHP (SCMH, 1998). These factors all combine to pose great challenges to mental health services.

In study 1, after ethical approval, in-depth, semi-structured interviews were used to elicit the experiences of people who experience SMHP and who also have a history of disengagement from mental health services. An interesting finding of the study was that the study 1

participants were a group of service users typically perceived as the most disengaged from mental health services, yet they were willing to engage in the research interviews. Through interpretative phenomenological analysis (IPA), themes were developed first for individual participants and then across the participants. Interpretative analysis of the participants' experience of disengagement from mental health services highlighted that disengagement was part of a wider experience of a limited connection to social structures. Given the phenomenon under investigation, a substantial part of the study was the examination of the participants' ambivalent and complex relationship with mental health services. There was a sense of sadness in all the aspects of the participants' experience. However, the participants had developed strategies to reinforce their personal resilience and to reassert their personal identity.

The findings of study 1 were investigated further in focus group interviews in study 2 with staff from assertive outreach teams (AOTs), teams specialising in providing care for people who experience SMHPs and have a history of disengagement. The aim of study 2 was to capture the views of AOT staff on the experiences of disengagement from mental health services for people (in particular for black men) with SMHP. The research questions for the focus groups were informed by both the questions and the themes derived in study 1. The focus groups were subjected to IPA, from which themes were developed.

The themes developed in this study can be employed to better understand the context of disengagement from mental health services and also to better inform future engagement with this client group. The implications for research are the need to investigate the experiences of long-term mental health service users further and to develop a stronger scientific base for the consequences of disengagement. The implications for policy are to continue efforts to lessen the impact of stigma which would improve engagement and well-being. The final implications for practice are for clinical staff to consider the relationship they have with service users in a wider social and political context, as well careful consideration of the use of medication.

CHAPTER 1: INTRODUCTION

This study set out to examine the experiences of people with SMHP who also have a history of disengagement from mental health services. The participants' relationship with mental health services, their perception of their role in society, and their understanding of health, well-being and illness were investigated and the links between those concepts and their disengagement from statutory mental health services were analysed. This qualitative study used IPA to investigate the experiences of service users with SMHP who were being treated by AOTs in the West Midlands. These participants were selected through purposive sampling, and interviewed using semi-structured interviews.

As highlighted by Biddle et al. (2007), whilst mental disorders are disabling they are also treatable. Therefore, there is a need to develop the understanding of peoples' experience of disengaging. Both Kemp and David (1996) and Tait et al. (2003) argued that further research is essential to develop an understanding of the relationship between peoples' beliefs about themselves and why they disengage from services. Both these papers proposed that any such research would inform the development of interventions to enhance engagement and treatment adherence. SCMH (1998), Priebe et al. (2005) and Chase et al. (2010) all suggest that further qualitative research needs to be done to gain a better understanding of the phenomenon of disengagement (or inhibited engagement) from mental health services. Furthermore, Claassen and Priebe (2006) suggested that qualitative research needed to be carried out to determine whether AOT service users experienced services as impacting upon their autonomy.

Previous research has examined the effects of disengagement from mental health services for people with SMHP. Fenton et al. (1997) reviewed the consequences of non-compliance with medication, acknowledging that compliance with medication is often the single biggest factor in an individual's recovery from mental illness. *Keys to Engagement* (SMCH, 1998) reported that people with SMHP who find it hard to engage with services have a greater risk of homelessness, dual diagnosis, medication non-compliance, suicide, self-harm and severe self-neglect. Not only does this group encounter the issues caused by their mental illness but they also face significant social hardship and experience stigma, which is prevalent within society

(SCMH, 1998). Mueser et al. (1998) investigated treatment models for people with severe mental illness. The review found that poor engagement with services increased the chances of more time on psychiatric in-patient units, greater housing instability, increased time in jail, decreased symptom control and an overall poorer quality of life (Mueser et al., 1998). *Safety First* (DoH, 2001) a report into suicide amongst people with mental illness, reported that both being non-compliant with medication and missing appointments with community mental health teams were factors in people with schizophrenia who died by suicide in the community. Kreyenbuhl et al. (2009) highlighted that disengagement from mental health services can have "devastating consequences" for people with SMHP, whilst O'Brien et al. (2009) provided detailed information about the demographics of those people most likely to disengage from mental health services. Davies et al.'s (2014) article, which explored what services 'hard-to-engage' people wanted from mental health services, stated that people with SMHP who were disengaged from services had "more unmet needs, were more unwell and were more socially impaired" (p. 1360) relative to peers who were engaged with services.

United Kingdom (UK) policy identified mental health as a priority in 1999 (DoH, 1999). Standard 4 of the National Service Framework (DoH, 1999) says that care should be organised in such a way as to optimise engagement with service users. Subsequent policy directives have focused on health and social care working more collaboratively with specific areas for improved service. These directives are aiming to improve user engagement and reduce hospital admissions (DoH, 2001) as well as developing better services for people from black and minority ethnic backgrounds (BME) (DoH, 2005, 2014a) and prioritising service development to address the needs of those with co-morbid substance misuse and mental health problems (DoH, 2005). Despite improvements (DoH, 2012), the UK continues to see an increase in mental health problems and significant inequality in mental health care delivery (Fearon et al., 2006; Fung et al., 2006; NICE, 2010; DoH, 2014a). The overarching mental health strategy by the current coalition government marks a significant move to detailing a coordinated approach in improving the mental well-being of the population (DoH 2011). Moreover, clear aims to ensure mental health services are accessible, equitable and user-focused have been identified (DoH 2014b). By rigorously examining the experiences of those who have disengaged from mental health services, there is potential to identify

shortfalls in strategic direction and to give voice to the experiences of the recipients of mental health services.

This study has implications for research, practice and policy. Lister and Gardner (2006) highlighted that there is difficulty in developing effective engagement strategies that are relevant to a hard-to-engage group. Therefore, it is important to investigate how service users with SMHP make sense of their experience of disengagement from mental health services to help clinicians and policy makers better understand the experiences of the client group and subsequently deliver more effective care.

1.1   Definitions

1.1.1   Severe mental health problems

SMHP affect 1-2% of the UK population (Mind, 2011). However, there is a lack of consistency in the definitions used as to what constitutes either a serious mental illness or SMHP. The Sainsbury Centre for Mental Health (2004) noted that the definition of SMHP changed frequently and similarly, Ruggeri et al. (2000) reported that there is no internationally agreed definition of SMHP. Cohen and Singh (2001) suggested that schizophrenia, bi-polar affective disorder and psychosis should be classed as severe mental illnesses and Tyrer et al. (2003) identified schizophrenia and bipolar disorder as the severe mental illnesses. Additionally, Clarke and Walsh (2009, p. 283) emphasised having a SMHP usually affects most aspects of life for people with this diagnosis. Davies et al. (2014) recruited similar participants to this study and the definition of SMHP they used adds further context to the definition by adding that people with SMHP usually have several admissions to acute in-patient services and frequently used illegal drugs and alcohol. For the purposes of this study, SMHP will be understood to include the diagnosis of schizophrenia, bi-polar affective disorder and psychosis.

1.1.2   Dual diagnosis

Mortimer (2005) highlighted that there have been advances in the medicines now available in order to treat people who have SMHP, but professionals, patients and society are not necessarily seeing the benefits because of non-compliance with medication, disengagement

and substance misuse. Up to 50% of people who experience SMHP will use illicit substances (DoH, 2002a), often referred to as 'dual diagnosis'. Kipping (2004) defined dual diagnosis as the co-existence of mental health and substance use. Furthermore, O'Brien et al. (2009) highlighted that dual diagnosis patients were more likely to disengage from mental health services.

Buckley (2006) demonstrated that the healthcare system's capacity to adequately treat people in the dual diagnosis client group is greatly reduced because of poor medication compliance; physical co-morbidities or poor health; poor self-care; increased suicide risk or aggression (see also Banjerjee et al., 2002); higher rates of illicit substance use; and possible incarceration. In comparison to those people who experience severe mental health problems but do not use substances in a problematic way, the dual diagnosis population have a higher prevalence rate of:

•   Homelessness;

•   Worsening of psychiatric symptoms;

•   Poor medication compliance;

•   HIV infection rates;

•   Contact with the criminal justice system;

•   and a markedly increased use of institutional mental health services.

(DoH, 2002a, Barrowclough et al., 2006)

There are a range of effective treatments for the dual diagnosis client group: psychosocial interventions such as Motivational Interviewing (Swanson et al., 1999; Kavanagh et al., 2003; Laker, 2007), Cognitive Behavioural Therapy (Schmitz et al., 2002; Marlatt & Gordon, 1985), Motivational and Cognitive Behavioural Therapy combined (Barrowclough et al., 2006), Behavioural Therapies (Carroll, 2004), Group Therapy (James et al., 2004; Bradley et al., 2007), Psychotherapy (Ostacher & Sachs, 2006), Psychopharmacology (DoH, 2002a; Green et al., 2002) and Integrated Treatment models (Drake et al., 2001; National Treatment Agency, 2002; DoH, 2002a; Graham et al., 2004; Rassool, 2006). However, regardless of there being a range of effective treatments available for people with dual diagnosis, engagement with mental health services is often poor.

Boydell et al. (2004) and Van Os et al. (2002) found that the social and environmental features, particularly in areas of concentrated poverty, play a role both in the relapse of schizophrenia and are also causal factors in the development of psychosis. Todd et al. (2004) found that these same neighbourhoods also had higher rates of people with a dual diagnosis. People with a dual diagnosis may be violent, with people living in these neighbourhoods being both victims and perpetrators of violence. It is important to note that the adverse consequences for people with a dual diagnosis are evident amongst people even with low levels of substance use (Drake & Mercer McFadden, 1995).

1.1.3 Disengagement from mental health services

It is generally recognised that many people who experience SMHP need a supportive mental health service that enables them to function effectively in the community (Herinkcx et al., 1997). Some services are failing to engage with people who could possibly benefit from their input (SCMH, 1998). Mueser et al. (1998) highlight that people with SMHP who disengage from mental health services have an increased risk of social isolation, suicide and homelessness, and have longer periods of time as in-patients. A review of suicide incidences between 1996 and 2001 highlighted that a third of people with SMHP who committed suicide had missed their last outpatient appointment with health professionals (DoH, 2001). The Mental Health Foundation (ND) reported that people from BME communities were more likely to disengage from statutory mental health services and consequently were more likely to experience social exclusion and deterioration to their mental health. Furthermore, the Mental Health Foundation also report that reluctance of African-Caribbean people to engage with services means that people are more acutely unwell when they do have contact with services and are more likely to experience coercive aspects of mental health care (Mental Health Foundation, ND).

Whilst studies discuss engagement and disengagement from mental health services, these concepts are poorly defined and there is no consensus on formal definitions (Lister & Gardner, 2006; O'Brien et al., 2009). Burns and Firn (2002) defined engagement as contact between mental health services and the patients which both parties find beneficial. Morgan (2008) defined engagement as services offering practical assistance within the context of having a therapeutic relationship. Wright et al. (2011) conclude that it is not easy to define

engagement for either the practitioners or for those people using services. For the purposes of this study the definition of disengagement used is that of Hall et al. (2001) who defined engagement as a term to describe adherence to treatment which involved several factors including: remaining in contact with services, collaborative involvement in treatment and openness about difficulties. The reason this definition was chosen was because "collaborative involvement in treatment and openness about difficulties" (p. 462) is an important component of engagement.

There are not any conclusive figures for how many people with SMHP have a history of disengagement from mental health services. The AOTs in the UK arose from *Keys to Engagement* (SCMH, 1998), which states that 14-200 per 100,000 adult population or 15,000 people nationally or 5% of adult population SMHP disengage. But these figures are now approaching 20 years old. The O'Brien et al. (2009) literature review concluded that about 30% of patients were disengaging from services, a figure supported by Simmonds et al. (2001) who stated that there is a 33% dropout rate from standard care. But herein lies the problem; firstly both these studies are talking about all patients within mental health services and secondly the age of the studies. *Keys to Engagement* was published in 1998, the ten studies cited in O'Brien et al. (2009) range from 1984-2003, were not all UK-based and do not exclusively look at SMHP. Despite searching the literature, up-to-date figures on the number of people in the UK who have SMHP and a history of disengagement from services are not readily available.

1.1.3.1 Reasons for disengagement

Keys to Engagement (SMCH, 1998) was a document that largely introduced the AOT model to the UK. The basis for the document was that despite the advances in the potential of psychiatric care in the UK this was not being realised because services and individual patients were failing to engage in effective working relationships. Why people with SMHP disengage from mental health services and also why, or how, they can be re-engaged by services remain important issues to be resolved by clinicians, commissioners and service managers alike (Chase et al., 2010).

Previous research has highlighted a number of reasons why some people choose to disengage from mental health services, as follows:

Individual experience.   For some people with SMHP, their contact with statutory services may have been characterised by long periods of neglect in the community followed by a traumatic experience of hospitalisation and subsequent poor continuity of care upon discharge (SCMH, 1998).

Early help-seeking behaviour.   Watts and Priebe (2002) found that when initial attempts to obtain help for mental distress were met with rejection it led to disengagement in the future.   However, when services did become involved, it was often in a crisis situation resulting in the traumatic experience of hospitalisation (as above).   O'Brien et al. (2009) highlighted that when people engaged with mental health services earlier in their illness they continued to be well engaged with services over time.

Illness characteristics.   A major feature of disengagement from services is the experience of the symptoms of the illness.   For example, symptoms such as delusional thinking, voice hearing and loss of motivation may contribute to the reasons for disengagement.   In addition, people who experience SMHP may be too unwell to engage with the services designed to meet their needs (Thurgood, 2004).   Brown et al. (2005) stated that symptom severity, cognitive impairment, longstanding treatment, substance abuse histories, low motivation to change behaviour and extremely poor social functioning are all specific symptoms which may contribute to people with SMHP disengaging from services.   Harrow and Jobe (2007) argued that one reason why people choose to disengage from mental health services is because they are satisfied that their symptoms and social functioning have improved sufficiently for them to no longer require input from mental health services.

Individual characteristics.   Many people who use mental health services as adults will have had experienced institutional care when growing up.   For many, this was a negative experience and their avoidance of statutory mental health services can be interpreted as a desire to avoid a replication of that experience (Thurgood, 2004).   Also, some people will have lost their home (whether that be private or social housing) either due to hospitalisation for mental illness or eviction whilst unsupported by mental health services.   This, again, may impact on future engagement as they may disengage from services to avoid a repetition of that experience (Dean & Craig, 2000).   Priebe et al. (2003) highlighted that socio-demographic

and cultural characteristics impacted upon engagement, especially in a patient group who already had an established pattern of disengagement. Prior et al. (2003) investigated whether stigma was a reason for people not seeking help for their mental distress but suggested instead that people did not conceptualise their difficulties in medical terms so did not seek help from mental health services. Biddle et al. (2007) suggest that the significance of seeking help from mental health services for mental distress led to people both avoiding seeking help and also denying that they were experiencing an illness. The review by Kreyenbuhl et al. (2009) suggested that disengagement was a reflection of the patient's perception that treatment was not necessary and that treatment did not meet their needs.

Medicalisation of service delivery. SCMH (1998), Thurgood (2004), Chase et al. (2010) and Davies et al. (2014) all highlight that because the care provided often has an overemphasis on physical treatment (often with distressing side effects of medication) and is thus experienced as dehumanising and punitive, it has a significant impact on engagement with services and treatment.

Discrimination or insensitivity from staff. Some people disengage from mental health services because of perceived discrimination and insensitivity from mental health staff (on the grounds of gender, race, culture, sexuality or even symptom related factors such as drug use or homelessness). Ethnic minority groups in the UK may feel alienated by negative discriminatory experiences; being subject to more severe and coercive treatments, poorer access to psychosocial interventions and cultural or language barriers in assessments (SCMH, 1998; SCMH, 2000; DoH, 2003; Thurgood, 2004; Keating, 2007; Chakraborty et al., 2010).

Nature of service delivery. People who experience SMHP (often in combination with substance use) have complex needs, and these needs should be addressed by specialist services including those in the following areas: physical health care, mental health care, substance misuse issues, housing and the criminal justice system. When different agencies are involved there is the potential for disruption in service delivery, for example when there is not effective communication between agencies or there is disagreement about lead responsibility. Problems in communication between agencies may lead to the patient feeling disenfranchised from the process (SCMH, 1998; DoH, 2002a; McCulloch & Parker, 2004; Thurgood, 2004; Rassool, 2009). In some cases it may be difficult for people with SMHP and chronic social problems to attend outpatient appointments. Non-attendance at outpatient clinics can result in service discharge (Timms, 1993). Some service users only seek help in

an emergency (via Accident and Emergency for example). The resulting intervention is often too brief and leaves the service user feeling further disenfranchised (Craig & Timms, 2000). The review by Kreyenbuhl et al. (2009) found that treatment not being delivered in a collaborative manner was a reason for some individuals to disengage. Burns (2009), in a critique of the AOT model, suggested that the size of a key worker's caseload potentially impacted upon the quality of engagement with services.

Skill mix of clinical team. Repper (2000) focused on what people want from a mental health service. One recommendation was that people want a service where they can access various types of specialist support from a single agency. The implication of the research being that, too often, people with SMHP (often in combination with substance use) found that mental health teams did not have the necessary skill mix to meet their complex needs.

The links between insight in SMHP and disengagement from mental health services have been discussed in the literature. Ghaemi and Pope (1994) propose that a failure to engage with services and to adhere to treatment is attributable to a lack of insight. A finding of Kessler et al. (2001) was that the majority of the participants in their study who were not receiving any treatment were not doing so because they did not believe they had a condition that needed treatment. O'Brien et al. (2009) suggest that it is "intuitively correct" that people would disengage from mental health services due to a lack of insight, however Kreyenbuhl et al. (2009) summarised that there were differing perspectives on how illness impacts upon engagement. Furthermore, Tait et al. (2003) stated that the evidence for a relationship between insight and treatment adherence is inconclusive, citing Trauer and Sacks (2000) as an example. Holzinger et al. (2002) found that whilst just over half the patients in their sample considered themselves mentally ill, they tended to endorse psychosocial causes of their mental illness more readily than biological causes. Therefore, Holzinger et al. (2002) concluded subjective illness beliefs might reflect different styles of coping with schizophrenia, but there was no evidence that subjective illness beliefs directly determined compliance with medication. Further, Mishra et al. (2009) highlighted that just because a person may have good insight it does not follow that the person will either adhere to a treatment regime or function well.

A review by O'Brien et al. (2009) examined the literature on why people with SMHP disengage from mental health services and also provided a demographic oversight of those people who were more likely to disengage. O'Brien et al.'s review was critically appraised using the Critical Appraisal Skills Programme (CASP, 2013). The CASP tool is a suitable instrument for critically appraising research literature (Aveyard, 2014). Whilst overall the CASP document illustrates that the review is a robust one, there are two issues that are not satisfactorily resolved. Firstly, the review itself highlights that there is no consensus on what disengagement means. Therefore, when looking at 14 international papers on the subject by various writers, these will inevitably be referring to a different understanding of the experiences of engagement and disengagement. There may also be another layer of complexity in the degrees to which patients are legally required to engage with services and to what extent this impacts on papers that are not included in the study thus not providing an accurate picture of the scale of disengagement. In summary, whilst the review itself was robust and provides context for this current study, the results simultaneously raise further questions which are not easily resolved. As a literature review, O'Brien et al. (2009) provided great detail and the paper concluded that the demographics of those people most likely to disengage are: younger people; people from ethnic minority backgrounds; socioeconomic factors such as living in the inner city, unemployment, poor social networks and low education achievement; people without family and social support; and people with a forensic history. The paper also highlighted clinical factors such as: dual diagnosis; insight (or lack of it); and stage of illness.

Another literature review written on the subject of disengagement was carried out by Kreyenbuhl et al. (2009). Whilst having a slightly different focus, the review came to similar conclusions as O'Brien et al. (2009) stating that those people at the highest risk of disengagement were those at the younger end of the age spectrum, male, from an ethnic minority background, with lower social functioning and with "a co-occurring psychiatric and substance use disorder". Furthermore, Kessler et al. (2001) in their study of untreated serious mental illness suggested that young adults living in non-rural areas were the most likely to be disengaged. Whilst Ishikura et al. (2014), who investigated disengagement amongst people with a first episode psychosis as opposed to a SMHP, concluded that the most important

variable for predicting disengagement was not age or gender but rather the trust the patient had in the treating professional.

The studies thus far have examined the reasons for disengagement from the perspective of the service users. Stanhope et al. (2009) asked clinicians about their perspective on why service users with severe mental illness and a history of homelessness and substance misuse disengage from services. Though from the United States of America (US), the paper offers a useful perspective on the phenomenon of disengagement. The primary reason given by the case managers for disengagement from mental health services in the Stanhope et al. study was substance misuse and the desire for alternative living arrangements. The case managers in Stanhope et al. (2009) understood disengagement as part of their work and viewed disengagement as poor decision making by the individual service users.

1.1.4   Assertive Outreach

AOTs are designed to offer a service to people with SMHP who through choice, circumstance or illness find it difficult to engage with mental health services (Morris & Smith, 2009, p. 434). AOTs have a strong emphasis on team working and have a high staff to patient ratio in order to offer more intensive input to their service users. Use of the AOT model was successful in the US (Dixon, 2000) and was imported into the UK as an example of 'international best practice' (McCulloch & Parker, 2004); there was a rapid take up in the late 1990s and early 2000s of AOTs across the UK following the NHS plan (2000). The Cochrane review by Marshall and Lockwood (2001) was based primarily on the experience of AOTs outside of the UK. The review concluded that the AOT model was an effective form of service delivery.

However, the UK700 trial (Burns et al., 1999) failed to replicate the US experience of reduced bed use and reduced service contact, and the model has not been an unqualified success in the UK (Killaspy et al., 2009a). Indeed, during the process of doing this study within the local NHS trust eight teams have been contracted to five. It is arguable that there has been a change in the focus of AOTs over the past decade and teams now concentrate on minimising risk to the public and to individuals; therefore, there is a focus on compliance, coercion and control (Williamson, 2002; Claassen & Priebe, 2006; Chakraborty et al., 2011). In this fluid

context, where both services and the focus of their work are rapidly changing, it is suggested that it is imperative that the voices of the people who use these services are heard.

Some literature indicates that mental health services are not addressing the need to use the least restrictive form of care possible, with the current emphasis on coercion, control and compliance (Bentall, 2013; CQC, 2013). Staff in the AOTs also struggle with these issues. Essentially, the issue which must be adequately addressed by staff is how to simultaneously balance the coercion, control and compliance elements of AOT whilst still working with clients in an individualised and humanistic way. These ethical dilemmas are addressed by Claassen and Priebe (2006). Claassen and Priebe (2006) proposed that unless the dilemmas of modern mental health care that are embedded in the AOT model (namely persistence versus coercion; public protection versus risk aversion; empowerment versus negligence; support versus harassment) are resolved, then the ethical contradictions may necessitate a re-evaluation of the model. Williamson (2002) discussed the perceived paternalistic and coercive aspects of AOT treatment. Williamson (2002) concluded that these issues could be resolved if treatment was in line with service users' values and the help provided was seen by the service user as pragmatically useful.

1.1.4.1 Critique of the AOT model

The debate about the viability of the AOT model in the UK has been evident in the literature since the turn of the millennium. Whilst *Keys to Engagement* (SCMH, 1998) and the National Service Framework for mental health (DoH, 1999) established AOTs as a cornerstone of good practice in the UK, simultaneously both Tyrer et al. (2000) and Burns et al. (2000) questioned the value and economics of the AOT model in the NHS. Burns (2009) proposed that there is well established evidence that traditional UK Community Mental Health teams (CMHTs) perform as well as AOTs in the care of SMHP patients. Numerous trials in the UK have failed to show that AOTs consistently reduce the use of hospital care as the model has done in the US (Burns et al., 2007). Both Killaspy et al. (2009a) and Burns (2009) argued that the treatment provided by AOTs could be just as effectively offered by CMHTs and in a more cost effective manner. The high staff to patient ratio in AOTs (SCMH, 1998) makes the model an expensive service relative to the standard care as delivered by CMHTs.

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Whilst CMHTs are able to support people with serious mental illnesses as effectively as AOTs, AOTs may be better at engaging clients and may lead to greater satisfaction with services (Killaspy et al., 2006, 2009b). Killaspy et al. (2006) conclude that policy makers and service planners should be encouraged to consider whether improved engagement and satisfaction for AOT patients justify the continued use of the model.

The final Mental Health policy document of the previous government was *New Horizons* (DoH, 2009). The focus of the document was on promoting the mental health of the community through localised initiatives and education. Functionalised teams, such as AOTs, were not mentioned in this policy document. The strategy laid out in *New Horizons* is supported by the current coalition government, aiming for strategies that improve the mental well-being of the country (DoH, 2011). The omission of the future of functionalised teams can be interpreted in two ways. Firstly, that the National Service for mental health (DoH, 1999) and NHS Plan (DoH, 2000) had adequately set up functionalised teams to provide a highly specialised service to specifically identified groups of patients and that it is now time to move onto improving the delivery of mental health services to a broader spectrum of the UK population. Or alternatively, that the decade-long use of a functionalised mental health service has not produced the anticipated results (e.g. reducing hospital bed days) and consequently it is time to reconsider whether supporting expensive functionalised teams is the best way to provide mental health services.

The current trend in UK mental health policy and service delivery is moving away from functionalised teams, condensing services and changing the emphasis of mental health working practices (DoH, 2011). Over the past decade there has arguably been a change in focus for mental health services and AOTs. It is argued that as AOTs (along with other mental health services) are now focusing more on minimising risk to the public and to the individual, there is a greater focus on compliance, coercion and control (Williamson, 2002; Claassen & Priebe, 2006; Chakraborty, et al., 2010; Bentall, 2013; CQC, 2013).

Further questioning the viability of the AOT model, Commander et al. (2005) concluded that patients under AOTs remain in contact with services and spend less time in hospital.

However, the same patients showed no improvement in symptoms, risk behaviours or social functioning, nor did AOTs impact upon substance abuse or risk to others despite patients' extensive histories of problems (Commander et al., 2005). Possibly this finding reflects the failure to successfully address substance misuse problems (Graham et al., 2004) or address co-morbid personality disorders in some patients (Moran et al., 2003). Commander et al. (2005) noted that their findings indicate the need for a realistic appraisal of what AOTs can achieve and an acknowledgement that it may not be possible to adequately support all patients in the community.

Shetty (2010) argued that the focus of AOT work is on engagement without addressing what teams should do after successfully engaging patients with services. The suggestion by Shetty (2010) is that after engagement the focus of care should then become 'recovery' and social inclusion. The proposed change in emphasis would address concerns raised by Claassen and Priebe (2006) and Spindel and Nugent (2000) about marginalisation and stigmatisation. Once these issues have been addressed then potentially the UK AOT model may become as successful as it has been overseas.

The future of the AOT model is unclear nationally and whilst there has been a reduction in services locally, there continues to be an AOT service. It is uncertain whether studies indicating improvements in concepts that are difficult to measure such as 'engagement' and 'satisfaction' are sufficient to retain an expensive service; commissioners of services may also need to see improvements in more quantifiable outcomes such as bed days for services to continue.

1.1.5   Summary

The literature introduced above highlights the key concepts that are involved in this study, namely SMHP, dual diagnosis, AOT, issues in disengagement from mental health services, the reasons behind disengagement and the demographics of those more likely to disengage from services.

1.2   Literature Review

Between October 2008 and May 2010 a review of the literature was undertaken. A systematic combination of the search terms, using the Bolean operative '&', was used:

Table 1: Search Terms for the Literature Review

Search terms	Key search terms
'assertive outreach team', 'assertive community treatment', 'bi-polar affective disorder', 'case formulation', 'disengag', 'engagement', 'engage', 'engag', 'health belief model', 'interpretative phenomenological analysis', 'mental health', 'mental health services', 'mental illness', 'phenomenolog', 'psychosis', 'schizophrenia', 'SEMI', 'self-concept', 'therapeutic alliance' and 'qualitative'.	''co-morbidity', 'denial of illness', 'disengagement', 'disengage', 'dual diagnosis', 'help-seeking behaviour', 'identity', 'insight', 'perception', 'unawareness of illness' and 'self-perception'.

The following databases were searched: MEDLINE, PsycINFO, Royal College of Nursing, CINAHL Plus (EBSCO), PubMed and EMBASE: Excerpta Medica (Ovid). These databases were chosen as they are pertinent to healthcare, nursing and psychiatry research (Parfrey, 2003; Fink, 2010, p. 19; Aveyard, 2014, p. 83). When relevant authors were found separate author searches were completed and reference list searches were done on all relevant papers (Aveyard, 2014, p. 89). Whilst global published literature was sought, the search was restricted to English language papers only. An alert system was also created through a well-known search engine to alert the researcher whenever articles were published with either 'disengag' or 'engag' amongst the keywords.

The initial searches yielded 17,827 results

After discounting duplicates, reading the title or the abstract 371 papers were found to be relevant to the research subject area.

After snowballing searches and on-going databases searches 8 papers were found which addressed the research question.
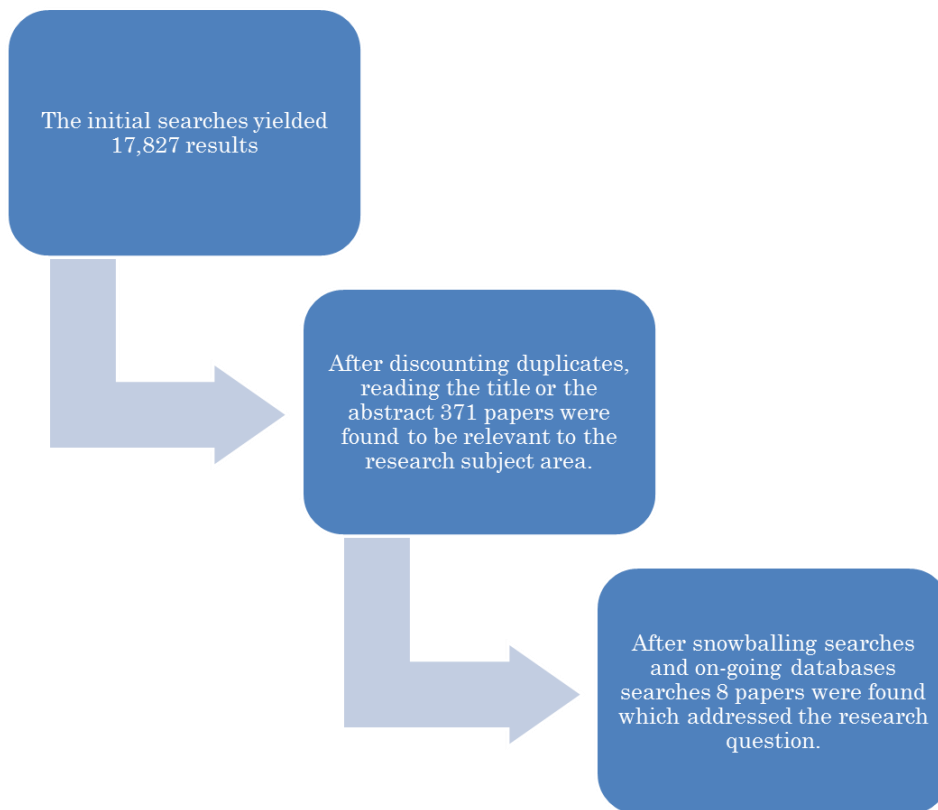
Figure 1: Process of the Literature Review

At the start of the literature search no specific inclusion or exclusion criteria were set beyond papers that needed to address the research question. However, those found were all similar in nature. Theoretically the search strategy did not exclude papers from outside the UK, there was an open-ended time frame, qualitative, quantitative, literature reviews or opinion pieces could have been used. After the search was complete all the papers were from this millennium, all were from the UK and all were qualitative studies. The eight papers found through the search strategy that addressed the research question are listed below:

Watts, J. & Priebe, S. (2002) A phenomenological account of users' experiences of assertive community treatment.

Keating, F. & Robertson, D. (2004) Fear, black people and mental illness: A vicious circle?

Priebe, S., Watts, J. & Chase, M. et al. (2005) Process of disengagement and engagement in assertive outreach patients: qualitative study.

Biddle, L., Donovan, J., Sharp, D. et al. (2007) Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour.

Chase, M., Zinken, J., Costall, A., Watts, J. & Priebe, S. (2010) "These psychiatrists rate themselves as gods": Disengagement and engagement discourses of people living with severe mental illness.

Chakraborty, A., King, M., Leavey, G. & McKenzie, K. (2011) Perceived racism, medication adherence and hospital admission in African-Caribbean patients with psychosis in the United Kingdom.

Wright, N., Callaghan, P. & Bartlett, P. (2011) Mental health service users' and practitioners' experiences of engagement in assertive outreach: a qualitative study.

Davies, R.L., Heslop, P., Onyett, S. et al. (2014) Effective support for those who are "hard to engage": a qualitative user-led study.

1.2.1   Summary and critique of the literature

The following section examines the literature that was found as a result of the literature search into the experience of disengagement from mental health services for people with SMHP.

1.2.1.1 Watts and Priebe (2002)

Watts and Priebe (2002) used a grounded theory methodology with 12 people under the care of AOTs to examine their perspective on being assertively engaged with services whilst simultaneously services were striving to maintain a therapeutic relationship. That study suggested that the rejection of service users seeking help from mental health services early on in the course of their illness had a subsequent impact upon their future engagement. Similar to both Priebe et al. (2005) and Chase et al. (2010), the participants in Watts and Priebe

(2002) perceived involvement with mental health services as an attack on their identity. The study concludes that the cultural and historical aspects to disengagement are potentially more important than insight in regards to disengagement.

Watts and Priebe's (2002) study was appraised using the Caldwell et al. (2011) framework for critiquing health research. This framework was chosen because of its clear design and layout and is suitable for use with both qualitative and quantitative papers. The title of the study was, *A Phenomenological Account of Users' Experiences of Assertive Community Treatment.* However, the aim of the study was to examine service users' experience of the tension between sustaining long-term therapeutic relationships whilst simultaneously exercising social control. This was explained as a central dilemma of community psychiatry. Therefore, there was a slight mismatch between the title of the study and the content. The authors are both academics but their position and qualifications were not stated. The abstract provided a good synopsis of the study. The study provides context and explains the dilemma it is examining.

The rationale for the study was that the patient's experience of having forced therapeutic interactions had not previously been examined. Without having a separate literature review section, the study is supported with up-to-date literature. Ethical approval was obtained, participants were assured of anonymity, the aims of the study were explained to the participants and informed consent was given. Grounded theory was used for the data analysis; whilst, the process is explained to the reader the philosophical assumptions of grounded theory are not presented. The recruitment strategy was done via care coordinators and the only selection method was that the participants were under the care of an AOT. Other than lacking in detail about the recruitment of participants, the methods of data collection were auditable. Through the use of a research group, the analysis was credible and confirmable. The paper focused on the presentation of the results as opposed to the discussion of methodological issues. As the study has a qualitative methodology there were only 12 participants and as such there are limitations on the generalisability and transferability of the results. There is a robust discussion of the results. The conclusion found that the phenomenological research methodology was suitable for the purpose but was not fully comprehensive regarding the findings.

1.2.1.2 Keating and Robertson (2004)

The participants in Keating and Robertson's study (2004) found using mental health services to be an alienating and degrading experience, echoing their experiences of wider society. Use of mental health services was considered to be a last resort. Keating and Robertson (2004) suggested that there is a perception amongst black service users that mental health services replicate the experiences of racism and discrimination that black people experience in the wider society. Furthermore, they also suggested that black service users who had experienced more oppressive and controlling regimes in other aspects of their lives found that mental health services mirror this experience.

Keating and Robertson's (2004) was a qualitative study into the 'circles of fear' that exist between the black community and mental health services in the UK. The study was critically evaluated using the Caldwell et al. (2011) framework for critiquing health research. Service users, families and professionals were all interviewed in the study. The title of the paper – *Fear, black people and mental illness: A vicious circle?* – tells the reader about the content, but not the methods. One author is a senior researcher fellow but the role of the other author is not stated, meaning the lead author at least is credible. The abstract focuses on the context and findings but not the method. The rationale for undertaking the research was not only that the African-Caribbean community is the most over-represented ethnic group in mental health services but also the community appears to be the one to which most fear is directed, both by mental health services and the community in general. The literature review was comprehensive and up to date and provided useful context for the study. The aims of the research are clearly stated. Interestingly, despite the sensitivity of the material, no ethical approval was needed as the researchers were accessing neither hospital records nor recruiting via hospital records. Whilst the philosophical underpinning of the study was not explained, the study design was identified and justified. The major concepts of fear, mental illness, mental health services and issues facing the black community were clearly explained. The selection of participants was described and the sampling method was identified. The data analysis highlights that efforts were made to ensure inter-rater reliability between coders. The research process involved the preliminary research findings being presented to steering and advisory groups and the panel of interviewers in order to promote transparency and reliability, promoting the dependability of the paper.

The use of external review panels and the steps taken to ensure agreement between coders meant that enough steps were taken for the analysis and results to be credible and confirmable. The results are presented in an appropriate and clear manner. The use of quotes allows for the development of thick description emphasising to the reader that the results could have broad application. Both the discussion and conclusion were comprehensive.

1.2.1.3 Priebe et al. (2005)

Priebe et al. (2005) used a grounded theory methodology to explore the personal and social contexts that led to people with SMHP disengaging from mental health services and then defined the contexts in which people then re-engaged with services; 40 patients were interviewed all of whom had manifest difficulties in engaging with mental health services.

Priebe et al. (2005) was critically evaluated using the Caldwell et al. (2011) framework for critiquing health research. The title of the paper – *Processes of disengagement and engagement in assertive outreach patients: qualitative study* – reflects the content of the study. The lead author, Stefan Priebe is a professor and thus is a credible author. The abstract clearly and concisely summarised the key components of the study. The rationale for undertaking the study was outlined; little is known about what staff actually do to engage patients with AOTs or the psychological processes that patients go through when they are re-engaged. However, the aim of the study was to explore the views on engagement and disengagement of patients under the care of AOTs, with no mention of staff activity. Whilst the literature review was up to date for 2005, it was not particularly extensive. Other than the participants being given a verbal and written explanation of the study, there is no identification of the ethical issues that the study gave rise to. The data was analysed using thematic analysis, the philosophical background for which was not provided. Why a qualitative research methodology was required was explained as the study wanted to examine participants' experiences. The main concepts of the study, disengagement and engagement, were not defined for the reader but the overall context for the study is provided. Greater emphasis was put on the research method; the paper clearly details the inclusion and exclusion criteria for the participants, the sampling method is detailed and the method of data collection was auditable. Similarly, the method of data analysis was credible and confirmable. The results were presented in a clear and appropriate way but, as the study

highlights itself, the results are reflective of 40 AOT patients in London and, therefore, may not be transferable. The discussion and conclusion are both comprehensive.

Priebe et al. (2005) highlighted "individual agency and identity" as crucial in understanding the disengagement and any re-engagement process. The study described the process of disengagement as a desire on the part of the participants to become, or remain, independent people. The majority of participants in the study found it difficult to accept their diagnosis of SMHP and therefore distanced themselves from mental health services in an effort to 'prove them wrong'. The other two themes related to the experience of disengagement were "lack of active participation and poor therapeutic relationships" and "loss of control due to medication and its effects". Both of these themes reinforced the idea that the participants experienced a loss of self-determination as a result of being involved with mental health services.

1.2.1.4 Biddle et al. (2007)

Biddle et al. (2007) examined the experiences of 24 young adults who were experiencing 'mental distress'. The participants were divided into help seekers and non-help seekers. The Cycle of Avoidance (COA) model is an interpretative framework for evaluating distress, designed to examine the experience of young people who were anticipating discrimination as a consequence of diagnosis. It suggests that people are involved in an internal cyclical process of lay diagnosis wherein the person engages in a repeated negotiation with themself regarding the meaning of symptoms, in order to avoid the diagnosis of 'real' distress. In the next stage of the COA people develop a range of strategies for normalisation and 'coping' with symptoms to facilitate avoidance of mental health services. The framework suggests that people create a moveable threshold to define when professional 'help' would be needed or why in their own circumstances there is no need for professional input. The COA suggests that people perceive there to be negative social meanings attached to what constitutes 'help' and 'distress' which drives this cycle of avoidance. The perceived negative impact of the involvement with mental health services includes changes to identity, biographical disruption and stigma.

Biddle et al.'s (2007) COA is represented below:

NORMAL DISTRESS

Avoidance of meanings of 'real' distress and help

Repeated attempts to 'cope' and normalise increasingly severe distress

THRESHOLD

'REAL' DISTRESS AND HELP

Shifting threshold for real distress and help

Continuum of distress

Crisis
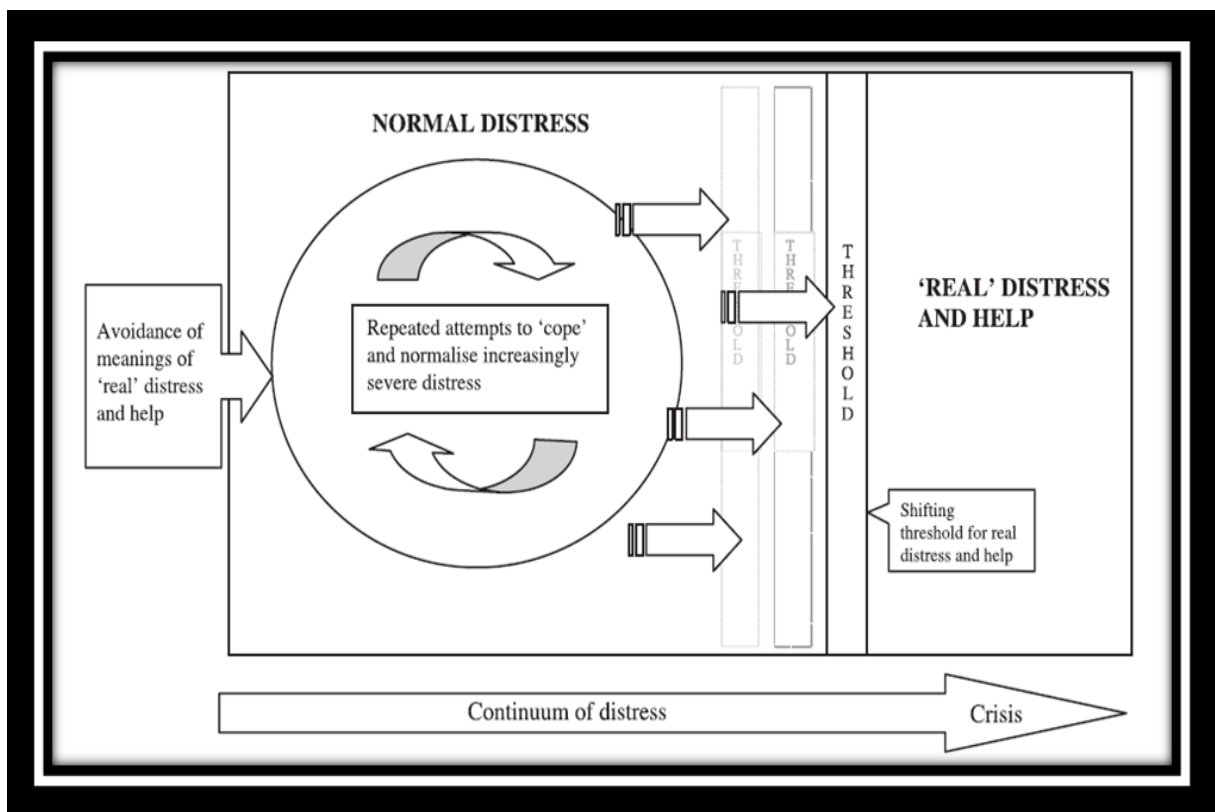
Reprinted with permission of John Wiley and sons (Appendix 1)

Figure 2: Biddle et al. (2007) Cycle of Avoidance (COA)

The Biddle et al.'s (2007) study was critically evaluated using the Caldwell et al. (2010) framework for critiquing health research. The title of the paper – *Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour* – reflects the content of the study. All four authors are academics; therefore, they can be considered credible. The abstract summarises the key components of the study. The rationale behind the study was that help-seeking behaviour for mental illness is least likely to occur in the 16-24 age group. Subsequently, the aim of the study was to provide an explanation for that non-help-seeking behaviour. The study is strongly supported with reference to the literature. The major concepts are explained and context for the study is provided. The paper does provide a broad picture of the recruitment strategy but does not raise any ethical issues. The method of data collection is auditable; the data analysis is credible and confirmable and as the model was being developed it was continually tested

against existing cases for 'fit'. Whilst the reader is told that the principles of grounded theory were employed in the theory building, the philosophical principles of grounded theory are not expanded upon. The presentation of the results is expansive and details of the results are supported by extensive quotes. The discussion covers both theoretical and clinical implications of the study. The study ends with a comprehensive conclusion but, despite the robustness of the research methodology, it needs to be borne in mind that the theory building is based on the experiences of 23 help- and non-help seeking young people.

The participants in Biddle et al.'s study (2007) understood mental distress in two categories: either 'normal' or 'real'. The mental distress that was perceived as 'normal' was understood as part of the universal experience of life. The 'normal' mental distress was not considered either serious or an illness. But as the distress became more serious it was then seen as 'real'. 'Real' distress was perceived as abnormal, rare and permanent and also as mental illness.

The COA model suggests that participants indefinitely delayed seeking help until such time as their worsening condition made it impossible to continue seeing their symptoms as normal. This meant that as the participants struggled with the process of defining their distress as either 'normal' or 'real' the threshold between the two shifted. So, as the participants' symptoms worsened the threshold for 'real' distress got pushed further back to the stage where relatively severe symptoms such as 'suicidal behaviour', 'hearing voices' and having a 'nervous breakdown' became contained within the normal category. In the COA model it is only after help had been enforced that the participants realised that they had crossed the threshold into 'real' distress.

The participants in the COA model saw crossing the threshold into 'real' distress as both negative and significant. The catalyst for participants in the COA model making the transformation from 'normal' to 'real' was seeking professional help. Experiencing distress that was perceived as 'real' would initiate irreversible negative changes – frightening treatments, a change of identity (both public and private), the record of treatment would stay with them and the inevitable stigma of mental illness would follow. The participants understood that as a consequence of help-seeking there was an acknowledgement that the distress was real, long term and offered worse prospects for recovery being possible.

1.2.1.5 Chase et al. (2010)

There are parallels between Chase et al. (2010) and the ideas of Biddle et al.'s (2007) Cycle of Avoidance (COA) wherein people disengage from mental health services to stop themselves from having the passive position of 'patienthood' and the association with the debilitating side effects of medication and the stigma associated with a psychiatric diagnosis.

Chase et al. (2010) examined the research data used by Priebe et al. (2005) and it was critically evaluated using Caldwell et al.'s framework for critiquing health research (2011). The title of the paper – "*These psychiatrists rate themselves as gods*": Disengagement and engagement discourses of people living with severe mental illness – reflects the content of the study. The lead author, Mike Chase was a PhD student and the other four authors are either senior lecturers or professors and are thus credible authors. The abstract summarised the key components of the study, and put a strong emphasis on its methodological features. The rationale for undertaking the study was outlined: why people disengage and then subsequently re-engage with mental health services is a matter of interest to both clinicians and commissioners. The study aimed to contribute to the understanding of how psychosocial factors help or inhibit people's engagement with mental health services. The studies included in the literature review were from 1997-2008 and, within the limitations of space, the review was extensive. In Priebe et al. (2005) the only ethical issue noted was that the participants were given a verbal and written explanation of the study; this study elaborated that ethical approval had been gained via the local NHS, that participants were interviewed at home and that all participants had been judged to be well enough to participate by their keyworker. The data was analysed using positioning analysis for which the philosophical background was provided. The main concepts of the study, disengagement and engagement, are not defined but the overall context for the study is provided. The study clearly details the inclusion and exclusion criteria for the participants, the sampling method is detailed and the method of data collection is explained. Great emphasis is put on the data analysis as this separates the study from Priebe et al. (2005) and ensures that the method of data analysis was credible and confirmable. The results are presented in a clear and appropriate way, but as the study is reinterpreting data from another study the study itself acknowledged that there may be further

ways in which the data could be reinterpreted. The discussion was very comprehensive and the conclusion focused on the success of the data analysis.

Despite using a different research methodology, Chase et al. (2010) re-emphasised the importance of 'agency' and 'identity' in making the difference for some people when engaging with mental health services. Furthermore, the study also identified that the participants struggled to continue to have an active role in their lives and treatment and successful re-engagement was brought about by clinicians facilitating this to happen. Chase et al. (2010) suggested that service users needed to regain the identity of who they were before they became involved with mental health services and were diagnosed with SMHP. Regaining this identity meant that they were able to stop themselves from sliding into the passive position of 'patienthood' with the associated debilitating side effects of medication and the stigmatising effects of psychiatric diagnosis. However, in the re-engagement process the participants needed the professionals to invest time and effort into the therapeutic relationship and for that relationship to move away from a purely medical focus (see also Cuffel et al., 1996; McCabe et al., 2000; Watts & Priebe, 2002; Holzinger et al., 2002; Tait et al., 2003).

Chase et al. (2010) highlighted that the passive voice frequently adopted by the participants in the research interviews was indicative of a lack of belief in their personal agency. Another linguistic feature of Chase et al.'s (2010) interpretation was that the participants referred to professionals collectively, creating a sense that the professionals presented a united front against the participants, and continuing the idea of patients being in a passive position relative to professionals. Chase et al. (2010) concluded that for the participants, disengagement was experienced as "the struggle to remain active agents in their lives and treatment."

1.2.1.6 Chakraborty et al. (2011)

Chakraborty et al.'s (2011) research was a UK-based study that recruited 100 participants who were of Caribbean descent, aged 18-65 and diagnosed with psychotic symptoms. Over a 12-month period the participants' perception of racism was measured against standardised scales. Chakraborty et al. (2011) proposed that British African-Caribbean people with SMHP perceive racism from mental health professionals as a contributing factor to them rejecting

mental health services. The evidence of this rejection of mental health services was the poor adherence to medication leading to poorer outcomes, such as longer hospital stays.

Chakraborty et al.'s study (2011) was critically evaluated using the Caldwell et al. (2011) framework for critiquing health research. The title – *Perceived racism, medication adherence, and hospital admission in African-Caribbean patients with psychosis in the United Kingdom* – reflects the content of the paper but not the method. The first two authors are academics, but the job role of the other two is not stated, however the authors are credible. The abstract provided clear background, method, results and conclusion. The rationale, that the links between racism, medication compliance and psychosis are under explored, is clearly stated. The literature review is up to date, detailed and provides context, though given the scope of the paper it would be difficult to be comprehensive. Whilst a hypothesis was provided, the aim of the study was not. The hypothesis was that there was a prospective link between perceived racism and poorer medication compliance amongst UK Caribbeans with psychosis, and secondly if there is a link between perceived racism and poorer service-related outcome then it is mediated by medication adherence. The hypothesis was clear and variables defined. Ethical issues were neither identified nor addressed. The study design was identified and some rationale for choice of design was evident. The research population was identified, described and reflective of a specified population. The methods of data collection and analysis were reliable and justified. The results were presented in a way that was appropriate but, as the authors say, it is important that the study is replicated elsewhere to see if the results can be generalised. Whilst there was an informative conclusion in the abstract, there was no conclusion in the main body of the text. There were, however, implications for practice.

1.2.1.7 Wright et al. (2011)

Wright et al.'s (2011) UK-based study examined the experiences of AOTs for both practitioners and service users. Thirteen patients were interviewed and the data was analysed using philosophical hermeneutics as the research methodology. Four themes emerged as important for engagement with AOTs (Wright et al., 2011): contact, dialogue, transformation and shared understanding. Therefore, if these four processes are necessary in engagement then when these processes are not adequately implemented they also contribute to the

experience of disengagement. Additionally, AOT service users also valued the practical support that AOTs offer.

Wright et al. (2011) was critically evaluated using the Caldwell et al. (2011) framework for critiquing health research. The title of Wright et al. (2011) is an accurate reflection of the content of the paper. The authors of the paper are either research fellows or professors making them credible authors. The abstract summarised the key aspects of all the sections of the paper. The rationale for undertaking the paper was outlined and justified. The literature review was comprehensive, up to date and provided context for the study. The research aim was clearly stated and ethical issues were addressed. Whilst there was some writing on the philosophical background to the design and analysis, this area of the paper could have been improved. The major concepts of the study – engagement and AOT service delivery – were discussed. The selection of the participants was described, but no sampling method was identified. The reader is told how long the researchers spent collecting the research data and how long they interacted with individual participants. Both a reflective account and internal and external supervision were used during the analysis process to ensure the greatest transparency, as was participant verification. Given the detail provided in the methodology and analysis sections of the paper, another suitably trained research team could replicate the study. Despite there being no external review, the use of participant verification, a reflective journal and both internal and external supervision are sufficient to view the study as dependable. The results are presented in a clear and appropriate way. The four themes in Wright et al.'s (2011) findings resonate as credible. The use of quotes in the findings creates a thick description of the data allowing the reader to make a judgement that the results could have applicability to other participants in similar settings. The discussion chapter in Wright et al. (2011) was comprehensive but there was no conclusion chapter as such, just 'implications for practice'.

1.2.1.8 Davies et al. (2014)

Davies et al. (2014) was again a UK-based study exploring which services 'hard-to-engage' people with SMHP wanted from mental health services. The study used a mixed methods methodology, interviewing 47 people in different settings, all of whom had a history of disengagement. The main findings of the study were that the participants wanted help and

support with the problems that they, not the services, prioritised. In many cases this was practical support that the participants needed. The participants had negative perceptions of in-patient care and also believed that services put too much emphasis on medication. Davies et al. (2014) concluded that just because people were hard to engage it does not necessarily mean that they do not want some form of help or support from mental health services.

Davies et al. (2014) was critically evaluated using the Caldwell et al. (2011) framework for critiquing health research. The title of Davies et al.'s study (2014) – *Effective support for those who are "hard to engage": a qualitative user-led study.* – may be slightly misleading as the study focuses on what service users perceive as useful from their respective AOTs. The authors are credible: three from an academic background and one working for the NHS. The aim of the study was to explore the perceptions of hard-to-engage service users in order to inform future engagement with services. The literature review was only brief, as too was the outline of the major concept; as such, the paper does not provide a comprehensive context for the study. The ethical issues involved in the study were not highlighted in the paper. The research design was comprehensive, the recruitment strategy was meticulous and inclusive, the method of data collection was auditable and the method of data analysis was both credible and confirmable. The philosophical background for the data analysis was not highlighted. The main focus of the study was on the presentation of the results, which was done in an appropriate and clear way. The discussion was comprehensive and paves the way for a brief conclusion that services need to reconsider what 'hard to engage' or 'disengage' mean.

1.2.2 Background literature summary

Research by Mueser et al. (1998) highlighted the increased risks that people with SMHP who disengage from mental health services have. The Kreyenbuhl et al. (2009) and O'Brien et al. (2009) literature reviews highlighted the demographics of those people who were the most likely to disengage from mental health services. Watts and Priebe (2002) examined the experiences of people who were assertively engaged. They concluded that cultural and historical aspects to disengagement are more important than insight, and also participants who perceived themselves as having been rejected by services early on in the course of their illness were more likely to become disengaged. Keating and Robertson (2004) suggest that mental health services are another institution from which respective participants feel a sense of

alienation. They also reported that the participants in their study feared and mistrusted mental health services. Priebe et al. (2005) examined the personal and social contexts under which people with SMHP disengage from mental health services and then defined the contexts under which people then re-engaged with services. The study highlighted that "individual agency and identity" are crucial in understanding the disengagement and re-engagement process. Chase et al. (2010) examined the same data as Priebe et al. (2005) using a different research methodology. Chase et al. (2010) emphasised the findings of Priebe et al. (2005) that it is the importance of 'agency' and 'identity' that make the difference for some people when engaging with mental health services. Biddle et al.'s (2007) COA model examined the decision-making process that young people with a mental illness went through in deciding whether they were mentally ill and whether or not to engage with services. Davies et al. (2014) explored what services 'hard-to-engage' people with SMHP wanted from mental health services.

The contribution that this study makes to the body of literature on disengagement from mental health services for people with SMHP is that it sought both to provide an in-depth understanding of an individual's experience of disengagement from mental health services and to understand the perspectives of clinicians who work with this client group. Previous qualitative studies have examined disengagement from mental health services and the experience of being under the care of AOTs (Watts & Priebe, 2002; Priebe et al. 2005; Chase et al., 2010) but have not focused on the experience of disengagement or sought an idiographic understanding of each participant's experience of disengagement. Thus there is a gap in the research literature.

1.3   Study Aim and Research Questions

Previous studies have examined models to explain avoidance of mental health services, the fraught relationship between service users and mental health services, the language used when discussing engagement and disengagement, the perceived support required by this client group and the experience of engagement with AOTs. Thus, there is a gap in the research literature. The contribution that this study makes to the literature on disengagement from mental health services is that it seeks to develop an idiographic understanding of the participants' experiences of disengagement from mental health services and also to

understand the perspective of clinicians on the experiences of disengagement from mental health services for people with SMHP.

Research aim:

To examine the experiences of disengagement for people who have a diagnosis of severe mental health problems from the perspective of both service users and clinicians.

Research questions:

- What are the experiences of people with a diagnosis of severe mental health problems and a history of disengagement from mental health services?
- How do the research participants understand their own health, well-being and illness?
- How do the research participants perceive their needs in relation to statutory mental health services?
- What are the research participants' understandings of the role of drugs and alcohol within their lived experience?
- What are the perspectives of AOT staff on the experiences of disengagement from mental health services for people (in particular for black men) with SMHP?

CHAPTER 2: METHODOLOGY

2.1 IPA and Philosophical Underpinnings

2.1.1 Phenomenology, hermeneutics and idiography

Theoretically, IPA is based on three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography.

According to Dowling (2007) phenomenology has become the dominant philosophical underpinning for how nurses develop new knowledge. Phenomenology is the study of experience and provides a philosophical background for researchers to make sense of people's lived experience (Smith et al., 2009). The work of Husserl is considered to be the basis for the focus in IPA; the reflection and the attentive and systematic examination of experience. However, Husserl's pursuit of the essence of experience is too esoteric to be useful to phenomenological researchers and Crotty (1996) and Paley (1998) both argued that Husserl's phenomenology cannot be used as a research method as research is not an inward looking endeavour. The purpose of research is to generate new knowledge and understandings about the world. The practicalities of researchers moving from reflecting on transcendental consciousness to engaging in academic research would prove insurmountable according to both Crotty and Paley. The transcendental consciousness as defined by Husserl is about individuals being without the impediments of any social constructs, whereas the activity of engaging in academic research is itself a social construct. Thus, IPA also draws on the more contextualised, existential phenomenology of Heidegger and the work of Merleau-Ponty, Gadamer and Schleiermacher (Smith et al., 2009).

Hermeneutic phenomenology is one of the philosophical traditions underpinning IPA, employing an empathic yet critical cycle of hermeneutics to produce an interrogative account based on experience. Hermeneutics involves "the restoration of meaning" (Ricoeur, 1970, p. 8) and makes meanings, that are maybe hidden, manifest through looking for embedded meaning in human experience. The word 'hermeneutics' is derived from the original Greek, *hermeneuo*, which means to 'translate' or to 'interpret' (OED, 2001, p. 665). Thus hermeneutic phenomenology is the phenomenology of interpretation, and is informed by the

work of Heidegger and Gadamer. A central point of Heidegger's phenomenology was that humans are beings who are aware of their own being (Cerbone, 2008) and humans are also able to interpret their being. Gadamer developed the work of Heidegger and argued that people are embedded in a history and a culture which shape their consciousness (Honderich, 2005). Gadamer (1975) argued that in order for humans to interpret the meaning of any given situation they must use language, and conversations, in order to make sense of that situation. In addition, if any interpretation is to be obtained then the interpretation must sit within the person's cultural and historical contexts (Gadamer, 1975). So hermeneutic phenomenology as a philosophical tradition informs the IPA research method by implying that human researchers can only understand the world by interpreting the world through language done in combination with the researchers' cultural and historical contexts.

Whilst it is not unique to IPA as a research method, the idiographic focus of IPA allows the researcher to explore how a given person, in a given context, makes sense of a given phenomenon (Cohen et al., 2007) and allows participants to "think, talk and be heard" by using homogenous samples which are typically small (Reid et al., 2005, p. 25). IPA assumes a worldview in which the individual is not a passive recipient but an active interpreter of their subjective world. In such a world, any objective reality, or truth, is less important (Lyons and Coyle, 2007). However, because of the idiographic emphasis of IPA it is difficult to claim the transferability of results obtained to wider populations (Smith & Osborn, 2004). Nonetheless, readers are encouraged to reflect on the personal applicability of research findings. If studies are insightful enough then they will refer to "what it is to be human at its most essential" (Smith et al., 2009, p. 38).

2.1.2 Critique of phenomenology in nursing research

There is a large body of literature written between 1996 and 2010 discussing the relevance and importance of phenomenology to nursing research. The starting point of the debate was Crotty (1996) who said that the emergent phenomenological nurse research was a third person description of the phenomenon under investigation, as opposed to a critical examination of that phenomenon. Whilst Crotty (1996) understood the value of third person description of phenomenon to nursing research he did not believe that it could accurately be described as phenomenology. Barkway (2001) examined Crotty's 1996 critique of phenomenology in

nursing research and was largely supportive of Crotty's position. With particular pertinence to this study, Barkway (2001) highlights that whilst listening to someone's subjective experience is important, it should never be taken uncritically. Barkway (2001) highlights that Crotty (1996) had embraced a 'new' phenomenology in nursing research wherein subjective experiences of others were critically scrutinised by researchers, whereas philosophical phenomenology seeks only to understand the phenomenon itself (or the object of the participant's experience). Crotty (1996), Giorgi (2000) and Barkway (2001) were all of the opinion that 'new' phenomenological nursing research should not claim to be influenced by Heidegger. Mackey (2004) reflected the confusion highlighted by Crotty (1996), that nurse researchers are either engaging in phenomenological research without having a clear understanding of the philosophical traditions they are referencing or not describing the philosophical background of their study. The aim of Mackey (2004), however, was to offer a clear and concise description of Heidegger's phenomenology in order to promote its use in nursing research.

Independently, Paley (1997) had also argued that when nurse researchers stated that their research was in the tradition of Heidegger and Husserl, it rarely was. Paley's recommendation was that whilst nurse research could benefit from phenomenology, claiming that research fitted with the traditions of either Heidegger or Husserl was not useful. Paley (1998) advanced this idea stating that the study of 'lived experience' does not fit with Heidegger's phenomenology, questioning whether most nurse researchers had only read interpretations of Heidegger. Paley (1998) understood Heidegger to have said that human beings are self-interpreting and to an extent all understanding of lived experience and the cultural world must rest on interpretations; interpretations of human activity are built on understandings of a "network of practices". The former Paley paper was partially supported by Burke Draucker (1999), who stated that if nurse researchers were to continue citing Heidegger's phenomenology as a philosophical reference point in their research, the research needed to be more interpretative in its analysis.

Giorgi (2000) addressed the critiques of Crotty (1996) and Paley (1998). Giorgi agreed that some nurse researchers cited Heidegger and Husserl without reading the original texts or fully understanding what Heidegger and Husserl's phenomenology entailed. However, Giorgi

(2000) disagreed with Paley (1998) saying that nurse researchers should be encouraged to use the interpretative phenomenological work of Husserl whilst also having a greater understanding of the philosophical stand point that they are taking.

Van Der Zalm and Bergum (2000) highlight that whilst interpretative hermeneutic phenomenology does not advance action within clinical practice, its value lies in enhancing nurses' understanding of human experience, and that is the value of interpretative hermeneutic phenomenology to nursing practice. However, Van Der Zalm and Bergum (2000) reinforce another point raised by Paley (1998): understanding, and consequently changes to practice, will always be limited by an individual's ability to understand the language and culture underpinning any hermeneutic phenomenological study.

Sadala and Adorno (2002) embraced phenomenology in nursing research, in particular drawing on the work of Husserl. They explain Husserl's phenomenology as the description, not the explanation, of a given phenomenon, focusing on things as they manifest themselves and not searching for casual relations. However, they emphasised that Husserl's phenomenology never described a research method. The use of IPA to conduct this current research was supported by Fleming et al. (2003) who also believed that phenomenological and hermeneutic approaches had applicability to nursing research. In particular, they examined Gadamer's hermeneutic understanding; developing a research question, identifying pre-understandings, gaining understanding of the participants through dialogue, gaining understanding through dialogue with the text and establishing trustworthiness. This offers a step-by-step approach for nurses to carry out phenomenological and hermeneutic research, steps which are evident in this study.

Lopez and Willis (2004) were other authors who appeared to embrace phenomenology as a philosophical underpinning for nursing research as it reflects the lived contextual realities of peoples' experience. The paper aimed to explain how the traditions of both Husserl and Heidegger had a place in nursing research but that nurse researchers had to be cognisant that the two different philosophical paradigms sought to achieve different outcomes. Husserl's descriptive tradition sought to describe the essence of peoples' experiences as opposed to Heidegger's interpretative tradition which seeks to develop a being-in-the-world

understanding of a person's lived experience (Lopez & Willis, 2004). In the descriptive tradition, researchers consciously separate out their prior knowledge (or bracketing) whereas the interpretative tradition acknowledges that the researcher has expert knowledge which they use to generate further knowledge. Therefore, both traditions have value to nursing research; descriptive phenomenology allows researchers the opportunity to examine the essence of a phenomenon whereas interpretative phenomenology allows researchers the opportunity to examine contextual features of experience that are more directly related to practice (Lopez & Willis, 2004).

Paley (2005) continued to highlight the misrepresentation of phenomenology in nursing research detailing how frequently nursing research studies emphasise in their introductions the importance of phenomenology, generating findings that are unique to the personal experiences of the participants. However, when presenting their conclusions, the same studies become broader and make generalised comments about the experience beyond that of the participants and make inferences about reality (Paley, 2005).

Norlyk and Harder (2010) provide a summary of the critical debate about phenomenology in nursing research. They surmise that the debate can be characterised by three themes: 1) discussions about the correct interpretations of the phenomenological traditions; 2) a discussion about the value of phenomenological research as opposed to other qualitative research methods (including the differences between descriptive and interpretative research); and 3) a discussion about appropriate criteria for assessing the rigour of phenomenological research.

As demonstrated above, the use of phenomenology in nursing research has been discussed in detail. Accordingly, in completing this research study the primary researcher was aware the study needed to have an understanding of the philosophy of Husserl, Heidegger and Gadamer. Also, there was awareness that the study embraced descriptive and interpretative phenomenology, philosophical traditions important in IPA.

2.1.3   Interpretative phenomenological analysis and methodological considerations

IPA places emphasis on the subjective lived experience of participants and is, therefore, of value to researchers and practitioners who are seeking to emphasise the experiences of individuals (Smith et al., 2009).   Any research that is explicitly seeking the unique experiences of service users is in line with National Health Service efforts to promote patient-centred care and research (NHS constitution, 2013 and Keogh Report, 2013).

In the iterative development of the research design it was apparent that a qualitative study using in-depth, semi-structured interviews would be the most appropriate method to examine the research participants' beliefs about themselves and their experiences of disengagement from mental health services.   Qualitative research attempts to interpret social phenomena, placing an emphasis on the perspective of insiders in order to generate new understandings (Lapan et al., 2012).   It has the potential to explore research questions in depth and incorporate both the individual psychosocial aspects of a person's lived experience and the relationships between people and institutions (Slade & Priebe, 2006; Chase et al., 2010).   In addition, qualitative research makes it possible to reflect the health-related concerns of research participants that are framed by the environmental and cultural contexts (Sandelowski, 1996 & Dumas et al, 1999). Ignoring these contextual issues could threaten any study's internal validity.

Whilst it was apparent that a qualitative research method was appropriate to research the phenomenon under investigation, there was a question about which qualitative method could best address the research aims and objectives.   A number of research methods were considered but, after due consideration, dismissed in favour of using IPA.

Ethnography was not considered to be a viable option because in an ethnographic study there is an expectation that the researcher 'immerses' themselves in the culture or social field of the research participants over an extended period of time, researching the lives of the participants on their own terms.   Quite typically this is done by the researcher living within the same micro-community (Cresswell, 1998; Bailey, 2000; Mason, 2002; Flick, 2006).   Such a research method was rejected because not only did the participants in this study all live separately but simultaneously an inclusion criteria for this study was that the participants had

a history of disengagement from mental health services and would not have tolerated a researcher living with them. Similarly, as the research aimed to gain insights into the experiences of individuals, the use of an 'observational' research method was also considered unsuitable. Again, such a research method requires the researcher to be embedded in the community where the participants live and draw interpretative observations about the lives of the participants (Bulmer, 1982; Cresswell, 1998; Mason, 2002). Not only would the practicalities of both of these research methods have made them unsuitable but also they would not have addressed the aims and objectives of the study.

Oral history was considered as a research method and potentially could have been used to address the aims of the study. Oral history researchers look at the experiences of participants and are interested in generating narratives and narrative identities. However, oral history research attempts to generate shared memories, understandings and identities (Bertaux & Thompson, 2005). The aim of this study was to examine the experiences of individuals; the generation of a shared history between the participants was not an objective of the study.

A bibliographic life history study design was considered. The advantage of such a research design would have garnered rich data about particular individual participants; the research would have provided the reader with a detailed description of the participants; the research would have provided a description of the relationship between the researcher and the participant; typically bibliographic life history research revolves around a central issue or an 'epiphany' in the life of the participant; the researchers interpretation of the meanings of the 'epiphany' are explicit within the research; and the findings are related to the wider body of literature on the subject, as are the lessons learned from conducting the research (Cresswell, 1998). Such a research design may have been practical to meet the aims of this study. However, traditionally bibliographic life history studies focus on the life of one person and often relate the narrative developed in the research to historical documents (Cresswell, 1998). It may have been possible to relate the bibliographic life history narrative developed to the participant's medical records over the course of their involvement with mental health services. However, such a study would not have met all the aims and objectives of the study proposed. Additionally, bibliographic life history studies typically relate to only one person.

Another qualitative research method that was considered was grounded theory. Central to the ambitions of grounded theory is the generation of new theory. A grounded theory study starts from the position of asserting that no existing theory pertaining to the current subject under investigation should be applied. Any theory that is applied to the data is theory that has been discovered within the data (Flick, 2006). The aims and objectives of this study sought to gain an understanding of the experiences of a purposively sampled group of research participants and not to generate any theory pertaining to their collective experiences per se; therefore, grounded theory would not have fitted with the aims and objectives of this study.

Frequently, when research uses a case study design, there is a qualitative component. A case study research design seeks to have an understanding of a cohort of people (or case) and gathers data from a variety of different sources; for example, observations, Likert scales, focus groups and individual interviews. The case study method looks at a specific group, in a specific context over a specific time from a variety of different perspectives (Cresswell, 1998; Mason, 2002). However, a case study design was not considered a viable option as this study aimed to explore the experiences of disengagement from mental health services and the researcher believed that the participants would be unlikely to tolerate the high degree of interruption necessary for such research; in addition, the participants would not have been together as a group.

Descriptive phenomenology is a form of qualitative research that typically uses individual semi-structured interviews to gather data. The researcher in such a study aims to investigate the meaning that the phenomenon has for the study's participants. In keeping with the aim and objectives of this study, a descriptive phenomenology study uses small purposively sampled participants and looks at a particular phenomenon; in this instance, the experience of disengagement from mental health services. What descriptive phenomenology research studies are seeking is a description of a defined phenomenon in the words of the participants (Parahoo, 1997; Cresswell, 1998). To this extent such a research design definitely could have been used in this study. However, a philosophical problem with this approach is the bias the researcher introduces when interpreting and reporting on the data. With some strands of qualitative research (including descriptive phenomenology) there is the expectation that the researcher enters into the research with a blank slate and examines the phenomenon under

investigation without using any foreknowledge (Sadala & Adorno, 2002). As critics have highlighted, this is hard to achieve. Cerbone (2008), for example, concluded that the practicalities of suspending all foreknowledge through a process of bracketing, i.e. the phenomenological epoché in Heidegger's terms, was nearly impossible.

Distinct from descriptive phenomenology, IPA seeks to 'give voice' to a phenomenon and then to 'make sense' of the initial description in relation to wider social, cultural and theoretical contexts (Larkin et al., 2006). Furthermore, in contrast to other qualitative approaches, the researcher uses IPA to make inferences from 'data' (usually interview transcripts) to 'persons' (embodied and cultured beings who are seeking to make sense of the world) (Reid et al., 2005). The modified IPA research method detailed was designed to be the most appropriate method to study the phenomena under investigation, primarily because it allowed for close examination of the individual service users' experience and for the researcher to interpret and accurately reflect on the experiences of service users from the most informed position possible. As Watts and Priebe (2002) have previously argued, the use of phenomenological analysis allows for the examination of the differing perspectives in community psychiatry and recognises that there are different levels of explanation for such a complex phenomenon as disengagement.

IPA seeks to explore how people make sense of their own lived experience, particularly "significant existential issues of considerable moment to the participants and the researchers" (Smith, 2004, p. 49). IPA, as a phenomenological approach, seeks to locate research themes from underlying individual perspectives, and because of this, it is easily mistaken for a simple descriptive methodology and it "is easy to do badly and difficult to do well" (Larkin et al., 2006, p. 53). Smith (2004) defines IPA as "part of a stable of closely connected approaches which share a commitment to the exploration of personal lived experience" (p. 41).

As detailed in the previous section, phenomenology is concerned with human understanding, originating from the works of Husserl in the 1930s (Fade, 2004). Husserl rejected the value of empirical science and instead emphasised that in order to understand the world humans must value the lived experience. Hence, it has been argued that IPA should potentially not be considered as a phenomenological research method because it does not solely highlight the

essence of a participant's experience (Fade, 2004; Cronin & Lowes, 2015). However, in addition to the phenomenological pursuit of understanding the specific lived experience of individuals, IPA also acknowledges that the researcher's analysis and interpretations are central to bringing the research findings to light (Smith et al., 1999; Smith & Osborn, 2007). The beliefs and foreknowledge of the researcher should not be seen as biases artificially influencing the findings of the study but necessary in the endeavour of making sense of the participants' accounts of their experiences (Fade, 2004). Heidegger (1962) and Gadamer (1976) stressed that as humans are in the world then it is inevitable that they generate their understandings on the basis of their own pasts and also historical and socio-cultural backgrounds. Therefore, the analysis done by the researcher in IPA is central to the process of making sense of the participants' experience (Pringle et al., 2011a). They argue that without this active input in the interpretation of the data, the themes that may have otherwise been missed would not have been brought to light. Another way in which IPA is distinctive from other forms of qualitative research is that IPA offers the opportunity for researchers to engage with research questions at an idiographic (particular) level (Reid et al., 2005). IPA seeks to access unique and idiosyncratic experiences of defined groups of people.

The interpretative process within IPA necessarily brings in the foreknowledge and the preconceptions of the researcher as they travel around the hermeneutic cycle and develop their double hermeneutic regarding the phenomenon under investigation (Smith et al., 2009). Therefore, IPA is a distinctive research method in that it attempts to combine phenomenological, detailed, idiographic understanding of an experience with the interpretative analysis of the researcher to create dynamic, contextual and subjective findings (Fade, 2004; Smith & Osborn, 2007).

The findings of an IPA study can be written to reflect the experiences of an individual participants before expanding them to look at the collective experiences of all the participants. Despite the research design, it is important that the findings of studies are viewed as representative of the research participants but having limited generalisability beyond the small sample. Successful IPA research manages to be both subjective and interpretive, meaning the findings of the study should not be viewed as objective facts about the world (Reid et al., 2005).

One of the great advantages of IPA as a research methodology is that it is flexible in its application, allowing for use with a variety of different data collecting methods and data types (Brocki & Wearden, 2006). In study 1 this flexibility allowed the introduction of four distinctive features to the study design using individual interviews. In study 2, IPA was used with data collected from focus groups.

2.2 IPA and Focus Groups

Whereas study 1 used individual research interviews, study 2 used focus groups. IPA is traditionally used in individual interviews, and group interviews are less obviously suited to IPA research because of the idiographic focus of IPA research. By virtue of having more than one participant, group interviews create complex interactional environments (Palmer et al., 2010). The problem of this in relation to IPA is that it is harder for the researcher to reflect a particular idiographic focus because of the multitude of participants.

Millwood (2012) defines focus groups as discussion-based interviews that produce verbal data generated via the group interaction. The aim of focus groups is that the group builds conversation amongst the participants, as opposed to between the facilitator and the participants (Millwood, 2012). As focus groups allow for interaction between the participants the ambition is to create a broader, richer dialogue (Bradbury-Jones et al., 2009). Another advantage is that focus groups allow researchers to explore the experiences of more participants in a shorter period of time, due to the condensed data gathering format, which consequently also saves on costs (Palmer et al., 2010; Millwood, 2012).

In any group interview situation, regardless of the research method, the accounts offered by participants during the group interview are influenced by the researcher's questions, the reactions of other participants and also by the shared experiences of the participants in the group. Therefore, there is hesitancy about the influence these social dynamics may have on the responses of the participants (Flick, 2006; Green & Thorogood, 2014). Wilkinson (2004) suggested that there may also be power relations within a group which may influence how willing individuals are to speak in an honest fashion. There may also be difficulties in separating the perspectives of individuals from the group whole (Flick, 2006; Green &

Thorogood, 2014). IPA research celebrates detailed interpretation of unique individual experiences, but using group interviews as the means to gather data makes it harder to develop detailed narratives from single participants. The hope is that the group collectively will provide detail and depth (Green & Thorogood, 2014).

It is important to acknowledge that, because of the presence of multiple voices in complicated individual and shared contexts and the interactional nature of discussions, IPA focus groups do not develop personal phenomenological accounts. However, even though focus groups do not generate a single narrative from individual participants about their lived experience this is not an insurmountable problem (Bradbury-Jones et al., 2009). When using IPA with focus groups, just as with individual interviews, the findings are in part the result of the researcher's interpretations of the data. When analysing focus groups using IPA, the researcher needs to start from the standpoint of considering the group as a whole before considering the individual accounts (Morgan, 1997; Smith, 2004; Tomkins & Eatough, 2010). The IPA process for a focus group is socially situated and the coding practices used by the researcher may need to be more interactively aware than with individual interviews, because of the interaction between individuals in the group. However, using IPA as a methodology for the analysis of a focus group enables researchers to reflect on elements of shared meaning which have been created by the broader experience of multiple participants (Flowers et al., 2001; Wilkinson, 2003; Bradbury-Jones et al., 2009; Palmer et al., 2010).

Just as with individual IPA interviews, any experiential claims, narratives or reflections that are made with focus groups are socially situated by the variety of social and contextual relationships within the group (Palmer et al., 2010). Whilst all IPA studies have a contextual dimension as part of the hermeneutic phenomenology, usually this is an implicit aspect. When using IPA with focus groups the contextual dimension becomes more explicit as the participants in the group are not wholly separate from each other but are, for the purposes of the focus group, co-constituting and mutually disclosing (Palmer et al., 2010).

Bradbury-Jones et al. (2009) examined the appropriateness of using a phenomenological approach to analysis focus group data. The paper concludes that, providing researchers demonstrate that they are conversant with the philosophical traditions to which they make

reference and can justify their research methodology, the use of both descriptive and interpretative phenomenology are useful additions to nursing research. Consequently, supporting the use of IPA was an appropriate research method for study 2.

There are examples of IPA being applied to group interviews, e.g. Flowers et al. (2001), Dunne and Quayle (2002), de Visser and Smith (2007) and Palmer et al. (2010). In each of these studies the standard IPA approach of bottom-up analysis, grounded in the experience of their respective participants (Smith et al., 2009 and Palmer et al., 2010) was used. In conclusion, despite there being inherent differences when using IPA for focus groups as opposed to individual interviews, it does not mean that focus group IPA does not capture the contextual and contingent sense of lived experience that is important in hermeneutic phenomenology (Glendinning, 2007).

Pringle et al. (2011a) in their critical analysis of the contribution that IPA makes to nursing and healthcare research concluded that IPA allows for the experiences, and the meaning of those experiences, of individuals to be heard. It is only through understanding the meaning of experiences for defined groups of the population that professionals can make changes to healthcare delivery.

CHAPTER 3: RESEARCH METHOD

The following chapter describes and justifies the research method used in both study 1 and 2.

3.1 Summary

After ethical approval, participants were recruited through purposeful sampling to the research interview phase of the study. The study used in-depth, semi-structured interviews to explore and analyse the experiences of people with SMHP who also had a history of disengagement from mental health services. Through interpretative phenomenological analysis of the data, themes were developed first for individual service users and then across the participants. In study 1 there were two rounds of interviews, with a main interview with the seven service users followed by a second 'clarifying' interview with six of the service users.

Study 2 was two focus groups with clinicians working for AOTs, teams designed to work with people who have SMHP and a history of disengagement from mental health services. The aim of study 1 was to generate an interpretative account of the experience of disengagement for people with SMHP and a history of disengagement from mental health services. Whereas, the aim of study 2 was to develop an interpretative understanding of clinicians' perspective on the experience of disengagement for people with SMHP and a history of disengagement from mental health services. The clinicians had expert knowledge by virtue of the experience of working with the client group. The research questions asked in study 2 were a combination of the research questions and seeking perspectives on the interpretative themes generated study 1.

3.2 Study 1: Method

3.2.1 Sampling, access and recruitment

The research participants were recruited using purposive sampling. In purposive sampling participants are recruit on the basis that they have expertise in the phenomenon under study by virtue of it being an integral part of their life experiences (Cohen et al., 2007; Williams &

Hewison, 2009). Qualitative research, such as this study, does not seek to create a representative sample (Abrams, 2010). Small sample sizes are the norm in IPA (Brocki & Weardon, 2006) because it is anticipated that, through the detailed case-by-case analysis of individual transcripts, the researcher is able to comment on the perceptions and understandings of a particular group, rather than make any more general claims. Furthermore, Collins and Nicolson (2002) suggested that IPA thrives on detailed analysis of data and if the researcher was to attempt to interpret large quantities of data phenomenologically then subtleties of meaning could be lost. Smith et al. (2009) stated that most IPA studies are small groups of homogenous participants. There is a trend within IPA research for smaller sample sizes, and indeed some studies are single-case investigations (e.g. Eatough & Smith, 2007; Osborne & Coyle, 2002; Robson, 2002). Therefore, the sample size of seven for study 1 is considered acceptable and in line with the idiographic focus of IPA (Quin et al., 2009).

The study 1 participants were recruited from the AOTs in the West Midlands, UK. AOTs were used to recruit participants specifically because service users on such teams are diagnosed with SMHP and have an established history of disengagement from mental health services. Potential research participants were initially approached by the researcher, accompanied by a clinician whom they knew and trusted. This was followed by a meeting between the researcher and participant up to three times before the research interview took place, the so-called engagement phase.

At the beginning of the study the aim was to recruit anybody who was on the caseloads of AOTs but after the first four participants recruited to the study were men who described their racial identity as 'black', an opportunistic decision was made to create a homogenous data set and only attempt to recruit 'black' men onto the study. Taking this decision demonstrates that this study is both iterative and responsive in the qualitative research tradition.

A total of fourteen people were approached to take part in the research. One person agreed to be interviewed and then withdrew her consent and another man agreed to be interviewed but was felt to be too unwell by the researcher and was not interviewed. One participant declined to be interviewed but then approached the researcher, a few days later, asking to participate. Seven people were interviewed for study 1 and data from all seven people have been used to

inform the research findings. One research interview had to be repeated as the researcher believed, after reading the transcript, that the participant was too mentally unwell in the initial interview for his views to be considered reliable research evidence.

3.2.2 Development of the interview schedule

The development of the aim and objectives for the study was an iterative process which combined reading the literature on the subject, discussion with the study supervisors, responding to comments from the Birmingham, East, North and Solihull Research Ethics Committee (BENS NRES) and an external reviewer and also professional intuition. The research interviews followed a semi-structured interview informed by the aim and objectives of the study (Appendix 2). However, as fieldwork developed the prompts were also informed by ideas expressed by the previous participants.

3.2.3 Data collection

The modified IPA research method detailed was designed to be the most appropriate method to study the phenomena under investigation, primarily because it allowed for close examination of the individual service users' experience. The study is designed to allow the researcher to interpret and accurately reflect the experiences of service users from the most informed position possible. As Watts and Priebe (2002) have previously argued, the use of phenomenological analysis allows for the examination of the differing perspectives in community psychiatry and recognises that there are different levels of explanation for such a complex phenomenon as disengagement.

The role of AOTs is to engage and maintain engagement with people who have a history of disengagement from mental health services (SCMH, 1998). Just as this client group can be difficult to engage clinically, potentially they could have been hard to engage as research participants in study 1. Therefore, it was important for the researcher to work with the AOTs in the recruitment of participants. The process of collaborative working with the AOTs echoes Wilson's (2006) and Abrams' (2010) successful work of building connections with gatekeepers as a means to access 'hard-to-reach' populations. Taylor and Kearney (2005) and Rooney et al. (2012) have previously highlighted that differences in the racial identity between researchers and the participants and also the participants being drug users could

prove to be barriers to recruitment onto research studies. However, in this instance these barriers proved surmountable and the model for recruiting participants proved successful. There were four points of contact between the researcher and the participants during the interview process in study 1: the engagement phase, the research interview, the clarifying interview and the post-interview meeting. The research interviews and the clarifying interview were digitally recorded and transcribed by a professional transcribing service.

The engagement phase with each participant, before the research interview, provided the opportunity for a relationship and rapport to develop between the researcher and the participants. The engagement phase was also an opportunity for the participants and researcher to become more aware of the issues that were likely to be raised in the research interview. The engagement phase proved useful in engaging the participants in the research process and potentially contributed to the richness of data gathered. As Flowers (2008) found, meeting a participant more than once enhanced the relationship between the researcher and the participant. Moreover, given the sensitive and personal nature of the subject matter being investigated, developing a relationship prior to the research interview may have helped the participants share their private experiences (Parker, Herbt & Carballo, 1991).

The transcripts were reviewed twice by two service user reviewers, acting in an advisory capacity as suggested by Johnson (2012). The rationale for the use of service user reviewers was to assist the researcher in thinking about the participants' experiences from as an informed position as possible. The two reviewers had experience of working in academia and had used both in-patient and outpatient mental health services. Reflecting the demographics of the study 1 participants, one of the reviewers was a black man over the age of 30. The first service user review took place between the initial research interview and the clarifying interview. The first task of the service user reviewers was to read the transcripts from the initial interviews and to highlight any areas where greater clarity needed to be sought. The service user reviewers met with the researcher again after the clarifying interviews to discuss what they believed to be the emergent themes, and points of contradiction, arising from all the transcripts. Whilst the researcher listened to the suggested emergent themes from the service user reviewers, the final interpretation rested with the researcher. This interpretation was

informed by the various research interviews, previous knowledge, input from the study supervisors and the thoughts of the service user reviewers.

The clarifying interviews were also digitally recorded and were based on questions arising from the research participants' first interview. The purpose of the clarifying interview was to obtain a more detailed account of the participants' experience of disengagement. Smith et al. (2009) argued that most IPA studies are small groups of homogenous participants who are interviewed once but bolder research designs, as reported here, are optional. The precedent for interviewing participants twice, within IPA studies, has been demonstrated by Clare (2003), Ashby (2007) and Barr and McConkey (2007). Flowers (2008) highlighted that a researcher can gain greater clarity and richness from the interviewee when research participants are interviewed more than once.

The participants were seen for a post-interview meeting after all the interviews and transcriptions were complete and analysis was well-progressed. The purpose of the post-interview meeting was neither to check the accuracy of the emergent research themes nor to seek further clarification of the ideas expressed, but to present and discuss the major emergent themes of the study with the participants. Undoubtedly, these discussions had an impact upon the researcher's continuous interpretation of the themes, for example regarding the ambivalent relationships that all the participants had towards mental health services.

3.2.4   Data analysis

The existing literature does not provide a definitive account of how interpretative phenomenological analysis should be undertaken (Smith et al., 2009). There are several guides to generating emergent research themes (see Smith & Osborn, 2004; Biggerstaff & Thompson, 2008; Smith et al., 2009; Pringle et al., 2011b) and these all share similar principles. The data analysis process, employed within this study, was as reflexive and as participatory as possible. This included the level of interpretation from the researcher, the input from the service user reviewers in broadening the scope of the researcher's interpretation and through the use of the clarifying interviews giving greater opportunity for the service users to influence the emergent themes. Also, the researcher kept a diary in order to develop the themes and interpretative findings up until the researcher had the second

meeting with the service user reviewers. The diary has been included as Appendix 3. The process of data analysis performed closely resembled the work of Pringle et al. (2011b, p. 15).

The listening and re-listening of audio recordings was essential, initially, as it stimulated note-taking on possible emergent themes and issues that needed clarification. When each transcript was returned from the transcribing service, double checking of the transcript against the audio recording was undertaken. Reading of the transcript, on several occasions, was done and, at the same time, notes were made about possible emergent themes and issues that needed clarification. Thereafter, questions for the clarifying interviews were generated, in part based around emergent themes. This was followed by in-depth discussion with the service user reviewers about the emergent themes and issues for further clarification. When the transcripts of the clarifying interviews were returned from the transcribing service, notes were made about potential emergent themes, followed by phenomenological coding of the transcripts of both interviews (an example of a coded transcript has been included as Appendix 4). Clustering of the phenomenological codes, which entailed examining the texts more closely for greater depth of meaning and interpretation, was done, as was identifying and labelling emerging themes and meanings within the text (an example of the clustering of codes to develop themes has been included as Appendix 5). Themes from the texts with subordinate themes and related sub-themes were identified and were assisted by creating visual diagrams. Relating themes dialectically to excerpts of the text continued within a cyclical process. This was followed by writing a detailed, interpretative, reflective idiographic statement for each participant which was a statement of the researcher's interpretation of what each individual participant appeared to be saying. A table summarising all themes for all the participants was produced which facilitated the synthesis and integration of themes from the seven texts that led to superordinate themes being identified (Appendix 6).

The figure below demonstrates the progress of the analysis of the research data to the interpretative themes; a more detailed description is given above.

Research interview

Listening to audio recording.

Transcripts double checked.
Interpretative process commenced &
emergent themes noted

Meeting & discussion with two reviewers

'Clarifying' Interviews

Data Analysis:- Transcript
Phenomenologically coded,
Phenomenological clusters
developed, for complete transcript
including 'clarifying' interviews

Discussion/ feedback from
reviewers

Clarification of
superordinate &
subordinate themes

Discussion of
emergent research
themes at **post-
meeting**

On-going
interpretative
process

**Finalised
research
themes**

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Figure 3: Analysis Process (Wagstaff & Williams, 2014)

3.2.5 Ethical issues and trustworthiness of voice

Qualitative research, and associated sampling techniques, are not concerned with achieving representativeness (May & Pope, 1995, Barbour & Barbour, 2002). The participants in both study 1 and 2 were deliberately recruited for their unique ability to address the research questions, which is not to suggest that the data generated, both in the data collection and the analysis, did not bring unanticipated results to light.

The criteria by which the trustworthiness of voice can be measured in qualitative research has been widely discussed previously (e.g. Barbour & Barbour, 2002; Shenton, 2004, Morrow, 2005). Guba and Lincoln (1994) suggested four criteria to indicate the trustworthiness of a study: 'Internal Validity' (does the study make sense?, does the research data support the reported findings?); 'External Validity' (does the study correspond to the reader's preconceptions of the world?); 'Reliability' (did the study have a robust methodology?); and 'Objectivity' (was the researcher distanced and neutral enough?). Patton (2002) supported this framework adding that qualitative research should aspire to have similar criteria as traditional scientific research. For Patton, these included the researcher trying to minimise bias and remain as objective as possible; that the data should have validity, systematic rigour in the fieldwork and a form of triangulation that allowed for consistency of findings across methods and data sets; reliability in the analysis methods; the ability of the findings to be either generalisable or have external validity; and that the findings support the casual hypotheses. Using two different qualitative methods, for example individual interviews and focus groups, could serve as a form of triangulation (Shenton, 2004). Furthermore, Shenton (2004) highlighted that both these methodologies were interviews, of a kind, and therefore reliant on people accurately reporting their experiences. However, Barbour and Barbour (2002) were sceptical on the point of qualitative research conforming to the standards applied to quantitative research, highlighting that qualitative and quantitative research are looking for different findings and results; therefore, there was a value in keeping the two paradigms distinct. Additionally, another consideration that Barbour and Barbour (2002) raised was that a hallmark of qualitative research is that it provides context to understanding a phenomenon and will not necessarily provide sufficient detail for the research to be critically evaluated.

Regardless, Lincoln and Guba (2000) developed their framework in order to enhance the ability to appraise the trustworthiness of voice in qualitative voice, keeping in parallel with traditional standards set for scientific research. Qualitative research can achieve what traditional research methods would perceive as credibility by ensuring that studies have a high level of internal reliability. Engagement with participants, prolonged observation of participants, researcher reflexivity and participant checking are all examples of how this can be achieved (Lincoln & Guba, 2000; Morrow, 2005).

Lincoln and Guba's parallel criterion transferability (versus external validity or generalisability) refers to the extent to which the reader is able to generalise the findings of a study to their understanding of the phenomenon under investigation. In order for this to be achieved, the researcher must provide enough information about themselves and the context of the research. Parahoo (1997) argued that the methods for gathering data in qualitative research do not allow for data to be considered 'generalisable', instead researchers aim to provide insights in their research, which the reader is able to contextualise into their experience of the world (Darbyshire et al., 2005). This sentiment is echoed by Marriam (1998) who believes that the external validity of qualitative research lies in the extent to which a reader is able take the findings of a study and apply them to other situations.

Lincoln and Guba's parallel criterion dependability (versus reliability) requires that when researchers present their research it is evident to the reader that the work is consistent across both time and analysis techniques. Thus, the process by which findings were derived should be clearly stated and as replicable as possible. Lincoln and Guba (1985) argue that if the research method is confirmable then this is a strong indication that the findings are dependable. Fidel (1993) and Marshall and Rossman (1999) both note that because phenomena change and develop readers cannot realistically aim to replicate the findings of a study. What research can aim to achieve is to present a research method that a future research study can realistically replicate, though because of the changing nature of the world there is no guarantee that the findings will be the same (Shenton, 2004). So, activities such as keeping a detailed chronology of the progress of the research, issues in data collection and an audit trail of emergent themes enable a reader to follow the steps a researcher went through in the generation of their findings. In De Witt and Ploeg's (2005) proposed framework for

critically appraising the rigour of interpretative phenomenological nursing research, this process is described as 'openness'. In this study, an audit trail of emergent themes was available to the study supervisory team and is included as Appendix 3.

Finally, Lincoln and Guba's parallel criterion confirmability (versus objectivity) addresses the acknowledgement that research may never be objective. Patton (1990) argued that in quantitative or scientific research instruments can be used to generate objective facts about the world but qualitative research is dependent on humans reporting their experiences, and the intrusion of bias is impossible (Shenton, 2004). In most forms of qualitative research the confirmability of the research comes through the reader being reassured that, as far as humanly possible, the researcher has presented the findings as free from bias as possible. With IPA this is slightly different, with the researcher explicitly saying that through the interpretative process their foreknowledge and biases have impacted upon the findings. In most forms of qualitative research, for the reader to be reassured of the trustworthiness of voice and confirmability of findings they must rely upon the researcher being a person of integrity, providing an accurate representation of the data and findings. Through this implicit assumption, the reader is able to confirm the adequacy of the findings. Many of the procedures used to achieve confirmability have been applied in this study, particularly accountability through an audit trail, discussion with the supervisory team and the extensive use of quotations.

Yardley (2000) wrote about the dilemmas faced by qualitative research and, in part, its relationship to quantitative research. Most of the issues covered in that paper have been addressed above, apart from 'commitment'. The idea that Yardley was conveying was that one means by which a researcher can demonstrate the rigour of their method and the dependability of their findings is through commitment to the research. Not only must the researcher demonstrate that they have had prolonged engagement with the subject matter but also that they have committed sufficient time to develop the skills needed to successfully employ the chosen research method. In the case of this research, the analysis phase for both study 1 and 2 took two years each.

There is the potential that the researcher was prejudicial in the assessment of the participants' (and potential participants') mental state. One potential participant was not recruited onto the study because the researcher believed he was too suggestible; at the time of the introductory meeting he agreed with everything the researcher said and looked to the professional with him to answer questions on his behalf. Also, the first research interview with Black Zee was discounted because the researcher believed that he was too mentally distressed to provide reliable research evidence. As regards the ethical implications arising from the participants' mental state, safeguards were built into the study to protect the participants from potential exploitation: the engagement phase, the right of withdrawal, having another professional in the same building, the sensitivity of the approach and professional intuition.

The project did not employ any techniques that could be deemed potentially harmful to the participants. The proposal was submitted to the Birmingham, East, North and Solihull National Research Ethics Service (BENS NRES) for ethical scrutiny and received ethical approval (see Appendix 8). All research participants were guaranteed anonymity within any future published work and their right to withdraw from the project at any time.

The participants were given a verbal and written explanation of what the research entailed and were required to sign a consent form (Appendix 9). There was a gap of at least a week between the signing of the consent form and the research interview taking place. McIlfatrick et al. (2006) suggested that, when considering ethical issues in qualitative research, interviews may stimulate reflection, self-appraisal or catharsis and considerable self-disclosure. Therefore, researchers need to take these points into consideration and judge what provisions need to be made for the participants' well-being. The researcher was a clinical nurse specialist in mental health, with 14 years' clinical experience and hence felt confident about identifying appropriate sources of help, if necessary. Additionally, the interview took place in a venue of the participant's choosing and there was always someone else in the building, though not necessarily in the same room. These issues were explained in non-jargon, but in detail, within the 'patient information sheet' (PIS1) (Appendix 10), provided to each participant during the engagement phase. The PIS1 highlighted that the researcher had a duty of disclosure; therefore, if issues of immediate concern, such as the expression of suicidal ideas or an intention to harm other people, were raised during the interview then these would

have been fed back to the clinical team and decisions would have been made about how to proceed. However, no situation like this occurred during the 13 research interviews and the subsequent post-interview meetings. After each research interview, a brief entry was made in the participant's clinical notes to say that they had met the researcher for research purposes.

The research abided by the principle of deductionism (Jenkins, 2002) in that readers are not able to deduce who the participants are from reading the study. All the participants chose their own research name, and any identifying features of their bibliographic information were altered to ensure that anonymity was maintained throughout. Additionally, place names were changed and written in italics to highlight that they had been changed. The participants were provided with a nominal gift voucher as compensation for their expenses, such as travel.

The transcripts of the research interviews were read by the primary researcher and the two service user reviewers. Subsequently, the reports of the emergent themes were scrutinised by the PhD supervisors and the two service user reviewers, with comments invited. Copies of the final results were made available to the research participants. The recorded interviews were erased once they had been safely transcribed and stored. The transcribed data was stored in a locked drawer in the researcher's locked university office. Data stored on computers during the course of the project was password controlled. The project was managed within the University of Birmingham research governance guidelines (2014) and complied with the Data Protection Act (1998). Following the completion of the research, the data will be preserved and accessible for ten years.

The benefit of this research to participants may not come to those who participated. However, this study makes a contribution to the literature on this subject area and will inform future research. As such, the research will inform clinicians' insight into the experiences of disengagement for this client group, which will promote understanding and therapeutic relationships.

3.3 Study 2

3.3.1 Background

The overall aim of the study was to explore the experiences of disengagement amongst people with SMHP who also have a history of disengagement from mental health services. The aim of study 2 was to understand the same phenomenon from the clinician's perspective. In study 1 the participants' accounts of their experience were part of a complex interactive and social context. To further explore the context of the experiences described in study 1, study 2 sought to explore the clinician's perspective on the experience of disengagement.

The IPA focus group allowed for facilitated critical discussion of 1) clinicians' perspectives on the experience of disengagement for people (in particular for black men) with SMHP and a history of disengagement from mental health services; 2) the research questions; and 3) the clinicians' interpretations of the themes generated in study 1.

3.3.2 Sampling, access and recruitment

Purposive sampling techniques were used and the participants were recruited by the researcher meeting with each team and explaining the research to the potential participants. The aim of purposive sampling is to select participants who are best suited to provide essential insights or data to address the research aims (Williams & Hewison, 2009). The participants in this study were clinical professionals employed in AOTs within the local NHS trust. As such, the participants were experienced in working with people with SMHP who had a history of disengagement from mental health services. The participants were a homogenous group by virtue of all working for an AOT. Characteristics such as age, gender, professional background, location, ethnic background, religious affiliations or physical fitness of the participants were not important in the recruitment process.

3.3.3 Development of the interview schedule.

The research questions used in study 1 served as the basis for the questions in study 2. The aim of the questions in the focus groups was to examine the clinicians' perspective on, "What are the experiences of people (and in particular black men) with severe mental health

problems who have a history of disengagement from mental health services?" The essence of the questions used in the two focus groups was:

• What are the experiences of people with SMHP and a history of disengagement from mental health services?

• How do AOT service users understand their own health, well-being and illness?

• How do AOT service users perceive their needs in relation to statutory mental health services?

What are the service users' understandings of the role of drugs and alcohol within their lived experience?

• What, if any, are the unique features of the experiences of black men when disengaging from mental health services?

• Why is it important for people with SMHP to engage with mental health services?

• What were the clinicians' perspectives on the emergent themes of study 1?

3.3.4 Method

An advantage of the focus group research methodology was that it created synergism and access to a wider range of information (Millwood, 2012). The study design created the possibility of a 'snowball effect' being created, with one participant's comments triggering a response from others thus generating a higher level of stimulation within the group. Also, the focus group design meant that multiple participants could be seen simultaneously, increasing the speed at which the research data was gathered compared to individual interviews.

The focus groups in study 2 were facilitated by one researcher who asked questions to the group and ensured that there was a calm atmosphere throughout. Another researcher was in the room and noted the subtleties of interaction, for example facial expressions and body language. Each focus group lasted about an hour. The focus groups were recorded, transcribed and thematically analysed in accordance with standard IPA procedures. Whilst the existing literature does not provide a definitive account of how IPA analysis should be undertaken (Smith et al., 2009) they all share similar principles regarding the process of generating emergent research. The process of data analysis was as reflective as possible and included interpretation from the researcher upon the emergent themes.

The participants were guaranteed anonymity within any future published work. The research abided by the principle of deductionism (Jenkins, 2002) that readers are not able to deduce who the participants are from reading the study. All the participants chose their own research names and any identifying features of their bibliographic information was altered to ensure that anonymity was maintained throughout. Participants were asked to read and sign a consent form, acknowledging that they were providing informed consent to participate in the respective focus groups (Appendix 11). These issues were explained in non-jargon and in detail in the participant information sheet (PIS2) provided to each participant prior to the focus group (Appendix 12). However, it was also explained to the participants that it is logistically impossible to withdraw from the study once the recording of the focus group had started as their comments could not be removed from the subsequent transcript. It was explained to the participants that the researcher had a duty of disclosure, for example if one of the participants confessed to unprofessional conduct during the research interview then this could be taken to the appropriate authorities. The duty of disclosure was included in both the consent form and the PIS2. Ethical review was sought through the University for study 2 and ethical approval was granted (Appendix 13).

The recordings of the focus groups were erased once they had been safely transcribed and stored. The transcribed data was stored in a locked drawer in the researcher's locked university office. Data stored on computers during the course of the project was password controlled. The research conformed to the University of Birmingham research data storage and retention code of practice (2014) and following the completion of the research, the data will be preserved and accessible for ten years.

Once results had been generated for study 2, they were made available to the clinicians who participated.

3.3.5 Data analysis

The audio recordings were listened to on several occasions which stimulated notes about emergent themes. When the transcripts were returned from the transcribing service, the transcripts were double checked against the audio recording. Both transcripts were read several times and greater clarity was formed about the possible themes in the study. At this

stage the transcripts were phenomenologically coded. Subsequently, the phenomenological codes were clustered, which entailed examining the texts more closely for greater depth of meaning and interpretation. Interpretative themes were generated from the codes and text; subsequently, these themes were dialectically related to excerpts of the text within a cyclical process.

CHAPTER 4: FINDINGS

4.1   Participants' Characteristics

The first finding of study 1 was that all the research participants described their racial identity as 'black'. At the beginning of the study the aim was to recruit anybody who was on the caseloads of AOTs but when the first four recruited to the study were black men, an opportunistic decision was made to create a homogenous data set; Thereafter, only attempts to recruit black men onto the study were made.

The study 1 participants used a variety of phrases to describe their racial identity and cultural background. However, the common term they all used was 'black'. Therefore, throughout this study the inclusive term 'black' is used to refer to the racial identity of the participants. Below is a table highlighting the characteristics of the seven study 1 participants.

Table 2: Participants' Characteristics

Name	Age	Marital status	Current substance use	Accommodation	Length of time in service
Black Zee	31	Single	Cannabis	Independent flat with visiting support	12 years
Rebel	53	Single	Praised cannabis but currently was not using	Independent flat	31 years
Arthur	64	Single	Cannabis and alcohol	Supported group home	33 years
Clue	52	Single	Cannabis and crack cocaine	Supported group home	32 years
Josh	57	Single	Cannabis and crack cocaine	Supported group home	35 years
Bubbles	55	Single	Cannabis and alcohol	Supported group home	32 years
T	31	Single	Cannabis	Independent flat	12 years

One of the criteria for being on the caseload of an AOT and also inclusion onto this study was that participants had a diagnosis of a SMHP. The study 1 participants had a number of additional diagnoses but all had a primary diagnosis of a schizophrenic illness. All the study 1 participants had been admitted to a psychiatric hospital, all had been detained under the Mental Health Act and two of the participants were subject to a community treatment order (CTO) (DoH, 2008) All the participants were considered to have a significant risk history – six out of the seven had been convicted for criminal offences and five had served custodial sentences; four out of the seven had been detained in local regional secure units and additionally two of those had also been detained in one of the UK's special hospital. Six out of the seven participants reported that they regularly smoked cannabis, two smoked crack cocaine and two drank alcohol.

The participants were recruited from two AOTs in a local NHS mental health trust. From data supplied by the Trust regarding the two AOTs, 73% of the patients on their caseloads were men and 27% women. The age range of the study 1 participants was 31 to 64 years, with a mean age of 49 years. The average age of the patients of the two AOTs from which the research participants came was 44.8 years, with an age range of 24 to 82 years. All the study 1 participants described their racial identity as 'black'. On the caseloads of the two AOTs, 45.8% of the male and female patients combined described their ethnic group as Black/Black British – African; Black/Black British – Caribbean; Black/Black British – Other; or Mixed – White and Black Caribbean. Further break down of the figures highlight that 46.3% of the men (and 41% of women) on the caseloads of the two AOTs were from these specified ethnic groups.

Whilst it was not a criterion for recruitment onto the study, all the participants were single. Three of the research participants mentioned an ex-partner in the research interview and three research participants had children but did not mention their ex-partners in the research interview. From data supplied by the Trust regarding the two AOTs, 91.3% of the patients on their caseloads were divorced, separated or single. These figures break down further with 94.7% of the men (and 82.1% of women) on the caseloads of the two AOTs being recorded as divorced, separated or single.

The study 1 participants had been involved with mental health services for an extended period of time, an average of 26.7 years. From the data supplied by the Trust the average time that services users from the specified ethnic groups were involved was 27 years, both for men and women combined and also for men only. However, this figure would appear to be slightly shorter than the average time of 29 years that all the service users of the two AOTs had been known to mental health services.

The research participants lived in a combination of supported accommodation, housing association flats and supported group homes. From data supplied by the Trust regarding the two AOTs, 10.6% of the patients on the caseloads lived in supported accommodation, 24.6% lived in independent housing association housing and 11.1% lived in residential group homes. 42.8% of the research participants lived in residential group homes, which is unrepresentative of the two caseloads.

Four of the participants were born outside of the UK, two in different UK cities and one in the city where the study took place. By the age of 13 all of the participants who were born outside of the city had moved there. Six out of the seven participants had left school without any qualifications, but one of those had subsequently got qualifications in sound engineering. The seventh participant started university but left the course without completing the degree programme.

Comparing the characteristics of the participants in study 1 against the overall figures for the two AOTs from which the participants were recruited, the participants were not a representative sample of the respective caseloads. That they were not representative brings to light an important finding of the study that the researcher participants were black male service users with a primary diagnosis of schizophrenia, who were substances users with a history of disengagement. Intuitively, literature would suggest that service users with these characteristics would be difficult to engage both clinically and in research (SCMH, 1998; Taylor & Kearney, 2005; Kreyenbuhl et al., 2009; O'Brien et al., 2009; Rooney et al., 2012). However, the seven participants wanted to engage in the study and they were willing to talk about their experiences. This finding that the participants were willing to talk about their

experiences relates further to two other findings: the differing perspectives on engagement and the ambivalent relationship with mental health services.

4.2   Research Findings

Analysis of the research data demonstrates that while the participants had much in common with one another they also had key differences. The idiographic commitment of IPA research allows for the analysis to initially focus on the 'particular' and for the researcher to start analysis from the perspective of each particular participant. IPA provides a framework to make sense of each participant's experience. After analysis of each individual participant, the analysis unfolds into themes that branch across the participants.

Individual idiographic statements

4.2.1   Arthur

One of the key components to Arthur's experience of disengagement lies in understanding his relationship with hospitals and injections. Whilst acknowledging that he has symptoms of a mental illness, Arthur is not unduly distressed by these – he is quite happy to live with both his "voices" and his "signals". He appears not to understand the decision-making process of mental health services and cannot understand how or why decisions involving his life are made, which lead to a sense of powerlessness and loss of personal agency. Specifically he does not understand why he is made to take medication, occasionally detained in hospital and frequently moved to different group homes by mental health services. Whilst he expresses his ambivalence towards mental health services, "*does me no good, does me no harm*", he did tend to be more negative, "*my life has been ruined really*" {p. 2}. But there is an important comment towards the end of the interview where Arthur said that without the support of mental health services he would be living on the streets and begging, and he also credits an individual psychiatrist with saving his life. Arthur is unequivocal that cannabis helps him – it helps with pain control, it helps with "*the voices*" and that it "*straightens the mind*". It should also be noted that Arthur does not think of himself as disengaged from mental health services. He neither recalls nor recognises the pattern of disengagement that was described to him.

There are three experiences which are important in understanding Arthur and his experience of disengagement from mental health services and his ambivalence towards his own health. Arthur is a taciturn man. When his mental health team go to visit him they struggle to generate a discussion. As he said in his interview, "*Just by coming and asking questions, you know, 'What can I do for you? How are you? How are you keeping? What can I do for you? Have you been out today?' and that's all. They can take me for dinner; I don't want to go for dinner. And that's it really. That's all they done ....*" {p. 14}. He is ambivalent about them visiting, really does not want to talk to them and does not understand why they visit. In the first interview most of his answers were very brief. However, in the clarifying interview he was more talkative, particularly when discussing the complicated story of his involvement with mental health services; how his life story is intertwined with mental health services, how he did not understand the decisions that had been made about him and how mental health services managed to both ruin his life and save his life. It was a narrative that he wanted to tell, perhaps because of the impact that it had upon him and perhaps because he struggled to understand the underlying decision making.

With regards to his physical health, Arthur said that he has no breathing difficulties {p. 7} but on listening to the interview recording his breathing is so laboured that at times it was difficult to hear what he was saying. One of the research objectives was to explore participants' perceptions of their health and well-being. In relation to his physical health, he denies that he has physical health problems when they would appear to be very prominent. However, in relation to his mental health, Arthur does not deny that he has schizophrenia. Arthur has been described by others as having a history of disengagement from mental health services. However, Arthur does not perceive himself as having disengaged nor does he understand mental health services' role or purpose.

As with some of the other participants, Arthur showed anger towards me. We had agreed before the interview he would be compensated for his time with a £20 gift voucher from a high street store, but when he was given the voucher he threw it back at me in disgust. He wanted cash or a voucher for a supermarket, so he could buy "fags and booze" which were not on sale at the high street store.

4.2.2   Black Zee

In the research interview it was quite marked that Black Zee was angry and animated at the start of the interview but as the interview progressed he became noticeably quieter, passive and resigned. Equally, during the early parts of the interview he had a very pained expression on his face and really looked quite distressed by the material being discussed. Again, this distress seemed to dissipate as the interview progressed. At the end of the interview he thanked me for taking the time to interview him (!).

At the time of the research interview Black Zee was in dispute with the AOT responsible for his care – he wanted to take a third of the dose of a prescribed anti-psychotic medication. The doctors wanted to meet him to discuss this and he was refusing to meet the doctors. The impasse was discussed at the end of the research interview; Black Zee said that he was, "*alert already*" and therefore did not need the prescribed amount.

Black Zee did not dispute that he was mentally unwell, but similarly to other participants he did not understand the nature of the support that is on offer to him – "*I didn't know what the help was*." Part of the struggle for Black Zee certainly seems to be in the clash between what he understands to be happening in his mind and his perception of the doctor's understanding. Perhaps the difference is about failed expectations. He thought he would be understood ("*because I could understand the language*") and when his understanding clashed with the doctor's understanding he felt disenfranchised from the process and the relationship with the doctor. Consequently, he started to disengage from services. His anger at services is very much about doctors and about medication. The idea of not being understood by mental health services is reinforced at the end when Black Zee said, "*How am I known? How am I really known?*"

Black Zee has three inter-related processes which need to be understood when interpreting his experiences of disengagement from mental health services:
- His relationship with his father
- His relationship with mental health services and the impact of in-patient treatment
- His efforts to understand the world around him, which in many instances he fails to do.

Black Zee evidently feels the loss of a supportive relationship with his father very strongly, which affects his relationship with other people. Black Zee has very strong feelings about the staff who work for the mental health services. He does not always understand their actions and intentions and questions their morality and integrity. The notion of understanding, or trying to understand, features very heavily in Black Zee's interviews. For him it is very important to understand himself, the world around him, how other people understand the world and how mental health professionals understand him. As a consequence of this, Black Zee is conscious of how much he does not know or understand. For Black Zee the experience of not understanding many things is crucial to understanding his experience of disengagement. He does not understand much of mental health services' intentions when they are working with him.

In terms of my foreknowing, once the decision was made to focus only on the experiences of black men, I presumed that racism would be a component of their experience of disengagement. Black Zee talked about racism more than other participants but it was not a major theme. During the engagement phase, Black Zee spoke about racism and stigma and I presumed that racism was going to be an emergent theme from the research interview. However, during the actual research interview Black Zee only made a brief reference to racial discrimination. I acknowledge that there was the dynamic of a black man being interviewed by a white man, which may have inhibited what Black Zee (and other participants) wanted to talk about. Additionally, whilst the participants only briefly touched on direct and personal racism, the research interviews could be interpreted as highlighting incidents of cultural and structural racism.

4.2.3 Bubbles

Bubbles is slightly different from the other participants, in that I had previously worked with him clinically and knew things about him that he did not bring to the research interview. I see Bubbles out in the local community. He said in the research interview he does not like where he lives and, therefore, he spends a lot of time travelling around the city. I often see him on the buses and I see him on the local high street. His son met the criteria for inclusion in this study and I met with him to try and persuade him to participate but he declined. In the research interviews Bubbles took the position that he had never disengaged from mental

health services and in the research interview I did say, that in my opinion, he most definitely had disengaged, consciously or otherwise, from mental health services. In my interpretation of Bubbles' experience of disengagement from mental health services, the sentiments of "*I'm just an everyday person*" and "*I just want them to leave me alone*" {p. 33} are central.

As a consequence of believing himself to be an "*everyday person*", Bubbles is able to assert that he is no longer "*schizophrenic*" {p. 5}; he repeatedly said that mental health services should leave him (and others) alone as he is an everyday person {p. 21} and that it is not necessary for mental health services to be involved with him {p. 33}. His on-going drug use is justified by saying he is an everyday person {p. 4} and also "*Have a drink and a smoke, I'm just normal. I'm just normal*" {p. 33}. Throughout the interview it is clear that Bubbles feels very persecuted, whether by mental health services or by the anonymous "*they*" in the street. He has feelings of isolation as a result of there being, "*Ex-criminals in the middle, ex-cons and ex-patients like me and ... Then you've got the half-casts, the mixed minority, the ethnic minority in the middle and we get the blame*" {p. 21}. Bubbles used his identity of being an "*everyday person*" as a way of reasserting a sense that, despite the persecution and the isolation, he is an OK person. When I tried to explore these issues of identity and persecution further he was reluctant saying, "*Yeah, it's just life isn't? It's part of life going on.*"

The other central theme to understanding Bubbles' experience of disengagement from mental health services is that he is quite clear that he wants to be left alone – "*I just want them to leave me alone*" {p. 33}. There is also the impression that this applies both in his attitude towards people in wider society as well as to mental health services.

One of the important functions of mental health services for many of the participants is finding people a place to live, which in turn leads to people frequently moving home. This has had a big impact on Bubbles and he has been moved to parts of town that he does not know, or particularly want to live in. Bubbles said he gets confused – "*You know, they move me on and muddle me up*" {p. 27}. It was evident that Bubbles recognised that one of the most important services mental health services perform is finding him somewhere to live, but as a consequence of these frequent moves, or being moved to an area where he does not want to live, the sense of transience has had a destabilising effect. He feels as if he cannot

remember where he is or his way around the local area. Also, he is very worried about being attacked and this he attributes to being in a different area {p. 27/28}.

As with other participants, Bubbles dislikes taking the medication prescribed by mental health services – "*They* [tablets] *freak me out*" {p. 29} and Bubbles believes that medication is a key component to why he, and others, have disengaged from mental health services {p. 22}. Bubbles' experience of disengagement from mental health services is entwined with his awareness of his disengagement from social structures. For example, he barely knew his father, is dissatisfied with the limited contact with his family and he only had limited contact with his own children whilst they were growing up. However, as a point of interest, he still sees his mother and brother on a regular basis and his sisters too when they come up from London to visit. Also, now that his son is an adult they have an on-going relationship and see each other on a regular basis {p. 31 & p. 38}. However, it is my understanding that his ex-partner (and mother of his two children) has a restraining order against him and he has no contact with her or with his daughter.

Drugs have played an important role in Bubbles' life, both in his relationship with mental health services and also in terms of his own identity. When Bubbles says that he has stopped doing drugs he means that he has stopped smoking crack. He is very clear that he still uses cannabis and alcohol and feels the benefits that these give him, namely happiness and being calm {p. 23}.

Bubbles participated in the two research interviews and attended the post-interview meeting so it is perhaps understandable that he contradicts himself regarding his pessimism about the quality of his life. In the main research interview he said, "*Being weak and depressed and down and out, like I am. Just miserable*" {p. 5} and "*Well, I'm not really happy*" {p. 8}. However, in the post-interview meeting he said, laughing, "*Well, it's a false smile, but it's a smile, innit?*" {p. 34}; "*It ain't that bad, it could be worse. I could have no legs, no arms no ...*" {p. 38} and "*I can't complain, can I?*" {p. 39}.

4.2.4 Clue

The quote which best summarises Clue's experience of disengagement from mental health services is, "*Because I think it's a good idea to do a bit of changes*" {p. 3}. He will listen to mental health services ("*I listen*") but sometimes he wants "*changes*" and he views the changes as a means of not becoming bored: "*If you like pepper on way food, it's a way of life, innit? It burns you, but it's nice*" {p. 27}. Clue's experience of disengagement from mental health services is a conscious choice to add spice into his life. Clue greatly emphasised that he wanted me to understand that mental health services had helped him and this is in the context that mental health services had previously, " ... *beat me up, hold me down*" {p. 41}.

Clue views the role of mental health services as helping sort out housing and offering "*a bit of guidance*" and he is happy to listen to mental health services with the proviso that he does not always have to accept their guidance. Clue evidently feels persecuted and misunderstood by mental health services at times, as he said, "*I'm an individual. I'm not the same as every black person. They're not thinking that way, they thinking, 'I'm a leader, I'm some fucking, I'm a horrible one.' ... Yeah. I been punished. I don't know what they have against me*" {p. 11}. Yet, the ambivalence that Clue feels towards mental health services runs deep. He praised mental health services for finding him accommodation {p. 13} and also said he was dumped in his present accommodation {p. 19}. The quote that, "*Yeah they do it very well in a way they want me ... But they are against me as well*" {p.13} demonstrates that Clue perceives mental health services as doing some things very well whilst also acting against him.

As regards this pattern of listening to guidance and advice but then not always following it, he describes it as "*a way of life*". In discussing giving up drugs with his sisters he said, "*I listen in a way, I don't go out of my way to trust it. I listen, but don't trust it*" {p. 5}. One of the reasons that he chooses to live life this way is because he is trying to have a sense of normality. Clue believes that if he disengages from services this will represent normality and consequently, "*People will talk to me.*"

In Clue's opinion other people disengage because they "like badness" – "*doing things that the Government don't like, badness*"; "*Stopping people, shooting people, the things that mad*"

people do. Only a madman lives that way." In Clue's opinion because mental health services stop people from doing "*badness*" and the things that "*mad people do*" people stay away from mental health services. It is also a way of establishing themselves as "*the king*" to publically demonstrate that they will not be brought down by mental health services.

Clue has a relatively good relationship with his family, whom he feels support him {p. 20} and he has regular contact with "*My mother, father, my brother and my sister*" {p. 20}. But his relationship with his children is entangled in his relationship with mental health services. He has no contact with his children ("*I don't have no contact with them*"). Clue attributes not "*growing up*" his children to his involvement with mental health services, "*Because I was always locked in places like this. So I didn't get them right or they're not thinking my way and they're not trying to get me out of it. They think all I've got is Mental Health Act*" {p. 21}. He deeply regrets not having contact with his children to the extent that he believes the lack of contact has affected his mental functioning, "*Yeah, I regret it. I regret it a lot. I can't see where the blossom is not growing on the tree. That's one part of me that keeps me down. My mind just can't function. One part of the seed isn't functioning with you, your mind go blank*" {p. 21}. But, perhaps contradictorily, he said that it is his children's responsibility to come and look for him ("*they're supposed to come look for me anyway, soon, my kids*" {p. 22}). Clue's interpretation of why his children have not come to look for him is that "*They can't care because I take drugs ... and that's all there is to it to them*" {p. 22}.

Clue passed away between the research interviews and the completion of the thesis.

4.2.5 Josh

Josh's experience of disengagement from mental health services is linked to his relationship with wider society. He wants to be more connected to society and his local community but he feels that his involvement with mental health prohibits this. "[Mental health services] *take away my friends, take away my .... makes me feel lonely. I makes me feel alone, it plays with my ... my outlook, my outlook. My perceiving, you know? That's what it* [the injections] *does to me. So I don't think it's right that I should have injections*" {p. 33}.

Josh has a complex, mostly negative, relationship with mental health services. He admits that he has resented them, but this is in the past tense and there was not the level of anger that was so notable with other (younger) participants. Medication is an important component of that complex relationship. He is ambivalent about the role of medication – on the one hand he does not understand why he is given medication and he is angry that he has been given it for so long – *"... and I've been on it since 1976 ... Every fucking week ... Injections in me fucking arse. ... I could take them to court because that is against my will"* {p. 22}. However, he also reflects that medication helps him {p. 17/18}. Further, Josh discusses that in fact he has no choice but to take injections and he reflects upon those periods of his life when he was without medication, which further emphasises his ambivalence. In the interview he said that his life improved by not having medication but then also that some aspects of his life improved when he recommenced medication. He was comfortable saying that he has schizophrenia but then did not know what schizophrenia was, *"I don't even know what schizophrenia is"* {p. 5}.

One of the striking features of Josh's case is his relationship with his late mother, who died 30 years ago. Josh believes that he has lived his life in such a way as to make his mother proud – *"a good son make his mother have no heaviness"* {p. 20}. Whilst many of the other participants talked about the role that their families have played in their experience of disengagement (in terms of loss, death and separation), Josh placed greater emphasis and importance on the consequences of his mother's death. In terms of his working relationship with mental health services, he said he had never been offered the opportunity to discuss her death and this had negatively impacted upon his relationship with services.

Josh has a complex relationship with statutory institutions, his local community and society. Over time Josh had moved from having an antagonistic relationship with statutory institutions to a realisation that they were trying to help him. Josh desperately wanted to be part of his community but expressed discomfort that he does not completely feel at ease in his community and also dissatisfaction with his current living arrangements. Josh also felt that certain unnamed people were actively trying to keep him out of mainstream society.

Josh acknowledges the changes that he has been through as a person and spoke about when he had been a violent man. Josh stopped being violent around the time he got "*a girl*" pregnant which altered his life in different ways. These all contributed to his experience of disengagement from mental health services but also contributed to developing his personal resilience. The various inter-related changes that Josh described were:

•	His relationship with statutory institutions (his violence landed him in trouble with the police and in prison)

•	Religion (Jesus taught him to turn the other cheek)

•	Own identity ("*I was a violent man*"/ "*I ain't violent*"/ his attempts to lose the label of "*a menace to society*")

•	Josh wanting to make his late mother proud (no longer being violent is part of trying to live the life his mother wanted him to).

Josh's relationship with his brother is interesting – Josh's brother tries to give Josh instructions on how he feels Josh could live his life better. What was not evident in the research interviews was that his brother is indefinitely detained in one of the special hospitals, which is presumably why the conversations only take place over the phone.

Josh believed that smoking cannabis was of benefit to him. He felt that smoking cannabis was a component of his identity; Josh believed that smoking cannabis made him a friendlier person, helped him fit into the local community and did not negatively impact on his health. Confusingly Josh said, "*I don't do drugs, but I do smoke cannabis*", but Josh also smokes crack cocaine (indeed when I first met him he was coming down from using crack cocaine). However, he placed much more importance on cannabis than he does on crack cocaine. Religion plays a part in Josh's life as, for example, Jesus impacted on his attitude towards violence.

At the end of the first interview Josh said that he wished he could talk to the AOT in the same way he had spoken to me. When I first approached Josh about participating in the interview he shouted at me and told me to "*Fuck off*". However, he approached me the next day and asked if he could participate. Josh smiled almost all the way through the interview and we laughed a lot more than the other research participants. Josh's first interview was

considerably longer than those of the other participants and the post-interview was longer than anticipated.

4.2.6 Rebel

Three themes are key to understanding Rebel's experience of disengagement from mental health services. These are that he did not always understand what was happening to him, he did not understand the role of medication and the role of "*bad luck*". These ideas are interlinked and partially explain each other, but they are also themes independent of each other.

Rebel did not understand many aspects of the care delivered. Listening to him it is evident that over the years he has been very troubled by his relationship with mental health services. It was unclear whether he was troubled by being admitted to hospital, being given injections, not being assessed properly, by worrying that he had caused offense by asking for his dose of medication to be lowered or by not understanding why he was receiving letters from particular mental health teams. Regardless of his uncertainty, these concerns are said with more of a sense of bafflement than a sense of anger.

Rebel disliked receiving injections, "*I was allergic to these things, these injections*" {p. 13}, but feels that taking oral medication is beneficial to him, "*I couldn't make no ends meet out of anything, what happened to me, it was like I was just lost. In a way I was lost before I was found as if I could have said I was blind before I could see*" {p. 5}. For Rebel, this is the difference made by being on oral medication. He does not deny that he has schizophrenia nor does he embrace the diagnosis; he says that, "*I was taken for schizophrenia by my personality the way that my nature has treated me*" {p. 13}. Rebel recognises that he needed to heal, "*... if I thought of myself medically, I don't know, I wouldn't heal. Like it takes time to heal. But mentally, subtlety mentally it's like I've been asleep*" {p.18}. For ten years Rebel was unmedicated and largely disengaged from mental health services and this is the period of "*sleep*" that he is waking up from. As with the other participants, religion plays an important part in Rebel's life and his experience of disengagement from mental health services. He surmised that when he was first admitted to a psychiatric hospital, spiritual guidance would have been "*medicine to me personally*" {p. 16} as opposed to psychotropic medication.

Some of the other participants talk about feelings of persecution but not in the same way as Rebel. Whilst he did feel persecuted, it was not by society, local thugs or mental health services but instead by experience of "*bad luck*" and Rebel's feeling that he was being persecuted by fate. Rebel used "*bad luck*" to explain some of the aspects of his relationship with mental health services, for example the perceived need for Rebel to be given injections.

At the time of the first interview he believed that his girlfriend was about to give birth to their baby, but by the time of the clarifying interview he reported that the baby was not his. His parents are dead, he did not report contact with any siblings, his girlfriend was with another man and the child that he and his girlfriend had previously had together had been given up for adoption. Whilst he accepts the social situation he finds himself in he did say, in relation to the adoption of his child, "*Well, I wept. I wept in a way because that is all I could do. Wept, I just wept*" {p. 10}. This is similar to the reactions of other participants. Regarding his social situation he said, "*I am a solitude*" {p. 11}. However, it should be said that Rebel does not view this negatively and, other than the adoption of his child, is apparently content with this relationship with society and the community.

For the other participants, the use of illicit substances is very important to their identity and reinforcing their resilience; however, Rebel is different. Whilst he says that cannabis is "*medicine*" and gives "*creativity*" {p. 9} and justifies its use by saying it is mentioned in the Bible he said that he had not used cannabis since he was at school.

4.2.7   T

An important feature of T's experience of disengagement from mental health services is that, whilst most of the participants disputed whether they had ever disengaged from mental health services, T was very forthright about his disengagement. He was clear that without the community treatment order (CTO) he would continue to be disengaged. He does not see much benefit from being involved with mental health services. When T was asked whether there was anything positive about his disengagement he replied, "*Yeah, I didn't get the support and the help that <u>they said</u> I needed*" {p.5} and he felt better without that support. In the year following his father's death T talked about how he went "*crazy*" and how he was

deeply affected by what he saw whilst he was on ecstasy during that period of time. Whatever the religious visions he saw were, they caused him to choose to disengage from the rest of society.

T had a strong dislike of medication and admitted that he only took medication because he was legally compelled to do so, *"If I wasn't on my CTO I wouldn't take a depot"* {p. 3} (a "depot" is a commonly used abbreviation for antipsychotic medication that is injected). Similar to the other participants, T makes a link between treatment with medication and disengaging from services. It should be noted though that T demonstrates some ambivalence (or contradictory attitude) towards medication, seemingly pointing out positive aspects of taking medication, yet very much disputing the value of continued treatment. Support is another area where T would appear to be contradictory saying both, *"There are a lot people out there who support me"* {p. 14} but also *"My friends and family don't actually support me"* {p. 24}. Within this, T was stating that he had friends, which the other participants did not mention. T said that he did not need input from mental health services and did not feel supported by friends and family but he got solace from cannabis and religion. He believed that, *"Smoking cannabis has helped me in a lot of ways"* {p. 9} and he is clear that religion helps him, *"Religion keeps me sane"* {p. 19}.

When asked about his relationship with his father before his death, T described the relationship as *"Rubbish, really"* {p. 23}. T's attitude towards his father and fatherhood is contextual and complex – that he had a *"rubbish"* relationship with his father, that his father had not known his own father, that T's father killed himself and that T himself is *"opposed"* {p. 24} to the idea of becoming a father. In T's experience of disengagement from mental health services, the loss of his father has deep and profound meaning for T, as his father's death served as a trigger for him first becoming involved with mental health services. The first time he was diagnosed and admitted to a psychiatric hospital was in the aftermath of his father's death. Whilst he denied that he had a mental illness, he did say that he was *"crazy"* at this point in time. The aftermath of his father's death was also linked to T's decision to actively opt out of mainstream society. T disengaged from wider society because of what he experienced whilst on ecstasy. Whilst there is a temptation to dismiss this experience as drug fuelled hallucinations, there is no doubting the profound effect that this experience was for

him and the far-reaching consequences of that experience on T's life. It should be noted that T had an on-going relationship with his family.

"It's just health. We've all got to die one day. So it's going to go one day isn't it?" {p. 7}. This is a very interesting comment – taken in the context that up until this point T was answering in only one word answers in the research interview. When asked how he would define health, he made the connection between his health and the finiteness of his own existence. It was delivered in a deadpan way, perhaps belying ambivalence towards his continued existence. Many people may define health in terms of life, positivity or even absence of disease and illness; T made the connection between his health and his demise.

On a reflective note, the two participants who appeared both the angriest and the most disengaged from services, T and Black Zee, were also the two youngest.

4.3   Superordinate and Subordinate Themes

The idiographic statements from each of the study 1 participants demonstrate that they had much in common, but simultaneously highlight important differences.   The idiographic commitment to the particular within IPA allows for the development of an understanding of each participant. But then the IPA methodology allows for examination of those individual accounts from broader perspectives, both those of the primary researcher but also the individual participants in relation to each other (Wane et al., 2009). Thus after examining the particular cases of the individual study 1 participants the focus of the 'Findings' now examines the themes across the participants. There are two superordinate themes that explain different aspects of the study 1 participants' experience of disengagement from mental health services.   Interpretative analysis of individual participants' experience highlights that the study 1 participants experience disengagement in the context of having only limited connection with different social structures.   However, the second superordinate theme demonstrates that over time the study 1 participants developed strategies which reinforced their personal resilience and enabled them to have a more positive sense of identity. The superordinate and subordinate themes in study 1 were:

4.3.1   Theme A: Limited connection with social structures

4.3.1.1   Ambivalent relationship with mental health services

4.3.1.1.i   *"People just keep hounding me"*

4.3.1.1.ii   Medication as a key component in the experience of disengagement from mental health services

4.3.1.1.iii   *"Leave me alone"*

4.3.1.1.iv   Perspectives on disengagement

4.3.1.1.v   *"... well, it's not my choice, you know?"*

4.3.1.2   Living with uncertainty: Health, uncertainty and anxieties

4.3.1.2.i   Idiosyncratic understanding of mental health problems

4.3.1.2.ii   Not understanding

4.3.1.2.iii   Concerns about physical health

4.3.1.3   Belonging to and exclusion from community and society

4.3.1.3.i   Identity

4.3.1.3.ii   Feeling threatened and persecuted

4.3.1.3.iii   Mental health services

4.3.1.3.iv   Relationship with community and society

4.3.1.4   Family and fatherhood: Inconsistent and fragmented relationships

4.3.1.4.i   Intimate relationships

4.3.1.4.ii   Fathers

4.3.1.4.iii   Fatherhood

4.3.1.4.iv   *"I'm waiting for them to come and look for me"*

4.3.1.5   Life is sorrow: Threats to well-being

4.3.1.5.i   "I am a solitude"

4.3.1.5.ii   Life is sorrow

4.3.2	Theme B: Multiple strategies to reinforce personal resilience and to reassert personal identity
4.3.2.1	Medication – "… *I was blind before I could see*"
4.3.2.2	"*Drugs make you the man you are*"
4.3.2.3	Faith, spirituality and solace
4.3.2.4	Age, experience and maturation

4.3.1 Theme A: Limited connection with social structures

Theme A highlights that the experience of disengagement from mental health services for the participants was characterised by a lack of connection to social structures and institutions. Whilst they did not discuss the issues they faced in life using the same terminology as professionals, they nonetheless expressed awareness and anxiety about their mental health, their role in society and the impact these had upon their identity. The participants had a complex and ambivalent relationship with mental health services, and medication plays a key role in their experience of disengagement. Most of the participants (Black Zee and Bubbles, for example) quite forcibly felt that mental health services could best help them by leaving them alone. Interestingly, many of the participants did not recognise themselves as having a history of disengagement from mental health services, despite how professionals may have conceptualised them. Furthermore, the older participants no longer saw any point in actively disagreeing and disengaging with mental health services and this was combined with a collective sense of learned helplessness amongst the older participants.

The sense of disconnection from society felt by the participants worked on different levels. On one hand, they talked of feeling part of their local community (e.g. the bookies, the pub, the corner shop) but then disconnected from the society outside their local community. All the participants were chronically unemployed. Some (T, for example) have actively chosen to distance themselves from society but others (Josh, Clue and Arthur, for example) have also chosen to distance themselves from society due to the shame they feel at being involved with mental health services. The feelings of both belonging to and exclusion from community and society led to questions about their own identity and were accompanied by constant feelings of being threatened and persecuted. The participants experienced fractured relationships with

their families, in particular with their fathers, and for those who were fathers, with their own children.

The participants lived with a great deal of uncertainty and this uncertainty caused them anxiety. Through both their actions and their words, the participants actively questioned the need for mental health services in their lives. However, only one participant actually denied having mental health problems in the research interview. The others did not understand their diagnosis and had developed their own idiosyncratic understanding of their mental health problems. The participants were also aware that there was much they did not understand about their involvement with mental health services. Most expressed concerns about their physical health. The different means by which the participants experienced limited connection with social structures and the uncertainties regarding their mental health led to feelings of sadness which permeated the research interviews.

4.3.1.1 Ambivalent relationship with mental health services

The participants appeared to have an ambivalent relationship with mental health services, and many of them experienced loss and sorrow due to their involvement with services. Arthur, for example, said, " *... started me off on injection so ... from that my life has been ruined really*" {p. 2}". Despite there being numerous quotes from other participants that express similar sentiments it would be wrong to characterise the relationship as a wholly negative one. There are examples in the interviews of the participants making positive comments about their working relationship with mental health services, for example Bubbles said, "*Yeah, they help me out. They help me out a lot really*" {p. 36}.

Despite aspects of positivity, the depth of dislike for mental health services that the participants held was evident in all the participants. When asked what mental health services had brought him, Arthur responded, "*No good, nothing good ... Just misery*" {p. 14} and Black Zee said of mental health services, "*I know that I have been denied a life more than anything else, because they reckon I can't deal with my own problems*" {p. 45}. Another dimension of the negative relationship appeared to be the length of time that services had been involved – the length of time was both incomprehensible and disconcerting. For

example, Josh said, *"... and I've been on it since 1976 ... Every fucking week ... Injections in me fucking arse. ... I could take them to court because that is against my will"* {p. 22}.

The five older participants were better able to highlight the positive aspects of their respective relationships with mental health services. They were able to reflect on the benefits that mental health services have brought them. For example Rebel said that *"... you have got no reasons so you couldn't put that together and 2 and 2 make 1. I couldn't make no ends meet out of anything, what happened to me, it was like I was just lost. In a way I was lost before I was found as if I could have said I was blind before I could see"* {p. 6}. The quote may be talking about medication but medication is an important facet of mental health services (indeed some participants felt that medication was the only thing that was offered by services) and, therefore, illustrates that Rebel and others acknowledged the benefits of involvement with services. Arthur highlighted the negative impact of services (*"my life was ruined"* for example) but illuminates the complex and mixed relationship when he says that a particular psychiatrist, *"... saved my life, really"* {p.28}. Perhaps this ambivalence is best expressed by Arthur: *"they've not done me any good and never done me harm really"* {p. 14}.

As with other themes in the study, the younger two participants – Black Zee and T – diverge from the five older participants. Black Zee was shouting during some stages of the research interviews to express the anger that he felt towards mental health services and T struggled to find anything positive to say. To quote Black Zee *"... they talk some rubbish and you get everything that they say is supposed to be the stuck truth to what people are not understanding... If you want to get out of the service understand something positively that is not rubbish to yourself, then you have got to get out"* {p. 15}. It is over simplistic to say that the age gap between the participants explains the different attitudes and in the intervening years the participants have acquired learned helplessness and been metaphorically beaten into submission over time. Such a stance does not capture the true nature of the experience. There is genuine conviction and meaning when Clue said, *"Help me a lot. ... That's what I'm trying to tell you"* {p. 33}, in an exasperated fashion. To provide further context, Clue also said that *"They beat me up, hold me down and give it to me. ... You hear me?"* {p. 41}. It is to Clue's credit that he is able to see mental health services as helping him and to mental health services' for being able to rebuild a therapeutic relationship with him.

As stated previously, one of the findings of this study was that people who should not have not engaged with the study. However, that they did is an illustration of the ambivalent relationship with services. Whilst there are numerous reasons why the participants may have chosen to disengage yet they still wanted to share their experiences with a researcher that they did not know well, had a different racial identity and was connected to mental health services.

4.3.1.1.i *"People just keep hounding me"*

The question of why people disengaged from mental health services was not directly asked nor was it sought in this study. Nevertheless, it is perhaps inevitable that when talking about their experiences of involvement and their relationship with mental health services, the participants would talk about why people disengage from mental health services, consciously or otherwise. Without prompting (and also without directly using the word), the participants described an experience of persecution over many years that clearly had great resonance for them, for example: Josh, "*... I done my time and they still trying to control my outlook in life*" {p.4}; Bubbles, "*I don't know, people just keep hounding me, hounding me*" {p. 14}; or Clue, "*I can't have any peace in my life with those people around*" {p. 24}.

4.3.1.1.ii *Medication as a key component in the experience of disengagement from mental health services*

Medication is an important component of the treatment that people receive, and for some of the participants it would appear that it is also symbolic of the relationship they perceive they have with mental health services. Indeed, Bubbles characterised the attitude of services as "Take a tablet and just say nothing" {p. 12}. Just as the participants appeared to have an ambivalent relationship with mental health services, by extension they also had an ambivalent relationship with medication. The participants appeared to be dismissive of the value of medication whilst also recognising its value. There are many components of this theme: all that mental health services offer is medication, medication "messes you up", the dislike of depot medication, misunderstanding the purpose of medication and the lack of control that the participants felt regarding the prescription and ingestion of medication.

Some participants believed that the primary reason why people (including themselves) disengage from mental health services is because of the use of psychotropic medication. For example, Arthur said that, "*Well, maybe the pain of taking a needle and those who are on tablets – they are not doing them any good they; refuse to take it*" {p. 18}.

As stated, the participants have a complex relationship with mental health services and medication is a component of that complexity. Some of the participants characterised the care delivered by mental health services as purely about medication; for example, T said "*I just didn't want the help.* [CW: Okay. What help do you think was being offered to you?] *Drugs*" {p. 1}; and Bubbles characterised the attitude of services as "*Take a tablet and just say nothing*" {p. 12}. Black Zee stated that he believed the only form of treatment mental health services understood was medication: "*They will give me the drugs gladly, but they won't understand anything else except for that medication*" {p. 11}.

An important part of the experience of disengagement from mental health services for the participants would appear to be the negative attitudes towards psychotropic medication, both oral and depot, with one participant expressing surprise that people take psychotropic medication when not legally compelled to do so. "*Poison*", "*allergic*", "*mess up my head*" are all expressions used to describe the experience of being on psychotropic medication and so it is no surprise that there is such animosity towards these medications. Black Zee said, "*... these drugs – none of it chills out my mind. None of it*" {p. 10}. Arthur {p. 18} further highlighted this lack of perceived benefit when he said that people he knows, "*are taking it but are still hearing voices. ... and they are not cured anymore. There isn't one man I know that's schizophrenic and that cured.*" Everyone he knows that takes 'medication' still hears voices and still has schizophrenia. This sentiment is extended by Clue who said that "[treatment is a representation of] *...white violence against the mental act and then when you are cure they are still giving you medication*" {p. 40}, i.e. that medication is symbolic of the *violence* and hostility between mental health service and the people who use the services.

There is particular animosity reserved for depot medication and this animosity is not only from the experience of being under the influence of the medication but also the physical process by which the injections are administered: Josh: "*Sticking the needle and dropping my*

trousers and looking at my arsehole and all that" {p. 17} and also Arthur: " ... *the only problem is that I got the problem with the needle on me bum. I ain't any space in my bum for the needle*" {p. 30}.

When discussing their diagnosis, many of the participants appeared to have developed idiosyncratic understandings of what their diagnosis meant for them. Similarly, they also appeared to have developed idiosyncratic understandings of why they were prescribed medication or alternatively they appeared not to understand why they were prescribed psychotropic medication. For example, Josh said that he was prescribed a depot to "*counteract the injection they gave me in prison, so that I can think better and live better in the community, amongst all nation of people and all that. And try to not cause no racist business in the community*" {p. 5}. An example of a participant not understanding why they are prescribed a depot was Rebel, "[CW: ... What do you think the injections were for?] *I don't know, I didn't really get it resolved*" {p. 2}.

A further component of both the complex relationship with mental health services and the dislike of psychotropic medication would appear in the sense of lack of control over the medication that they were required to take. There was genuine anger at the lack of control. Some of the participants described experiencing coercion, as Josh said when he was asked if he had ever disengaged, " ... *well it's not my choice you know. I ain't got a choice because I got, if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it*" {p. 1}. The two quotes below further show that the participants felt as if they had very little control over whether to take medication: "*But I want to know why they keep giving me injections from in the jail. ... Now I am a free man they are still treating me like a prisoner*" Josh {p. 22}. Rebel felt he was not listened to when he tried to influence the dose of depot medication he was receiving. This subsequently impacted on his experience of taking the medication: "*I used to communicate to them to say that I wouldn't like that, in other words, 'Don't give it me'. But they insist ... I just seemed to drift away and just slumber*" {p. 15}.

In the discussions with the service user reviewers between the initial interview and the clarifying interviews, one of the issues that the service user reviewers wanted clarity on was

whether those people who were on CTOs understood the legal position that they were in. The participants appeared to understand their legal position regarding taking medication, as Josh said, "*I've got my choice but it's complicated*" {p. 21}. There is, however, ambivalence towards medication and in Theme B the participants also highlighted how they have benefitted from being prescribed medication.

4.3.1.1.iii   "Leave me alone"

As previously stated, the participants' relationship with mental health services was complex and contradictory and some of the participants (Black Zee and Bubbles, for example) quite forcibly felt that mental health services could best help them by leaving them alone. Through their actions and their words, the participants actively questioned the need for mental health services in their lives. Indeed, Bubbles indicated that he believed that mental health services gave him symptoms of psychosis. For example, Bubbles and Black Zee say respectively, "*I just leave them alone, leave people to sort their own minds out*" {p. 21} and " *... tell people to just leave me alone, leave me alone to live my life*" {p. 16}. However, the older participants appeared to express a sense of no longer seeing a point to actively disagreeing and disengaging with mental health services. The participants were able to appreciate the practical qualities that mental health services brought, housing for example, whilst still resenting the involvement of services.

Josh, Rebel and Clue had previously believed that mental health services should leave them alone but over time they had realised both that mental health services were not going to leave them alone and also that they may benefit from the input of services. Clue in the first interview said that he did not want "*these people*" involved because they did not believe in God, yet in the clarifying interview he put strong emphasis on the fact that services had helped him.

4.3.1.1.iv   Perspectives on disengagement

One of the emergent themes relating to the participants' relationship with mental health services was that the participants did not appear to perceive themselves as disengaged. The older participants denied that they were disengaged from services; for example, Rebel: "[CW: So do you feel that there was a time when you have disengaged?] *Not really*" {p. 4} or

Arthur: "[CW: Would you say that you have ever disengaged from the services?] *No*" {p. 4}. Arthur admitted that he was angry with mental health services but denied that he had ever disengaged from services, despite professionals' descriptions of his behaviour. Bubbles did not believe that he had ever deliberately disengaged from mental health services. He said that he would not take depot medication unless he was forced to and that people who were "*ill*" should not be given "*tablets*" {Bubbles, p. 21}. To explain this perception that he had disengaged, Bubbles attributed it to being "*busy*" {p. 2} or a misunderstanding. According to Rebel, "*They left me here and so I was receiving letters in the post saying, we need to assess you and that was, I had no idea what was going on.*" {p. 8}. The younger participants were more forthright, Black Zee said, "*I really want to disengage from this service, you know that, that's the thing. I really do*" {p. 14} and T admitted that if he were not on a community treatment order that he would have nothing to do with mental health services.

Disengagement is a term that is generated by professionals to describe the behaviour of some service users. The study 1 participants did not think of themselves as disengaged. The study 1 participants may have felt persecuted and hounded by services (see quotes above) but they were able to pick and choose those aspects of the service they felt that they needed. Housing is one example but also oral medication. Clue said that he was happy to listen to guidance from mental health services but he added the proviso that he does not always have to accept it, "*I carry on with them rather than listen to them*" {p. 2}. This finding is also illustrated by the participants' willingness to engage in the study. Services described these participants as disengaged yet they wanted to speak to a mental health professional about their experiences.

The Bubbles quote, "*I'm not the only one, I mean, people they got nowhere else to go, nothing to do, the sad people, funny people, and they go round other people's houses and they just come unstuck*" {p.15} is important to the study and the imagery struck by Bubbles' quote is very stark. Not only is he describing a group of people who are disengaging from mental health services because the services do not meet their needs, "*people they got nowhere else to go, nothing to do*" is an expression of unmet needs but he is also describing his peers' experience of mental illness, "*the sad people, funny people*". The phrase becomes an expression for a collection of people experiencing complex social problems accompanied by on-going mental distress, and "*They go round other people's houses and they just come*

unstuck" reflects Bubbles' metaphorical understanding of the perceived untreatability of that mental distress. Whilst professionals would never use the language because it is too imprecise and too judgemental, the images that the quote presents highlights the experience of mental distress and the perceived inadequate response by mental health services to constructively help people.

4.3.1.1.v   "... well, it's not my choice, you know?"

Another component of the complex relationship that the study 1 participants had with mental health services is that they have learnt over time to feel as if they have very little control over the care they receive. As described above, part of the experience of lack of control is about medication. However, the theme expands into other areas of care. Arthur said,

I went into the office, I says, 'Hello' Dr ▓▓▓▓ says, 'Hello, are you Jesus Christ?', I says, 'No, I am not.' He says, 'Yes, you are. I'm putting you on medication.' I told him that the Home Office had released me from that. He told me that the Home Office had written to him, asking him to take charge of me. So there was nothing I could do. I went home until Dr ▓▓▓▓ came with the police and took me to ▓▓▓▓▓ Hospital and from that my life was finished. {p. 30}

The following quote from Josh ties together ideas that run through the ambivalent relationship with mental health services: " *... well it's not my choice you know. I ain't got a choice because I got, if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it*" {p. 1}.

The study 1 participants' complex relationship with medication is an example of the lack of active participation. Oral medication is also one of the strategies that reinforced their resilience and helped to reassert their identity. However, the study 1 participants were genuinely angry at the lack of control over the choice surrounding medication, in particular depot medication. Awareness of this anger is important in understanding both the complex relationship with mental health services and the dislike of psychotropic medication. Some of the study 1 participants had experienced coercion; when asked if he had ever disengaged, Josh said, " *... well it's not my choice you know. I ain't got a choice because I got, if the mental*

health people come with me or come to give me medication, I take it. ... But deep down I really don't want it" {p. 1}.

The component parts of this theme are that medication played an important role in the disengagement experience. The participants did not perceive themselves as having disengaged from mental health services and also the participants felt that they had little choice in the process of being treated by mental health services.

4.3.1.2 Living with uncertainty: Health, uncertainty and anxieties

The overall superordinate theme is concerned with the experience of disengagement from mental health services within the context of fractured social connections. The following subordinate theme highlights some of the issues that underpin that experience of disengagement. None of the study 1 participants have a comfortable relationship with mental health services and one of the reasons is that they do not conceptualise mental health and mental illness in the same terms as the statutory services.

4.3.1.2.i   Idiosyncratic understanding of mental health problems

In interpreting the experiences of the study 1 participants, it is important to note that the participants were not denying that they have a mental health problem and had developed their own idiosyncratic understanding of their own mental health. Regardless of that discrepancy of definition, the participants were very unsure of many aspects of their health, illness and healthcare, and this was a source of anxiety for them. Some of the participants straightforwardly denied that they experienced mental health problems. T, for example, said, "[CW: You still don't think you've got schizophrenia?] *No*. [CW: Okay.   Do you think you've got any mental health problems?] *Nah*" {p. 2}. T said that it is up to everyone to decide for themselves whether they are mentally ill {p. 6}. Additionally, T believes that he was only "*crazy*" in the year after his father died and as such struggles to see the value of mental health services.

However, a more consistent theme across the participants was that they had their own idiosyncratic, and at times contradictory, understandings of their own mental health and were aware of the pertinent issues in their life that they did not understand. For example Arthur

said, "*I'm always mentally well. ... hearing voices doesn't bother me*" {p. 5}; "[CW: What is it for someone to be healthy?] *Well, not hearing voices, I suppose. Not hearing the voices. ...* [CW: So do you believe that you have schizophrenia?] *Yes*" {p. 6}. Additionally, Arthur spoke of his perception that his experience of voice hearing and "*signals*" were normal parts of his life. Rebel described his schizophrenia as, "*... just a way, it is a set back memories of worst times that I can't even describe, I can't even put words*" {p. 8}. Referring back to the Bubbles quote on page 81, not only does his metaphor talk about the unfulfilled needs of some participants it also describes mental health problems that are very much from the perspective of those experiencing those problems.

4.3.1.2.ii   Not understanding

A finding of the study was that there were lots of things that the participants simply did not understand, particularly when discussing their physical and mental health. Josh said of his diagnosis, "*No, I don't understand what it is. They say it's a split personality or something like that*" {p. 24} and also " *... Is schizophrenic that person who ... to mean schizophrenic is a nice person, nicer person ... Not sick.*" {p. 24}. In terms of not understanding the treatment package that mental health services were trying to deliver, Rebel said, "*I didn't know I was on medication because I thought I was, I had nothing to do with medication at the moment. I was discharged from hospital and discharged from medication*" {p. 3}. Similarly, Arthur did not understand why he was being readmitted to hospital, "[CW: Why do you think you were taken to hospital by the police?] *Because the nurses requested.* [CW: Why did the nurses request?] *I don't know. They just says, 'You're going to hospital'*" {p. 3}.

Also, two of the study 1 participants misunderstood the purpose of depot medication; Josh believed he was given an injection to counteract the side effects of the medication he was given in prison and Arthur believed he was given a depot to keep him "*skinny*" {Arthur, p.3}. Again Bubbles knew that he was taking oral medication but he did not know what it was or what the purpose of the drug was {Bubbles, p. 12}. Black Zee and Rebel both expressly said in their respective interviews that there are many aspects of the care that is delivered to them that they do not understand.

There is an element of contradiction about Black Zee, with some quotes indicating that he refuted his diagnosis of schizophrenia. Yet elsewhere he said that "*Recovery is possible*" and his quotes about both medication and religion would indicate that he had ambivalent feelings about his diagnosis. In the post-interview he appeared to be praising medication and stating the need for it in his life. To provide context, there were months between the first interview and the post-interview and in between Black Zee had come off medication and started again.

The findings of this study would suggest that the study 1 participants did not always understand the motivations and decision making of mainstream mental health services and, therefore, did not see why engagement with services is necessary. Nonetheless, for a multitude of reasons, the participants did engage with services to varying degrees.

4.3.1.2.iii   Concerns about physical health

One research questions was "How do the research participants understand their own health, well-being and illness?" Physical health is evidently important to the participants. Clue said, "*It* [health] *would mean a lot to me. It would mean a gracious kingdom of the world for me. I want part of... I can in this world that's all been seen*" {p. 6} and Rebel described being in good health as, "*You're on top of solid ground, your feet on the ground; you have got your head on your shoulders and got no worries and problems*" {p. 7}. The participants had realistic concerns about their physical health. Again it was Clue who said, "*Infection on my lungs. It's like some people can take in air, my lungs can't take in so much. Holes in it*" {p. 6}. Clue was suffering with emphysema at the time of the interview and, as stated previously, he subsequently passed away at a relatively young age due to his poor physical health.

With Arthur there is a large discrepancy between what was empirically evident and how he conceptualised his own health. Whilst he said that, "[CW: … You've always been a heavy smoker?] *Yes*. [CW: That you have some breathing difficulties.] *No*. [CW: OK, so you feel your lungs are still pretty good, your lungs are pretty healthy?] *Yes*" {p.7}. His breathing was so laboured that at times it was hard to hear the recording of what was said.

T made a very interesting comment, "*It's just health. We've all got to die one day. So it's going to go one day isn't it*?" {p. 7}. This quote has to be taken in the context that up until

this point T was answering in only one word answers. When asked how he would define death he made the connection between his health and the finiteness of his own existence. It was delivered in a deadpan way, perhaps belying an ambivalence towards his continued existence (or contempt for the interview). Many people may define health in terms of life, positivity or even absence of disease and illness; T made the connection between his health and his demise. T's ambivalence is further demonstrated when discussing his use of cannabis, "*I choose to ignore the bad part and I choose to smoke it and enjoy it and not think about its harming my health*" {p. 11}.

4.3.1.3 Belonging to and exclusion from community and society

In addition to the ambivalent relationship that the participants had with mental health services, the complex relationship also impacted upon the participants' ability to integrate into their local community. They have fractured and inconsistent relationships with their families. They felt threatened and persecuted on different levels, all of which contribute to their sense of isolation and their hopes of maintaining a positive identity in their local communities and with wider society.

4.3.1.3.i   Identity

One aspect of the difficulties faced by the participants was maintaining a positive identity in relation to the community in which they lived. The experience of struggling to maintain a positive identity was related to being a user of mental health services, to the participants' social class and to the participants' racial identity. Bubbles, for example, spoke at length about his lack of positive identity, "*Ex-criminals in the middle, ex-cons and ex-patients like me and then on the other side there's goody-goodies and the other side is the baddies. ... and then they're like the backstreet kids and just ... fall over again.*" Additionally, with reference to racial identity, Bubbles said, "*… Then you've got the half-casts, the mixed minority, the ethnic minority in the middle and we get the blame*" {p. 21}. The findings suggest that the participants believed that their association with mental health services had a detrimental effect on their identity. Clue, for example, said that because he was always in mental health institutions his children believe that that is all there is to his identity. The Rebel quote that, "*Being unemployed it isn't any riches or any goal or anything it is just a way of saying that I struggled and struggled but I made it. I entered by the door in society, I didn't climb in*

through the window, like a thief" {p. 15} demonstrates that despite the numerous social factors that could impact upon these individual participants, they have the personal resilience to forge an identity of which they are, nonetheless, proud. Josh explained that because of the stigma associated with having an injection it changes how he thinks about himself. As a consequence of this perceived change in identity he lost his friends, leading to loneliness.

4.3.1.3.ii   Feeling threatened and persecuted

Some of the participants felt threatened and persecuted both on a local level and on a larger societal level by the agencies of the state, of which mental health services are a part. Bubbles, in particular, physically demonstrated in the research interview how he had to walk when out so that he was ready and able to respond to an attack, *"… I just keep my guard down just in case someone comes and attacks.* [Bubbles put his arms rigidly straight down by his sides at this time as if to demonstrate what he meant] *Cause you don't know. You might be out walking and someone out there throws a tantrum. You have to keep your guard down"* {p. 27}. The feeling of persecution had an impact on the participants' sense of identity; for example, Bubbles said, *"I keep on thinking that people are talking about me. Everywhere I go. They are thinking of me like I'm the village idiot"* {p. 33}. Indeed, Bubbles had broken a tooth in between the clarifying interview and the post-interview meeting after being involved in a violent incident. The participants struggle to have a clear sense of their identity and persecution, because of their racial identity, played a part in their experience of disengagement from society and their local community. Only two of the participants talked about experiencing racism as a component of disengagement from both society and mental health services; Black Zee said, *" … There is racism isn't there? Nobody bonds through racism. I have read in the paper that every Briton is supposedly racist … And Dr* ▬▬ *was racist towards my life because he didn't see me as a British man"* {p. 6}, and Bubbles said that, *"… Well I'm picked on anyway, but just you know racial, fascists some people"* {p. 6}.

Clue felt persecuted within society because of his ethnic background, for example describing himself as a *"red man"* as opposed to a black man, which he interpreted as a reason why he is persecuted, *"They don't look at me as black, look at me as red; they see one where I am the red man; there's a red man and the red man, and they don't look at me as black"* {p.12}. The

word "*they*" in this sentence is ambiguous. The sentence could be interpreted as meaning that people in general within society were punishing Clue for being of mixed heritage or the text could also be interpreted as Clue saying that he is persecuted by mental health services for being of mixed heritage. Clue also felt persecuted by his family because of his cultural identity, "*My wear the dread, my wear the dread. They don't want to know me. They cast me as an ... coz I wear the dread. It cost me a lot, an outcast*" {p. 42}. Additionally, Clue feels pressure from people whom he sees as big-time criminals, whom he feels "*can get over*" him, "*think they can use*" him and "*leave him in the dump*" {p. 13/14}.

Other participants had a sense of persecution at a macro level, "*the government*" or they were persecuted by the anonymous "*they*" or "*people*", the sense that they were being persecuted even if they were not clear who was doing the persecuting. For example, Josh said that, "*The government ain't right coz ... because they say certain things and then they go against it. They laugh at yea*" {p. 30} and "*But they community they don't like me because they don't believe, they don't understand what I am... So they treat me vile and disgusting*" {p. 23}. Similarly, Clue was unspecific about who was persecuting him, "*They like to think I'm a bad influence and they want to get rid of me. I wonder why*" {p. 29}.

4.3.1.3.iii   Mental health services

Part of the complexity of having mental health services involved in their lives, with medication being an integral part of that involvement, is that the participants felt they were not able to associate with people in the community as they would wish. Josh explained this very well when he said, " [mental health services] *take away my friends, take away my ... makes me feel lonely. I makes me feel alone, it plays with my ... my outlook, my outlook. My perceiving, you know? That's what it* [the injections] *does to me. So I don't think it's right that I should have injections*" {p. 33}. He also said that, "*... I can't get to where I like to go out in the community and make a name for myself or try to help people. ... Yeah, the injection stops me from being out there*" {p. 13}. Black Zee also expressed the sense of being rejected by society because of his mental illness, "*People out there they just make you mentally ill if they don't like you or know what you've been like*" {p. 14}.

It is not just the loss of friends and feeling part of the local community that are impaired by the involvement of mental health services. It is also a consequence of living in mental health residential facilities. Clue felt that his children could not be with him: "*I don't have no contact with them. ... Because I didn't grow them up. ... Because I was always locked in places like this. So I didn't get them right or they're not thinking my way and they're not trying to get me out of it. They think all I've got is Mental Health Act.*" As a consequence of not being involved in raising his children Clue concludes that "*All my life is sorrow*" {p. 20}.

4.3.1.3.iv   Relationship with community and society

Whilst Bubbles talked about feeling very threatened and needing to avoid people to stay out of trouble, Josh felt the rejection of his community very strongly: "*I'm not part of the community where they've rejected me. I tried to help them but they rejected me, they don't want no help*" {p. 7}. Additionally, to compound this feeling of rejection, Josh wanted to feel that he was part of the community, "*I want to be a part of that system but probably I haven't got the education*" {p.18} and " *... but I don't want to do things or make a person life be miserable and inferior, you know, so, so I try to get on with everybody*" {p.19}. Josh openly acknowledged the poverty he was living in when he jokingly said he wants to, "*... just live in this luxury*" {p. 11}. Furthermore, Josh explained that because he receives injections from mental health services he believes that he is not able to immerse himself in his community as he would like. With the quote "*People will talk to me*", Clue appeared to be indicating that he believes that if he disengages from services people will be willing to talk to him again and this will represent a return to normality. Amongst the participants was a sense of frustration borne of frequently moving home; it is of note that in the period of time between the initial interview and the post-interview meeting two participants had moved homes and one participant had been re-detained in hospital.

The participants were aware that people in the broader community had little understanding of mental health issues and because mental illness was not visible, it was not always recognised. Josh said that, "*People ... if I tell them that there is something wrong with me they say, 'No, there's nothing wrong with yea.' But there is something wrong with me, and I have things bothering me. And they say, 'There's nothing wrong with yea.' ... So, what should I do?*" {p.30}. Clue also feels that people in the local community do not understand mental health

problems: " ... *what I'm saying to you is that people on the street don't understand it*" (mental health problems){p. 40}. Black Zee also expressed the sense of being rejected by people who knew him because of his mental illness – a powerful sense of being disliked because of his mental illness. These experiences further lead to the feeling of being isolated within the local community.

T, however, was different. He was adamant that, despite apparently being very isolated from everyone and everything, it is him that actively took the decision to disengage himself from mainstream society. When T is discussing his separation from wider society he said that he had chosen to disengage because of a drug experience. T described the experience of taking drugs in the aftermath of his father's death and having visions of an unspecified religious nature. T actively chose not to be part of the community as a result of those religious visions. Whilst some of T's explanation of his experiences may be the result of his drug use, there is no doubting the profound effect that the experience had on him or the far-reaching consequences of that experience.

The relationship that the participants had with their communities should not be portrayed as only negative. Some of the participants very much felt that they were part of the community but none of the participants felt as if they were part of the wider society. For example, Black Zee said, "*Yeah, I do feel part of this community. I get a lot out of this community*" {p. 30} and Arthur too said, "[CW: ... Do you feel part of the local society, the local community?] ... *Of course I am!*" {p. 26}.

When discussing the experience of disengagement in relation to their social standing within society, two quotes from the participants inadvertently demonstrate how materially deprived these men have become and this material poverty again demonstrates a degree of separation from mainstream UK society. When asked about in-patient care, Clue talked about how proud he was to be in a place that provided both showers and breakfast. Most people in contemporary UK society take showers and breakfast to be the norm but Clue is so alienated from mainstream society that these seem novel and extraordinary. Again, Bubbles, when talking about his son, lists the commodities that his son has, "*Sofa, carpet, stereo*" {p. 39}. Again these are everyday items that most people take for granted but such is the state of

Bubbles' material poverty that he sees these as symbols of cultural attainment. Bubbles' son lives in a tower block in what is generally considered an undesirable part of town but in relative terms Bubbles believes that his son is doing well.

4.3.1.4 Family and fatherhood: Inconsistent and fragmented relationships

The 'family and fatherhood: inconsistent and fragmented relationships' theme further emphasises the limited connection with social structures that the participants have. Whilst the participants did make some reference to members of their families supporting them, the most abiding sense was how fragmented their family relationships are. The different issues which can be interpreted from the participants about their fractured family relationships were the lack of romantic relationships. All the participants are largely indifferent to the fact that they did not have a close relationship to their father when they were growing up, but the five participants who were biological fathers themselves expressed deep regret about not being involved in raising their children. A counter-intuitive theme was that the participants who were fathers felt that it was their children's responsibility to seek them out rather than the other way around.

The interpretative sense from the participants was that not only did they have fragmented and fractured relationships with their families but those fragmented relationships carried on over many years. There is upset and anger in equal measure and also a sense of incomprehension about why their relationships are the way they are. The younger two participants were clear that they took the decision to remove themselves from their families (T: "*I weren't around them as much. I distanced myself from them and I just wanted to be on my own*" {p. 19}) but the other participants left the impression that they were rejected by their families (Bubbles: "*Nobody wants to know or get involved*" {p. 9}).

4.3.1.4.i Intimate relationships

A component of having fractured family relationships was that none of the participants were in an intimate relationship. Josh spoke about how, in his ideal life, he would be with his ex-partner and child, " ... *to live with me woman. That's what I want to do. And my kids*" {p. 30}. Bubbles described the fact that his ex-partner now lived with someone else as a "*Sore subject*" and "*the less said the better*" {p. 10}. Whilst Rebel did describe himself as having a

girlfriend with whom he was about to have another child, it became clear over the course of the two interviews that whilst she may have been on the verge of having another child, the child was not his nor were they still in a relationship, "*This is a mess about now, she's gone*" {p. 19}. Just as Black Zee had been very affected by the breakdown of the relationship with his father and family, he also expressed profound sadness about no longer being together with his partner: "*... rid of me from her life because she didn't want to be with somebody schizophrenic*" {p. 9}. Black Zee made many references to his partner leaving him and his inability to find an acceptable reason why.

4.3.1.4.ii   Fathers

The following two sub-themes are linked; the participants either grew up not knowing their father or, if they did have contact, they were not close. Also, the five participants who had fathered children had not had any involvement in raising their children and this caused a great deal of distress.

It is only Black Zee who expressed anger about not being close to his father, "*... but he has used us as family, ... He has drained us out of life, right, and when we feel ill he doesn't give a shit*" {p. 20}. The rest give the impression of being indifferent. When asked about his relationship with his father before his father died T described the relationship as "*Rubbish, really*" {p. 23}. In T's case there are added layers of complexity – that he had a "*rubbish*" relationship with his father, that his father had not known his own father, that T's father killed himself and that T himself is "*opposed*" {p. 24} to the idea of becoming a father. Within this context T raises the issue of him first becoming mentally unwell (or indeed the only time he believes he has been mentally unwell) as a consequence of the death of his father: "*It made me go crazy*" {p. 16}. In the months following his father's death, T had the drug experience in which he had religious visions which caused him to choose to distance himself from mainstream society. It was very prominent in T's case that the fragmented relationship with his father had a profound effect on him, socially, medically, spiritually, emotionally and, for the purposes of the phenomena under investigation, his experiences of disengagement from mental health services.

4.3.1.4.iii   Fatherhood

Five out of the seven study 1 participants were fathers but all of those had little or no contact with their children whilst their respective children were growing up. The other side of the participants not being close to their fathers theme was the amount of anguish felt by those who had fathered a child, of not being involved in their children's upbringing. The quote which best illustrates this sub-theme is from Clue who said, "*Yeah I regret it. I regret it a lot. I can't see where the blossom is not growing on the tree. That's one part of me that keeps me down. My mind just can't function. One part of the seed isn't functioning with you, your mind go blank*" {p. 21}. The quote and metaphor is interesting, in particular with reference to other sub-themes, such as those about sorrow and age and experience. An interpretation of what Clue said is that he can understand how parts of himself did not blossom as a consequence of not being involved with his children's up-bringing. It is these aspects of his personality that have not blossomed over the years which are now keeping him down. He feels that his mind cannot function. With his mind not functioning he feels that his mind (or that of anyone else who finds themselves in a similar situation) goes blank. To summarise, as a consequence of being involved with mental health services, living in residential units and his parents turning his children against him because he takes drugs and "*wear the dread*" he did not see his children as they were growing up. As a consequence of not seeing his children as they were growing up, he feels he has not fully developed as a person. This has the knock on effect of his mind going blank. Elsewhere in the research interviews, Clue also said that he has a relatively good relationship with his family, whom he feels support him {p. 20} and he has regular contact with his "*mother, father, my brother and my sister*" {p. 20}.

In addition to Josh's interesting relationship with his late mother, which is covered in his idiographic statement, Bubbles also seemingly had a relatively good relationship with his family. He is dissatisfied with living in the north of the city and travels on the bus every day to visit his mother, son and brother, all of whom live in the south of the city. Despite not being involved with his son as his son was growing up (and he still does not have a relationship with his daughter) he now has a seemingly good relationship with him, "*I'm proud of him, yeah I'm proud. He's doing better than me, he's got more things. He don't trouble nobody anyway*" {p. 38}.

4.3.1.4.iv   "I'm waiting for them to come and look for me"

As has already been discussed, the participants were separated from their children and felt great anguish about it. In light of this it seems counter-intuitive that three of the five participants who were fathers believe that it is their (adult) children's responsibility to seek them out and re-establish contact: Bubbles: "*I'm waiting for them to come and look for me*" {p. 10} and Clue: "*Apart from that, they're supposed to come look for me anyway, soon, my kids*" {p. 21}. This is counter-intuitive by the standards of most accepted personal values. It would be supposed that the participants would have seen trying to re-establish relationships as beneficial to their well-being given the anguish felt.

The 'family and fatherhood: inconsistent and fragmented relationships' theme provides another perspective on how the experience of disengagement from mental health services is a component of a larger scheme of limited connections with social structures for the participants. Whether that is through choice on the part of the participants or by their family distancing themselves from them, there is a sense of fragmentation and inconsistency evident in the research interviews. In specific instances this had particularly poignant meaning for the participants.

4.3.1.5   Life is sorrow: Threats to well-being

4.3.1.5.i   "I am a solitude"

As a consequence of the different ways in which the participants experienced exclusion and disengagement from society, they found themselves leading very solitary lives. Rebel probably best exemplifies this when he says that, "*Yeah, I am a solitude*" {p. 13}. Whilst some participants undoubtedly preferred this lifestyle (Bubbles: "*I want to be on my own*" {p. 38}), others have not led this lifestyle through choice. The sense of isolation was profound and only Rebel acknowledged a possibility that there may be an end to this way of living when he talked about having a girlfriend. Some of the participants had friendships through drug use but these relationships did not appear to hold great significance for them.

4.3.1.5.ii   Life is sorrow

Conducting the research interviews and also reading the transcripts of the interviews there is an enduring sense of sadness and sorrow that permeates the participants' thinking, Clue said

that, "*All my life is sorrow*" {p. 21}. This sense of sorrow has deep seated meaning for the participants and informs their identity and world view. It is not possible to locate the source of this sadness and sorrow to one causal event. It is not just housing, or family, or the relationship with mental health services or position within society. This sorrow should also not be interpreted as a symptom of mental illness. The sense of sorrow comes from all aspects of their being. Rebel talked throughout his research interview about bad luck and everything being linked to luck, the quote "*...but I am not lucky*" builds into the overall sense of pessimism.

Most themes within Theme A are connected together through the sense of misery and unhappiness that all the participants express. With reference to his relationship with mental health services, Clue said, "*... I can't have any peace in my life with those people around*" {p. 25}. Arthur said that after starting depot medication, "*From that my life is ruined*" {p. 2}. Black Zee felt that as a consequence of the perceived enforced engagement that, "*...This life chose me, I did not choose this life*" {p. 12}. Regarding medication and the on-going relationship with mental health services, the participants believed that they did not have much choice in the provision of care, as Josh said, "*I've got no choice.*" Josh also said, "*I'm a free man now. But I want to know why they keep giving me injections from in the jail. In the prison. Now I am a free man they are still treating me like a prisoner*" {p. 22}. The participants had their own idiosyncratic understanding of their mental health problems and Bubbles described himself as, "*Being weak and depressed and down and out, like I am. Just miserable*" {p. 5}. Part of the experience of living with uncertainty was that the participants did not understand important issues in their lives which in turn impacted upon their happiness, as Black Zee said, "*I don't know why this life came against me*" {p. 24}.

Some of the participants felt that, as a consequence of being involved with mental health services and receiving medication, they were not able to mix with their local community. Josh put it this way, "*But when I look at it I'm just say, 'I can't go nowhere'. I'm just stop in this room, I got no friends, nobody*" {p. 23}. The perceived exclusion from community and society impacted upon their identity, Clue perceived his identity in society as "*... while you just feed off the little fucking bottom feeding*" {p. 25}. Some participants felt threatened and persecuted both by mental health services and also in the communities in which they live as

Bubbles said, " … *I'm tired of being picked on to tell you the truth*" {p. 8}. The solitary lives the participants lead was noticeable and felt by them. The solitary nature of their lives also contributed to the sorrow experienced, Black Zee: "*I might go to sleep at night .... When I wake up I understand that there is not too much there for me, all over again. Waking up alone. No phone calls. All this kind of stuff putting a few bits and pieces together from nothing. What are you supposed to do about this? How do you go about having a sense of work?*" {p. 46}.

The participants most acutely felt and expressed their sorrow and sadness when discussing not being involved in raising their own children. When talking about not having contact with his now adult son, Josh said, "*I believe that I must reap what I sow, but I ain't sow nothing*" {p. 19}. Rebel said in connection with the decision of giving his child up for adoption, "*Well, I wept. I wept in a way because that is all I could do. Wept, I just wept*" {p. 12}.

4.3.2   Theme B: Multiple strategies to reinforce personal resilience and to reassert personal identity

Theme A emphasised the meaning of the experiences of disengagement from mental health services for the participants in the context of having limited connection to social structures. However, there is another important aspect to the experience of disengagement for the participants. Over time the participants had developed strategies to reinforce their personal resilience and to reassert their personal identity in the face of multiple threats to their well-being and cope with their limited connection to social structures. As Black Zee said, "*There are all different levels of interpretation of how you are able to break free*" {p. 45}. Theme B explores these strategies and themes. Throughout these themes about strategies for reinforcing personal resilience and striving to maintain a positive identity, there is also a sense of the participants seeking normality. The quote which perhaps best exemplifies this is from Rebel: "*Being unemployed it isn't any riches or any goal or anything, it is just a way of saying that I struggled and struggled, but I made it. I entered by the door in society, I didn't climb in through the window, like a thief*" {p. 15}, which could be interpreted as demonstrating he has had the resilience to establish an identity that he is proud of within his community.

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The means by which the participants reinforced their personal resilience and reasserted a more positive identity were: medication: "*...I was blind before I could see*"; cannabis: "*Drugs make you the man you are*"; faith, spirituality and solace; and age, experience and maturation. Throughout these themes the participants were looking for a normality. When talking about why he was now comfortable taking oral psychotropic medication, Rebel commented that he was, "*... trying to come back to my normality*" {p. 4}, when talking about why spiritual beliefs were important to him. Bubbles said that, " *... Just brings me back to reality*" {p. 7} and when talking about the normality of drug use, Black Zee said, "*It is everywhere isn't it, it was everyone*" {p. 23}.

4.3.2.1 Medication – "... I was blind before I could see"

The first strategy that the participants had developed to maintain their personal resilience and reassert a more positive identity was through the use of prescribed medication, particularly oral medication. In Theme A the participants spoke about the use of medication as an important component of the experience of disengagement. However, just as the relationship with mental health services is complex, some of the participants also highlighted that taking psychotropic medication was beneficial to them. In Theme A it was apparent that the participants had developed their own idiosyncratic understanding of their mental health. Similarly the participants had also developed their own idiosyncratic understanding of how psychotropic has benefitted them. Rebel, who saw himself as allergic to depot medication and was angry about how poorly he had been treated by the people prescribing medication, had developed a personal understanding of his symptoms and how these were now being effectively treated by a relatively small dose of oral medication that was delivered to his home on a weekly basis: " *... you have got no reasons so you couldn't put that together and 2 and 2 make 1. I couldn't make no ends meet out of anything, what happened to me, it was like I was just lost. In a way I was lost before I was found. As if I could have said I was blind before I could see*" {p. 6}. Rebel further described the effects of oral medication as, "*This is trying to come back to my normality, to save up my health, to put me back on my feet again*" {p. 5}. Rebel is aware that he does not think of himself in the same terms as the professionals who are working with him: "*…if I thought of myself medically, I don't know, I wouldn't heal. Like it takes time to heal. But mentally, subtlety mentally it's like I've been asleep*" {p.18}.

Other themes from this study are evident in Josh's attitude towards medication. He had previously been reluctant to take medication but had changed his attitude and felt that as a consequence he was living a better life: "*I'm trying to say that the injection or the medication or the doctors make me, help me to disregard that life that I was living because I think I'm living a better life now*" {p. 17}. Further, reflecting on his personal development and the impact that medication has had upon that development over time, Josh understands the reason why he has been prescribed depot medication as, "*To keep me calm. Coz I was a violent kind of person. So they are trying to get rid of the violence, the violent attitude*" {p. 25}. Referring back to his identity within the community and the need for him to change so that he can view himself positively from his late mother's perspective in his community Josh said, "*Well... I can't refuse it, can I? Coz the doctor said ... I would get myself in more trouble.* [CW: What do you think that trouble is*?*] *Well ... Let's say ... They would say that I was a menace to society or something*" {p. 22}. Another consequence of taking medication, again in terms that professionals would not use, is described by Josh: "*... when they like give me the medication, I'm alright in my surroundings*" {p. 2}. Arthur again displayed ambivalence, despite saying that being prescribed a depot had ruined his life, he also said that he has, "*Always been happy to take medication*" {p. 16}. Arthur felt that he benefits in similar ways from both cannabis and depot medication, "[CW: ... Alright so what's the relationship between hearing voices and smoking marijuana, does it make it worse or does it make it better?] *Make it better and injection makes it better. The injection sort of straightens the mind, you know? ... And cannabis straightens the mind.* [CW: So cannabis and the injection do the same?] "*Yes, it straightens the mind*" {p.11}.

T, like Black Zee, struggled to see anything positive about mental health services, and came across as resentful in his interview. Yet in spite of this, T did say that there were differences between being on and off medication, "*Yeah, I'm just calmer.* [CW: Are you calmer on it or off it?] *On it.* [CW: ... Do you like being calmer?] *Sometimes*" {p. 3}; he also said as a consequence of not taking medication, "*I become more angry quicker*" {p. 3}.

Despite ambivalence, most of the participants were able to explain how and why medication helped them. Whether that was straightening out their mind or being returned to reality the participants were able to explain the benefits in their own language.

4.3.2.2 *"Drugs make you the man you are"*

Another strategy that the participants used to reinforce their personal resilience and promote a more positive identity for themselves was through the use of cannabis. This was also one of the themes where the participants placed the greatest meaning and emphasis. Variously the participants cited fitting in with their local community, becoming closer to God, experiencing a little happiness, lifting misery, creativity, relaxation, enjoyment, way of life, identity, pain control, being good for your health, straightening the mind, helping with the voices, medicinal cure, making you conscious of things you want to be conscious of and sleeping, as the benefits they individually experienced. Two of the participants smoked crack as well but there was not the same degree of reverence for this.

Central to the experience of using cannabis was the contribution cannabis made in forming an identity, with Clue going as far as to say that, "*Drugs make you the man you are*" {p. 42}. Josh cites that, in addition to other benefits of cannabis use, it also contributed significantly to his personality: "*it's all to do with my person that makes me, if I smoke that it makes that person who I am become, people become friendly with you because there's a lot of people smoke those things and do those things, you know, and they're more friendly with you*" {p.8}.

The participants only felt benefits from using cannabis and none highlighted negative consequences of use or concerns about the legal status of cannabis. Their comments suggest that cannabis was prevalent throughout the communities in which they live and was very much part of normal life. Bubbles said, "*Have a drink and a smoke, I'm just normal. I'm just normal*" {p. 33} and Black Zee questioned that given cannabis was so prevalent within the community why were professionals trying to stop people from using it: "*It is everywhere isn't it, it was everyone. I am not sure, but the thing is 'What are they trying to get rid of?' is my question*" {p. 22}. Across the participants there were three different benefits related to using cannabis; help with physical ailments, help with mental well-being and enjoyment.

Whilst there was confusion about what physical conditions Arthur had had, in his opinion, "*I have had my prostate gland removed. ... And I used to have bowel cancer ... So marijuana helps it you know.* [CW: Did it help with the pain control?] *Yes, yes*" {p.8/9}.

Remembering that Clue has emphysema, it was of note that he said "*... I like cannabis... it's good for your lungs as well. It's herbs*" {p. 7}.

In addition to physical help, the participants felt benefits to their mental well-being from smoking cannabis. The use of cannabis was a strategy that the participants used as a means of reinforcing resilience, promoting a more positive identity and maintaining their mental well-being. Arthur and T compared the effects of cannabis to the effects of medication. When asked about the relationship between hearing voices and smoking marijuana, Arthur said, "*Make it better and injection makes it better. The injection sort of straightens the mind, you know? ... And cannabis straightens the mind.* [CW: So cannabis and the injection do the same?] *Yes, it straightens the mind*" {p.11} and T replied, "*Cannabis would make you sleep. ... And the medication doesn't*" {p. 10}. Whereas Clue, who had at times been very dismissive of the effects of psychotropic medication, understood the benefits of cannabis on the symptoms of his schizophrenia: "[cannabis] *keep the voices down ... Yeah, they keep the voices away from me*" {p. 9}. Whereas Bubbles felt that he benefitted from cannabis because of the impact on his prevailing sense of sorrow: "*Being weak and depressed and down and out, like I am. Just miserable. That's why I smoke to get me out of my misery*" {p. 5}. Josh's experience though was more generalised, that cannabis helped him with his thinking: "*When I smoke weed I feel like it's a knowledgeable being helped to me, it makes me see things clearly .... clearly and helpful*" {p. 9}.

The third theme of the benefits that the participants expressed was simply that they enjoyed the experience of smoking cannabis. Touching again on the normality of cannabis use, Clue said, " *... taking drugs to me it's a way of life. ... I enjoy drugs yeah, weed and crack*" {p. 5} or re-emphasising his ambivalence towards his physical health T said, "*I choose to ignore the bad part and I choose to smoke it and enjoy it and not think about its harming my health*" {p. 11}. Returning to the theme of moving from a sense of misery to a sense of mental well-being, Bubbles said, "*I just get high and just have a bit of enjoyment in life*" {p. 4}.

Rebel was clear that he had not smoked cannabis since school, and he is exceptional amongst the participants in that he does not smoke. Yet, despite not smoking, he certainly was not condemning it and praised its value: "*Herb is a medicine, it is a plant which is a green plant*

and it is a medicine and it's written in the Bible. It is used as a medicine for creativity, it's creation" {p. 10}.

4.3.2.3 Faith, spirituality and solace

Another strategy that the participants had developed to reinforce their personal resilience was through the solace found in faith and spirituality. Similar to the use of cannabis, this was a theme where the participants placed great meaning and were convergent with each other. Perhaps Rebel attached the greatest meaning to the role that faith played in his life but all the participants, bar Arthur, talked about how God, prayer and the scriptures helped them. The crucial quote that exemplifies the meaning that most participants attach to their faith comes from Rebel: "[CW: ... if some of your treatment hadn't been about medication, but had been about spiritual guidance instead, would that have helped you?] *It would have been medicine. It would have been medicine to me personally*" {p. 16}. In a similar vein Josh also said, "… *the Mental Health Service, when they're trying to control me with their medication, ... and due to my spiritual outlook and my spiritual guidance, ... I believe that I don't, it's not necessary for me to have it*" {p. 8}. A means by which the participants' spiritual views contributed to their experience of disengagement from mental health services can be seen in Clue's comment that he wanted services to stay away from him because they were not Christians: "*They don't believe in God.*" [CW: Do you think that makes a difference to the way they treat you, because they don't believe in God?] *Yeah it makes a difference. I can't stand them. I don't want them near me*" {p. 12/13}. Though he did contradict this attitude in the clarifying interview, this quote does highlight that he feels he would be better off without mental health services in his life because of his beliefs about the religious beliefs of mental health professionals.

An overriding theme that runs through Theme B is that the participants were engaged in efforts to find normality. With regards to his spiritual beliefs, Bubbles said that, "… *Just brings me back to reality, you know what I mean*" {p. 7}. Both Rebel and Clue felt that they are physically protected by their faith, with Rebel saying, "*Yes, it helps me a lot amount, a lot of help. It is a way of, it's backboned root me, supported me, supported me in my times of ups and ... but I had the scriptures with me to protect me. It's like carrying your cross.* [CW: So, almost in a physical sense that the Bible protects you?] *Yes* {p. 8}. T said of his spiritual

belief, "*... It keeps me sane ... It just keeps me sane. I stay away from the bad and do the good*" {p. 19/20}. Whilst it could be interpreted as a negative comment, listening to the audio recording it is clear that Black Zee intended the quote, "*Believe in God and how he can work basically because I'm sorry if it wasn't for God I would have not got out of this situation*" {p. 24} to mean that without his belief in God his situation would be worse. Complementing the help that their faith gives them, the participants' spiritual views also bolster their sense of identity. Rebel felt that he is humbled by having the spirit inside him and the eternal nature of the scriptures give him roots:

I humble myself like a child, ... humble myself as a child. ... It's the lusts of this world and heaven and earth shall pass it away and the word shall never be removed. The word remaining. In a way I could say that I am fit enough to hold onto my fate like spot on my finger. It's not there but it is there because it is in me, it is in my blood and it is a way of saying that is how rooted I am." {p. 15}

In Josh's on-going struggle to re-establish an identity in the community he said in relation to his religious beliefs that, "*I try to become accustomed to the book now and take an inspiration from it to help the community in certain ways*" {p. 7}.

The quotes above show that the participants, in the context of their limited connection to social structures, draw on their spiritual beliefs. These beliefs appear to help them have the on-going resilience to continue, despite feeling isolated, disadvantaged, powerless and excluded from mainstream society.

4.3.2.4 Age, experience and maturation

The participants acknowledged how they had developed as people over the years and developed in the context of being patients in the mental health system. This acknowledgement was the final strategy that reinforced their personal resilience and enabled them to live with their experience of limited connection to social structures. Whilst this theme was not evident for the two younger participants – T and Black Zee – the reflections on personal development were evident amongst the others.

Rebel commented, regarding the medication, that over time he understood how his perspective on the value of medication had changed, "*... That's how my personality is and it turned out for the change. ... I have lost myself but I have found myself. I was lost but now I am found. In a way, I was blinded but now I can see*" {p. 14}. Clue was contradictory in what he said but in the clarifying interview he did place emphasis on mental health services having benefitted him. With that in mind, it is useful to note Clue's attitude towards medication: "[CW: You don't like the depot but you take it.] *Yeah.* [CW: Why?] *Coz I have to. It's the law. ... They would take me back to hospital. ... I tried it out many times! ... I used to. ... When I was young I used to refuse*" {p. 37}. To provide further context Clue also noted positive changes in himself, "*I'm grown up. ... Yep. I've changed. ... I can think more better... than before. Yeah*" {p. 30}.

The development of perspectives and identity did not just relate to medication. Josh, Arthur, Clue and Bubbles had all been violent men who, over the passage of time, had changed their behaviour for a variety of reasons. Josh changed when he realised that people cared for him, "*I was like hating people when people love me and I didn't know that they loved me in that way or people cared for me, or should I say care, you know what I mean? Like the schools and the police cared for me ... I didn't realise at the time*" {p. 4}. His actions led to trouble with the courts and the police and the following quote appears to have had a lasting impression upon him, "*They think I was a menace. The judge said to me before he sentenced me he said 'I got good reason to believe you are a menace to society' you know? I was just changing then, changing from that character, of a young person who didn't have no care in the world*" {p.5}. Clue changed his behaviour from being a criminal in an effort to live what he perceived to be a normal life, "*I'm changed from stealing and them things. Stealing people's property and changing to just live my life, as if I'm normal, what normal do*" {p. 5}.

The quotes from Bubbles indicate that he attributes his own personal development to changes in his drug use. As stated previously, when Bubbles said he has stopped drugs, what he means is that he has stopped smoking crack whilst continuing to smoke cannabis and drink alcohol. "*It wasn't getting me nowhere*" {p. 3}; "*I just eased off. The novelty has worn off and all that*" {p. 4}; "[CW: ... Why were you so violent?] *The drugs, innit? The drink and the drugs. ... I'm not violent really*" {p. 14}. Whilst the other participants spoke about the

development of a more positive identity, Bubbles continues to believe that others have a negative perception of him: " ... *I don't think I'm any different. People do, but I don't. They say I've changed, they think I've got nastier, dirtier, I got, they say I'm a tramp*" {p. 32}. Finally, Arthur attributes his change from being involved in crime, prison and frequent detention under the Mental Health Act to him being subject to a community treatment order: "[CW: ... what does that community treatment order mean to you?] *It just means I stay out of trouble. First for a period of time*" {p. 22}.

The reasons for the personal changes were borne of experience and each participant had their own idiosyncratic explanation. The recognition of personal development over time is a further process by which the participants were able to reinforce their personal resilience and reassert a more positive identity.

4.4   Study 2 Findings

4.4.1   Summary

There were 12 participants between the groups, a group of ten participants and a group of two. Across the two focus groups the demographics of the participants were:

☐   8 female/4 male;

☐   11 White British/1 British Caribbean;

☐   Majority of staff were in the 46-55 age range;

☐   8 nurses, 3 social workers, 1 occupational therapist;

☐   Average of 19 years' experience in mental health services;

☐   Average of 5.7 years' experience in AOT (range 4 weeks to 13 years).

The findings of study 1 contributed to the questions that were asked of the focus groups in study 2. After interpretative phenomenological analysis of the transcripts of the two focus groups the emergent themes from the study 2 were:

•   A reflection on the dichotomy of assertive outreach teams' roles.

•   A cultural aspect to disengagement, reflecting on the experiences of service users.

- The words used to describe a person's diagnosis and symptoms are both important and flexible.
- The significance of medication.
- Staff accepting that drugs are a significant part of everyday life for their patients.
- The importance of spirituality to patients.
- Does age make a difference?

4.4.2 The dichotomy of assertive outreach teams' roles

The professionals were aware of the dichotomy (or dual purpose) of AOTs' roles. One focus group concluded that ultimately the role of AOTs was one of risk management and that all other considerations were secondary to that; Greg: "*it's worth putting extra resources in to make sure that the risks can be at least minimised*" {FG2, p. 1}. However, this was complemented (or contradicted) by the other focus group who came to the conclusion that their primary function was promoting the well-being of their patients; Pat: "*It's about their well-being, it's about them being able to live their life to the fullest and developing their skills, maximising their strengths that they can lead their lives, as they would see it, interfered life as possible within the community and develop themselves as people*" {FG1, p. 11}. Within the focus groups there was discussion about which position had priority; however, in the end the two focus groups emphasised the different priorities.

An analogy that both focus groups drew on was that of family. In particular this analogy was used to emphasise that the relationships they had were there for an extended period of time and also a recognition that they would be working with their patients: "*you have your ups and downs and I think we get the reflection of that sometimes*"{FG1, p. 3}.

As previously stated, the study 1 participants' relationship with mental health services was a complex and contradictory one and some of the participants quite forcibly felt that mental health services could best help them by leaving them alone. Through their actions and their words the participants had actively questioned the need for mental health services in their lives. The professionals were well aware of this attitude amongst their patients.

Whilst for some it was by choice, the study 1 participants perceived themselves as having only limited support. This point was recognised by the focus groups who used two analogies to describe their role and relationship with their patients, namely "*safety net*" and "*family*"; thus introducing the idea of AOTs acting as a support structure for their patients that would not otherwise be there. The family analogy was used to emphasise that the relationships exist over an extended period of time and also in recognition that they would be working with their patients: "*we almost become a surrogate family for some patients, and with all families you have your ups and downs …*" {Pat, FG1, p.3}.

4.4.3   Words used were an important component of engagement

The study 1 participants either denied that they had mental health problems, developed their own idiosyncratic explanations of their mental health or did not understand the diagnosis they had been given. The study 2 participants were aware of the importance of the language used in diagnosis. The interpretative analysis demonstrated that the professionals were well versed in the linguistic pitfalls of discussing diagnosis. However, this was not a day-to-day concern. For example Greg said,

I've sometimes never mentioned their diagnosis to patients if they really don't want to discuss it as a diagnostic term. If they just want to talk about it as being stress or depression then that's fine as well, as long as they possibly acknowledge that there are some things they need support with; that is the main thing." {FG2 p. 11/12}

However, the strategy of adopting words that suit the patient's understanding does not always work. From a professional perspective it becomes very difficult to remain in the patient's perspective when writing care plans or relapse signatures. Interestingly though, patients choose to change the description of their mental health when a formal medicalised description is perceived to be beneficial, for example when completing benefit forms. Again Greg said,

They could have no insight whatsoever, but they are happy to put 'schizophrenia' on a DLA form because they almost separate it, they don't have to agree with it to get the money, they just want the money. So you can get someone who just wants to be discharged, 'there's

nothing wrong with me, I've never been ill in my life,' but they are more than happy to take part in the review of the DLA to get the higher rate. {FG2 p. 12}

4.4.4 Medication is a difficult issue.

In study 1 the participants spoke of their ambivalent and complex relationship with medication, saying that medication was "*poison*" or had ruined their life, but that medication had been an important mechanism by which they had reinforced their personal resilience and enabled them to reassert their personal identity. Similarly, the professionals in study 2 acknowledged that medication was a very difficult issue. The professionals recognised the ambivalence about medication, Dave in FG1 said, " *... medication is difficult but it is mainly down to the patient's insight into the need and what the outcome is from taking medication*" {p. 13}. The professionals also recognised that the patients had differing attitudes towards oral and depot medication. As Delores {FG1, p. 1} said, "*People blame the fact that they are involved with mental health services and the medication for the fact that they are ill. They say that's the reason they are ill.*" The professionals knew that their patients preferred oral medication and offered explanations. Part of the reason why patients prefer oral medication is that they gain more control over whether or not they take it. Simultaneously, this is also why the professionals advocate for depots, as opposed to oral medication. As Martha summarised, "*It is, unfortunately, if they were on a tablet, I would say, within a few days they wouldn't take it*" {FP1. p. 16}.

4.4.5 Drugs are part of everyday life for service users

As reflected in study 1, the use of cannabis was an important mechanism by which the participants reinforced their personal resilience and reasserted their personal identity. When this theme was put to the participants of the focus groups there was broad agreement and acceptance. The professionals acknowledged that they had to work alongside their patients' drug use and that it was very much part of the reality of the lives of the people on their caseload. For instance Pat said, "…*we have no control what cannabis they smoke or what they don't, regardless of what the research and information says. We can advise and educate and give information but we can't stop them smoking cannabis; that's a personal choice of theirs*" {FG1. p. 18}.

The professionals were willing to work with people who are using cannabis and did not necessarily see cannabis use as problematic. Both the focus groups said that they would neither encourage someone to smoke cannabis nor tell anyone that they had to stop. They fully recognised that they had to respond to each person's attitude to cannabis differently and respect their right to individual treatment. As Bernard said,

It's about understanding that some people can take humungous amounts of weed ... it does not really affect them too much mentally. It might make them lethargic and less gregarious but some people have just got good tolerance levels and other people haven't. And just because someone has got psychosis doesn't mean to say that they've got an intolerance to cannabis as well, which may be quite a useful thing to understand, because your approach has to be individual. {FG1, p. 19/20}

Similar to the study 1 participants, the professionals also took a different attitude towards crack than they did towards cannabis. Despite the strides taken to offer individualised care, the professionals were wary about the impact of crack on people's lives. Again it was Bernard who said, "*It attracts them down a route of crime and prostitution and needing money. The harsher comedown and the people they mix with may be a harder group of people than your friend around the corner who sells you a bit of weed. It drives you into the darker underbelly of the community*" {FG1, p. 21}.

4.4.6   Cultural aspect to the experience of disengagement

All the study 1 participants described their racial identity as black. The professionals were asked if there was something about being a black man that was distinctive when thinking about the experience of disengagement from mental health services, relative to other demographic groups. FG1 identified cultural aspects to the experience of disengagement: "*I think there is a level of pride as well with the young black men. They are proud, stubborn, independent, 'I can fend for myself, I'm keeping my own castle. Don't you come ringing at my door'*" {Pat FG1, p.30}. Dave paraphrased the attitudes of the black men on their caseload as, "'*I don't need you. Don't want you*'" {FG1, p. 31}. In FG1 the participants believed that this was a cultural aspect to the experience of disengagement from mental health services for black men, as opposed to a gender experience. This perception of the experience

of disengagement was illuminated by several of the professionals. Pat started by saying, " ... *But the cultural thing about pride, a bit of stubbornness, a bit of being king of the castle.*"

Victoria:	*The shame.*
Dave:	*The stigma.*
Victoria:	*The shame they hold.*
CW:	*From being involved in mental health services?*
General:	*Yes.*
Martha:	*They want to be accepted and respected in their community.*
Pat:	*It affects their street credibility.*
Delores:	*Absolutely.*
Pat:	*Peer credibility. And their peer groups hold such weight …*
Delores:	*Massive.*
Mr H.:	*The stigma of it, really. Being black and being on the mental health services.*

The stigma. The shame really." {FG1, p.31/32}

This proposed model of disengagement by black men from mental health services starts with the patients needing peer credibility and wanting to be accepted and respected in their local community. Their peer credibility is undermined by the stigma and shame of being involved with mental health services. This perception of the experience echoes the experience of some participants in study 1. Whilst Josh was clear that he could not leave the house and he could not "*associate*" because of the shame of having mental health services involved and receiving a depot, T had actively chosen to live his life separate from everyone apart from unspecified friends and a couple of family members. So whilst both these men were isolated and had few social contacts, their limited connection with their community and wider society were for different reasons. However, when this model was proposed to FG2 they did not recognise it. They were aware of the difficulties of engaging black men with mental health services. Their perception of the experience of disengagement from mental health services also had parallels with themes from study 1. Theme A in study 1 suggests that because the participants felt disenfranchised from social structures, mental health services become another strand of control to be avoided. Greg said,

… because they are already potentially feeling like they are getting the short end of the stick by other services ... that it is just another service that is telling them to do something they don't want to do. ... people who've had a harder time prior to coming to mental health services, who are going to be less willing to want to engage and regard it as just another service that they don't see any benefits in it for them. {FG2, p.2}

Further on, Pat highlighted,

… from their personal experience as children, teenagers growing up, their family, their life experiences, of a personal nature, or whether that is from previous experiences of other services. Not just health services, it can be police, probation, council, housing. All these people, how they get dealt with in life and how they confer, it can all have an impact then on how they are and how they engage or don't engage. {FG1, p. 10}

The two models are not necessarily incompatible, as Martha in FG1 said, "*We are another social control, aren't we?*" {p. 10}.

An interesting use of metaphor can be found in both study 1 and 2. When Clue was talking about why other people disengage from mental health services he said that people disengage from mental health services in an attempt to establish themselves as "*the king*", to publically demonstrate that they will not be brought down by mental health services. Then in study 2, Pat, when explaining the shame felt being the driving force behind disengagement from mental health said, "*... But the cultural thing about pride, a bit of stubbornness, a bit of being king of the castle*" {FG1, p. 31}.

Regardless of racial identity, the study 2 participants made suggestions about why service users found engagement with mental health services problematic, which gives a professional perspective on service users' experiences. Linking to other findings in this chapter (3.3.4.1.ii and 3.3.4.2.ii) the focus group participants suggested that service users did not understand their mental health in the same way as professionals. FG1 reported that some service users blamed both mental health services and medication for their poor mental health {FG1, p. 1}. A suggested reason why service users choose to disengage from mental health services was

that it was an effort to regain some of the control that has been lost by the intervention of services {FG1, p. 2}.

Through their actions and their words, the study 1 participants actively questioned the need for mental health services in their lives. The study 2 participants were well aware of this attitude amongst their patients.

4.4.7 Professionals' awareness of spirituality.

One of the strategies that the study 1 participants had developed to reinforce their personal resilience was through the solace they found in faith and spirituality. Similar to the use of cannabis, this was a theme with convergence amongst the participants. Accordingly this theme was raised in study 2. The participants in both focus groups were aware of the importance of spirituality to the people on their caseloads, though they did necessarily feel it was their role to work with patients from a spiritual perspective. The responses from the professionals were that they did not see actively working with people's spirituality as part of their job. An example being Martha who said, *"I don't actively do spiritual work with them"* {FG1, p. 23}. However, when the focus groups explored the ideas further a different perspective emerged. Four different narratives illustrate the point that collectively the professionals were aware of the importance of spirituality to their patients and that indirectly they did a lot of work to support their patients' spirituality.

In FG1, Bernard, Delores and Victoria, had all been involved in (or known of) exorcisms being performed on patients or on patients' houses whilst working for AOTs. The FG1 told of a patient under their care who was very physically unwell and they needed extra staff to help provide the care that the woman needed. The team specifically arranged for a member of locum staff, with whom the patient had a pre-existing relationship, to work for the team on a short-term basis. The foundation of that pre-existing relationship was that the two people had the same spiritual views. Both focus groups felt that it was part of their role and responsibility at the weekends to give their patients lifts to church if this was requested. The final narrative that illustrates the idea of professionals being aware of the importance of spirituality, without being directly involved, was from FG2. A patient on their caseload had been very mentally unwell for over a decade, in and out of hospital, regularly detained under

the Mental Health Act, was dangerously promiscuous, had no fixed abode and was not able to successfully live independently. Then her grandmother, who had always believed that her granddaughter was cursed, took her to the local spiritualist church and "*and from that day since she has improved*" {Ethel, FG1, p. 13}. The woman is now doing well, living independently and has stayed out of hospital for a considerable period of time. The professionals were clear that her improvement was not a consequence of medication or any therapeutic intervention but as a consequence of becoming involved with the church.

Two of the strategies that the study 1 participants had developed to reinforce their resilience and reassert a more positive identity were the use of (oral) medication and using cannabis. The responses of the focus groups demonstrate how dedicated the teams are in promoting the well-being of the patients. They will facilitate choice, will allow the patient to make choices that the team believe are bad for them and will try their very best not to interfere in the lifestyle choices that the people on their caseload make. Yet this facilitative attitude has to be played out against the background of managing high-risk people in the community. After consideration, the two focus groups' awareness of the spiritual needs of the people on their caseloads also reflects the focus groups actively wanting to support people on an individual level and promote their mental well-being.

4.4.8   Age does not make a difference?

The older study 1 participants acknowledged that over time and through experience they had changed and developed as people. This maturation process was one of the strategies by which they had reinforced their personal resilience and helped reassert their personal identity. They had developed in the context of being patients in the mental health system and this acknowledgement had helped them to live with their experiences of only having a limited connection to social structures. As with the other strategies developed by the study 1 participants, this concept was posed as a question in the focus groups. The focus groups did not wholly recognise this experience and as was pointed out in FG1 by Bernard, "*The person that we see most frequently on a long-term scale is in his 80s. ... And if we didn't see him, he could well be doing heinous things, I kid you not*" {p. 29}. What the focus groups did recognise in relation to the age of the people on their caseload was that the younger patients behaved in a way that was "*almost like a competition on who is the top dog on the ward. I*

feel like the older gentleman have been through it and 'Let them have their day'" {Susan, FG1, p. 28}. Interestingly, whilst the experience of people developing over time had been interpreted as a positive experience, FG1 did not necessarily see it as such. Martha {FG1, p. 28} commented that, "*It's an awful thought, but have we beaten them into submission?*" to which other members of the focus group agreed.

An incidental finding of study 2 was a genuine sense of the professionals wanting to do anything reasonable to help the patients they were responsible for. There was a powerful sense of wanting to deliver holistic care, with a deep sense of humanity (e.g. Pat, FG1, p. 11). The professionals wanted the "*best*" for their patients and were committed to the AOT model as a means to engage people with mental health services. Within that there was an understanding that different patients have different needs and that the service delivery needed to reflect this (e.g. Greg, FG2, "*also if you give them a different approach they might feel that there is a bit more in it for them than they thought, and it's not quite so draconian and they might be more willing to engage if they see there are extra benefits apart from just medication*".) Another feature of the two focus groups was that the teams in the focus groups were very bonded with each other. There was plenty of laughter, plenty of agreement, evidence of people taking time to listen to one another and they were able to finish each other's sentences (e.g. FG1, p. 31/32).

CHAPTER 5: DISCUSSION

Study 1 consisted of semi-structured interviews with individual patients who were under the care of AOTs, whereas study 2 consisted of focus groups with professionals who worked in the AOTs. The aim of the study was, "To examine the experiences of people who have a diagnosis of severe mental health problems and a history of disengagement from mental health services." Overall, interpretative analysis of the two components of the study reveal that disengagement from mental health services appears to be a complex phenomenon that needs to be understood within the context of a broader experience of having a limited connection with social structures. Nonetheless, the participants in study 1, supported by those in study 2, had developed strategies which appeared to reinforce their personal resilience and reassert their personal identity.

Some of the findings of the current study complement, and others contradict the current literature on disengagement from mental health services. This chapter discusses the findings from the two stages of the study. Implications for policy and service delivery in light of the findings of the study are also discussed.

5.1 What are the Experiences of People with a Diagnosis of Severe Mental Health Problems and a History of Disengagement from Mental Health Services?

Interpretative phenomenological analysis of the data suggested that the participants in study 1 did not experience disengagement from mental health services as a singular phenomenon. Rather, disengagement from mental health services was a component of the broader experience of having a limited connection with social structures. The notion of participants relating to mental health services as an extension of their relationship with wider society and as part of a broader experience of disengagement was acknowledged in study 2, "… *link us with authority and police still*" {Bernard, FG1, p. 30}. Therefore, it is proposed that, in order to truly understand the study 1 participants' experience of disengagement from mental health services, it needs to be discussed within the context of the participants having limited connections with social structures.

The study 1 themes of the desire for greater autonomy, fear of attack and the need to rebuild a more positive identity have been highlighted before. Padgett et al. (2006) examined the experiences of 13 formerly homeless mentally ill women. The findings of that study support the findings of this study: the participants in Padgett et al.'s (2006) study needed and wanted greater autonomy, protection from future victimisation and assistance in restoring their damaged identity and status to facilitate their on-going recovery.

Rogers and Pilgrim (2008) highlight two different frameworks for understanding on-going narratives in psychiatry, both of which are important to this study. Whilst Rogers and Pilgrim (2008) present the frameworks as separate, and opposing each other, this study proposes areas where the two frameworks overlap. The first framework proposed by Rogers and Pilgrim (2008) for understanding psychiatric traditions is a 'paternalistic and scientific' framework. This framework suggests that people who are mentally disordered are largely unaware of their needs, showing "a lack of insight" reflecting the current language of mental health services. Furthermore, the framework suggests there is a perception that the state has a duty and obligation to provide resources and facilities for highly trained professionals to deliver evidence-based interventions that will alleviate the suffering of mentally disordered individuals. The second framework proposed by Rogers and Pilgrim (2008) runs contrary to the former and is a more anti-paternalistic framework. Firstly, the framework highlights that the science behind evidence-based interventions is questionable (Bentall, 2003). The anti-paternalistic framework also proposes that the perceived benefits of these interventions are offset by the damage that involvement with mental health services causes; for example, stigma and the side effects of medication. This study touches on both these traditions and highlights some common ground between them. The study 1 participants had been diagnosed with a SMHP and did not understand their diagnosis or the role of mental health services. Furthermore, the study 2 participants felt it was their responsibility to engage their patients with mental health services and "*manage the risk*" the patients had. Yet simultaneously, both the study 1 and 2 participants were aware of the damage that involvement with mental health services can potentially have, for example, highlighting a model of disengagement based upon stigma.

5.1.1 Recruitment of participants

The demographics of the study 1 participants were similar to the demographics of people who had been highlighted in previous studies as more likely to disengage (O'Brien et al., 2009; Kreyenbuhl et al., 2009). As highlighted in those reviews, people from ethnic minority backgrounds are more likely to disengage from mental health services. But an interesting finding of this study was that, although recruitment initially sought to recruit a range of people from AOTs, those who did consent to participate were all men, who described their racial identity as 'black'. All the study 1 participants were identified as having a history of disengagement from mental health services and through interpretative analysis identified themselves as having limited connections to social structures. Yet, they engaged in the interview process and talked in depth to a white male researcher whom they barely knew. The factors that influenced this apparent contrasting style of engagement are of interest.

The participants were compensated for their time with a gift voucher which appears to have been a factor. The agreement was that the participants were given the voucher after the first research interview but most of the participants asked if they could be 'paid' again after the clarifying interview. Arthur, for example, said he would only participate in the post-interview meeting if he was 'paid'. Certainly, the use of vouchers could be construed as introducing bias into the study. The participants viewed themselves as being 'paid' and were therefore, perhaps, more willing to engage in the process. However, one of the research participants in the main research interview (when he received the voucher) was relatively scathing of mental health services. But in the clarifying interview (when he was not receiving any form of compensation) wanted to stress how much mental health services had helped him.

Another factor that may have influenced recruitment and participation was that the participants wanted to talk. One of the emergent sub-themes was that the participants felt that mental health services had consistently not listened to them. Potentially, the study offered a counterpoint to that, as the researcher wanted to hear their experiences. Most of the participants appeared to enjoy the experience of being allowed to talk to a researcher about the issues that were pertinent to them. For example, a participant, who dated his 30-year history of mental illness back to the death of his mother, claimed that he had never talked to a mental health professional about his loss and grief. Another potential reason why the

participants were willing to engage in the research was medication. It has been suggested that much contemporary psychiatric practice is based around medication (Moncrieff, 2009, p. 4), but the purpose of the research visit was to listen to the participants without an agenda of trying to persuade them to take medication.

It is unclear what impact, if any, the racial identity of the researcher had. As part of the interpretative process researchers need to be critically reflexive about issues within the research relationship (Glynn, 2012). The fact that the researcher was white was not raised as an issue by any of the participants or by any of the people who declined to participate. It remains unknown whether the participants would have given different responses to the researcher's questions had the researcher been black himself. The study 1 participants gave the impression of talking honestly and freely and the participants did not appear concerned about differences in racial identity. Furthermore, the participants barely mentioned the experience of racism and racist attitudes during the study. However, it may be due to a white researcher writing an interpretative account of the experiences of these black men, that the participants did not feel able to raise the experience of racism, or it is possible that the experience of racism was not part of the experience of disengagement for either the study 1 or 2 participants.

That the participants were recruited in study 1 suggests that if approached and involved in an appropriate way, engagement ceases to be an issue. A point that could be argued, though hard to prove, is that it is not the men who disengage from the system, rather the system does not engage them. The men wanted to discuss their mental health issues but at present they had not found the appropriate person to talk to. None of the men had a partner, they had fractured relationships with their families, most of the participants felt estranged from their community and society, and they felt hounded by mental health services that did not listen to them.

5.1.2   Limited connections to social structures

One of the themes of study 1 was that the (older) participants felt that they had lost choice about whether they engage with mental health services. The feeling of powerlessness expressed by the (older) study 1 participants, as reinforced by Chakraborty et al. (2011), has similarities with the hypothetical model proposed by Selten and Cantor-Graae (2005). Selten

and Cantor-Graae (2005) proposed that 'social defeat' could be a unifying factor which explains why a range of people, including those people from urban areas, both first and second generation migrants, people with a low IQ and people who frequently use illicit substances all have a greater predisposition to developing schizophrenia.

The first strand of Selten and Cantor-Graae's (2005) hypothesis was that both people who are first or second generation migrants (which accounts for six of the seven study 1 participants) and people who live in cities experience higher levels of social competition. Consequently, they are more likely to experience 'social defeat' (or an 'outsider status') and this may serve as a unifying mechanism for the other predisposing factors in the development of schizophrenia. Whilst not using the same term, both study 1 and 2 support a notion of 'social defeat' being an important factor in their experience of schizophrenia and the relationship with mental health services. Another strand of Selten and Cantor-Graae's (2005) hypothesis was that people who experience social defeat also have a higher propensity to use illicit substances. Whilst this study is not concerned with why people develop schizophrenia, it is worth noting that the study 1 participants had the predisposing factors of living in urban areas, being a first and second generation migrant and frequently using illicit substances which are contributing factors for developing a sense of social defeat in Selten and Cantor-Graae's (2005) model.

The original Selten and Cantor-Graae (2005) hypothesis was supported by Selten et al. (2013). That literature review concluded that social defeat was the common denominator of five of the major risk factors for psychosis – urban upbringing, migration, childhood trauma, low intelligence and drug use (see diagram below). In particular, migration and childhood trauma led to the development of chronic social defeat, playing a causal role in the development of psychosis. The diagram below demonstrates social defeat as the common denominator in the risk factors for psychosis (Selten & Cantor-Graae, 2005).
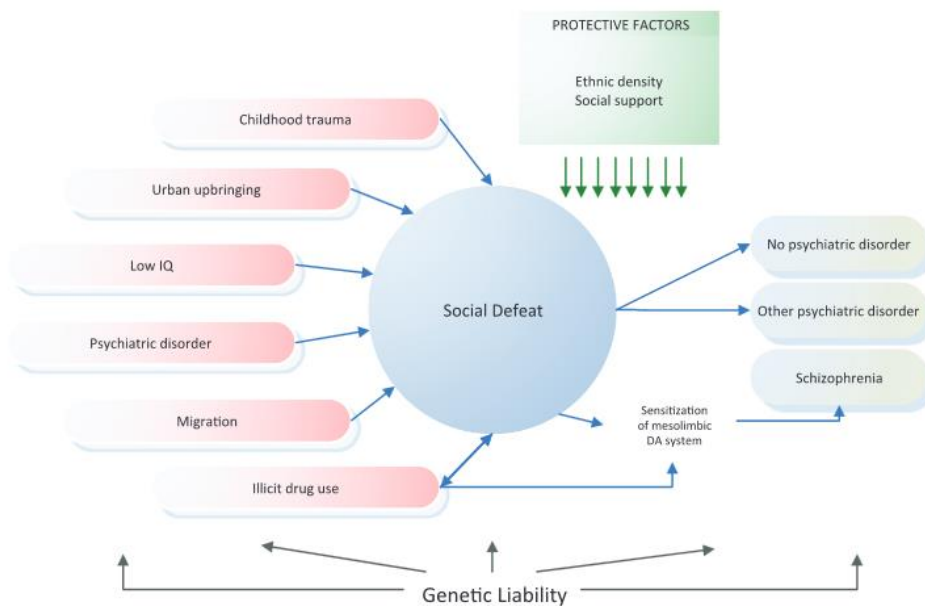
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Figure 4: Schematic Illustration of the Experience of Social defeat as the Common Mechanism Underlying Six Major Schizophrenia Risk Factors

'Ethnic density' in the above diagram refers to the ethnic density hypothesis, described in a review by Shaw et al. (2012). The hypothesis stated that people from ethnic minority backgrounds have better mental health outcomes when they live in areas where there is a higher density of people from the same ethnic background. The Shaw et al. (2012) literature review concluded that whilst this hypothesis probably holds true for people with psychosis, the results are tentative for other mental disorders. The study 1 participants described their racial identity as 'black' and about 10% of the population of the city where the study took place described their racial identity as Black/African/Caribbean/Black British and as such it is the third largest ethnic group in the city (www.statistics.gov.uk, accessed, 19/8/13). Shaw et al. (2012) do not comment about what constitutes a sufficient ethnic density to serve as protective factor.

As highlighted previously the study 1 participants experienced some of the predisposing factors (e.g. childhood trauma, urban upbringing, migration and illicit drug use) before being diagnosed with SMHP and coming into contact with mental health services. Also, the study 1 participants all described their racial identity as 'black' and a finding of study 1 was that the

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participants had limited social support, thus the participants may not have the protective factors proposed by Selten et al. (2013). This study, combined with Selten et al.'s (2013), suggest that the experience of social defeat (and subsequent development of psychosis) is intertwined with experiencing limited connections to social structures.

5.1.3 Relationship with mental health services

Study 1 participants had an ambivalent relationship with mental health services, as a component of wider limited connections with social structures. It may be that the length of time the study 1 participants had been involved with mental health services contributed to the complexity of the relationship they had with services. It was a relationship that dated back to the late 1970s in some cases. The main perception was of a negative relationship with services. The negative themes in the participants' relationship with mental health services were the feelings of being "*hounded*" and the desire to be left alone, the use of medication and the perceived lack of choice. But these comments were counterbalanced by positive comments which serve to highlight that the participants had a complex and ambivalent relationship with services. The positive themes within the ambivalent relationship were that there was a perception that mental health services helped people, with particular reference to housing and medication.

In the context of an ambivalent relationship, there was a prevalent sentiment amongst the study 1 participants that they were harassed by mental health services. Priebe et al. (2005) also noted this ambivalent relationship with assertive teams; despite a history of disengagement, not all their participants resented mental health services. One participant encapsulated this sentiment, expressing a need for the AOT to help whilst also saying that the AOT had previously been "*hounding me*" {Bubbles, p. 14}. Claassen and Priebe (2006) questioned whether the persistent nature of AOT services was in fact detrimental to patients, by negatively impacting upon their autonomy. However, Claassen and Priebe (2006) concluded that since satisfaction surveys amongst AOT patients was higher than standard care it was hard to say that AOTs negatively impacted on their patients' autonomy. The finding of an ambivalent relationship with mental health services in study 1 is supported by Wright et al. (2011) in their study into how staff from AOTs engaged with their patients. The persistent nature of the contact from the AOTs highlighted in Wright et al. (2011) was also construed

negatively in study 1. The participants in Wright et al. (2011) highlighted that they value the practical support that AOTs offer, as in this study. The study 1 participants expressed ambivalence in their relationship with AOTs, a finding reflected in both Wright et al. (2011) and Davies et al. (2014): contact was seen as useful but also as intrusive and as harassment.

The study 1 participants' complex and ambivalent relationship with mental health services is reflected in study 2's findings in section 4.4.2,, 'the dichotomy of assertive outreach teams' roles'. AOTs both foster and nurture engagement on a very personal level with service users whilst simultaneously being aware that there is an equally important role to protect individuals and the public from some very risky behaviours. In study 2 there was uncertainty across the two focus groups as to whether their primary role was risk management or active engagement with service users.

McAdam and Wright (2005) support this finding noting that each individual nurse on AOTs has to balance both engaging a chaotic client group whilst simultaneously managing high levels of risk to ensure the safety of both patients and the public. Lerbaek et al. (accepted for publication) was a focus group study of AOT case managers in Denmark. The aim of the study was to investigate the moral decision making their participants made in their day-to-day working lives. Lerbaek et al. (accepted for publication) concluded that the participants in their study made a conscious moral decision to override their service users' autonomy in order to achieve pragmatic professional related goals. As noted above in Claassen and Priebe's (2006) reflection on the ethical dilemmas facing AOTs, one of the main ethical issues was whether they detrimentally impacted upon a patient's autonomy. Both Claassen and Priebe (2006) and Spindel and Nugent (2000) suggested that the AOT model fails to empower people who are, by definition, stigmatised and marginalised in society. Additionally, Spindel and Nugent (2000) also reported that the power imbalance between the professionals and the service users in AOTs further stigmatises the service user.

However, Killaspy et al.'s (2009a) mixed methods study investigated staff and patient satisfaction with AOT services. A finding of this study was that professionals working in AOTs saw engagement as their primary aim. Fardella (2008) published an ethics paper examining the relationship between the 'recovery' model and the re-establishment of identity

for people with SMHP. In part, Fardella (2008) sought to resolve the tension between the imposition of services upon patients, who perceive the imposition as an affront to their identity, and the ability to become a self-determining agent. The resolution proposed by Fardella (2008) was that professionals should embrace the current 'recovery' philosophy in mental health services and adopt a critically reflective stance towards recovery which emphasises the importance of the individual and promotes recovery in a non-coercive manner.

In light of the literature questioning the future role of AOTs in the UK, the focus group participants argued that the AOT model remains viable. The participants believed that whilst their teams do not necessarily impact upon bed days or quantifiable rates of recovery, they are able to successfully manage risk, contrary to what Commander et al. (2005) suggested.

The findings of both Keating and Robertson (2004) and this study suggest that there are on-going difficulties in the relationship between black communities and mental health services. Similar to Theme A of study 1, 'limited connections with social structures', the findings of Keating and Robertson (2004) suggest that involvement with mental health services for black service users was similar to their experiences in society; they found the involvement to be alienating and degrading. As a consequence, becoming involved with mental health services was considered to be a last resort. Furthermore, the findings also suggest that the black service users who had previously experienced oppressive and controlling regimes in other aspects of their lives found that mental health services mirrored this experience (Keating and Robertson, 2004).

Previous studies (e.g. Fung et al., 2006) have highlighted that people of African-Caribbean descent in the UK are disadvantaged within wider society and there is a perception within both this study and Keating and Robertson (2004) that mental health services are another institution from which respective participants feel a sense of alienation. However, there are also differences between this study and Keating and Robertson's (2004). Whereas Keating and Robertson (2004) report that black people often fear and mistrust mental health services, that experience does not necessarily tally with this study. The study 1 participants felt harassed and misunderstood by mental health services and were angry at particular aspects of treatment, for example depot medication, but were only fearful of services in so much as they

were fearful of being detained under the Mental Health Act again. Further, Keating and Robertson (2004) also report that people in the black community do not believe that mainstream mental health services can offer positive help, so therefore delay in seeking help.

5.1.4 Medication and the relationship with mental health services

A finding of study 1 was that the participants were clear in their dislike of depot medication. Indeed, depot medication was described as symbolic of the "*violence*" (Clue, p.40) of mental health services towards them. Variously, the study 1 participants reported that all mental health services offer is medication and that medication "*freaks you out*". However, as with other issues related to their care, the study 1 participants either did not understand the purpose of medication or appreciate its role from the professional's perspective. Also, the study 1 participants experienced a lack of control regarding the prescription and ingestion of medication. Yet, simultaneously some study 1 participants viewed prescribed medication as a strategy that reinforced their resilience and develop a more positive identity (see section 5.1.5). The study 2 participants knew that their service users preferred oral medication, but were suspicious of their motives. Whilst oral medication may return personal choice to the respective service users, the professionals believed that the reason patients prefer oral medication is that they can choose not to take the medication, possibly soon after starting.

The difficult relationship that exists between people with SMHP, regardless of racial identity or history of disengagement, and medication is well documented in the literature. The study 1 participants felt that they had little choice but to take medication regardless of their wishes. A finding of Davies et al. (2014) was that the participants appeared to resent the emphasis mental health services put on medication in their treatment. Pierre (2000), Bowl (2007) and Chadwick et al. (2009) all report that people of African-Caribbean descent are more likely to be overmedicated relative to other ethnic groups and also that black people were not being given enough information about the medications prescribed to them. Furthermore, the Mental Health Act Commission (2006) and *Count me in* (Healthcare Commission, 2005) highlighted that people from black and ethnic minority groups were more likely to be given higher levels of medication. Additionally, both the Mental Health Act Commission (2006) and the DoH (2005) reported that relative to other ethnic groups, people of African-Caribbean descent had less access to talking therapies. A finding of Secker and Harding (2002) was that service

users of African-Caribbean descent found the experience of losing control of their medication to be the most distressing feature of their contact with mental health services. Fernando (2003) questioned whether racism was a factor in why black people appear to be overmedicated. In acknowledgement of these on-going concerns in the priorities for mental health care provision, *Closing the Gap* (DoH, 2014a) emphasised that ensuring more people from BME communities accessed talking therapies was a priority for improving care. These disparities and the findings of this study appear to demonstrate there is a continuing perception that the use of medication is the first choice treatment option for service users of African-Caribbean descent, which is viewed as more punitive and more restrictive.

That mental health services are sometimes being experienced as coercive, has been documented. Stanhope (2009) investigated how both the relationship between service users and clinicians and coercion impacted on the quality of service contact for homeless people with severe mental illness with assertive community teams. The results of the study suggested that for the service users, both a strong relationship with clinicians and the feeling of not being coerced were important in having a positive experience of services. Burns et al. (2011) investigated the rates of non-statutory pressures, or leverage, exerted on distinct clinical mental health populations in the UK. UK service users were statistically more likely to experience leverage than their US counterparts, according to Burns et al. (2011). Furthermore, that study also reported that housing was the most common form of leverage used, which is significant in relation to this study in light of both study 1 and 2 identifying that the organisation of accommodation was an important role that AOTs performed for their service users. Yeeles et al. (2011) reported that in their sample group, 35% of AOT patients had experienced staff using 'leverage' as a means for staff to achieve their objectives (see also Williamson, 2002; Keating & Robertson, 2004; Claassen & Priebe, 2006; Chakraborty et al., 2011 and Morrison et al., 2012).

5.1.5 Models of disengagement

The study 1 participants did not say that their mental health was affected by their limited connections to social structures but on an interpretative level, the participants were saying that having a psychiatric diagnosis and being involved with mental health services limited their social connections. This understanding contributed to both their desire to disengage from

mental health services and also to their pervasive sense of sorrow. There is literature (e.g. Biddle et al., 2007; Chakraborty et al., 2011) that seeks to explain the phenomenon of disengagement from mental health services and, within that, models that seek to explain how and why men of African-Caribbean descent disengage.

A component of the complex relationship that the study 1 participants have with mental health services is that over time they have learnt to feel as if they have very little control over the care they receive. The participants in Chakraborty et al. (2011) also perceived themselves as powerless. However, over time Chakraborty et al. (2011) state that this powerlessness and resignation has a paradoxical effect; the person no longer sees a purpose in actively rejecting the mental health system and therefore reluctantly agrees to the demands of the mental health services. Consequently, the person develops greater adherence to treatment regimes which leads to better quantitative outcomes.

The rejection of mental health services suggested in Chakraborty et al. (2011) is exemplified by the younger study 1 participants actively disengaging from services, rejecting medication and being frequently admitted to hospital. The younger two study 1 participants were in hospital more frequently than the other five. Before he became subject to a CTO, T was spending at least three months a year detained in hospital and Black Zee was in a continual cycle of being detained in hospital, being released, refusing to take the medication as prescribed and then soon being re-detained in hospital. In contrast, the five older study 1 participants had all remained out of hospital for at least five years. They may have not understood their diagnosis, they may not have agreed with taking the medication that was prescribed for them and they may have felt hounded by mental health services but they had greater stability in their lives. Three of the study 1 participants had been homeless at some stage in their lives but all now had stable accommodation. Most of the older five study 1 participants had been in prison but none had been in prison for at least five years and there was not the same palpable sense of anger and frustration as there was when interviewing the younger participants. When the age, experience and maturation theme from study 1 was raised in the focus groups one participant responded, "*It's an awful thought, but have we beaten them into submission*?" (Martha, FG1, p. 30). However, this change in attitude was not wholly recognised by the participants in study 2, which will be discussed later.

Biddle et al.'s (2007) Cycle of Avoidance (COA) is another model which partially supports the current study. The study 1 participants did not necessarily reject their diagnosis of mental illness and also they gave multiple indications about why they were perceived as disengaged. Biddle et al. (2007) developed the model to examine the behaviour of people who were unlikely to seek help from mental health services when in mental distress. Whilst the model was specifically designed to examine the experience of young people, Biddle et al. (2007) emphasised that the model had currency with other age groups. Whilst Biddle et al. (2007) discussed the experiences of people who were anticipating discrimination as a consequence of diagnosis, the study 1 participants had the lived experience of disengaging from mental health services over a number of years. Biddle et al.'s study (2007) supports the findings of both study 1 and 2, highlighting that the consequences of having contact with mental health services, or indeed having help enforced, both generates stigma and causes changes in identity. The COA model describes participants as struggling with the process of defining their distress as either 'normal' or 'real' with the threshold between the two constantly shifting. As the participants' symptoms worsened, the threshold for 'real' distress was moved further back so that significant symptoms such as 'suicidal behaviour', 'hearing voices' and having a 'nervous breakdown' were in the normal category. As an example, a study 1 participant spoke of his perception that his experience of voice hearing and "*signals*" were normal parts of his life. Both Biddle et al. (2007) and this study highlight that people have their own idiosyncratic understanding of their mental distress and reasons about when and why they choose to engage with mental health services.

5.1.5.1 Disengagement and stigmatisation

One of the reasons why the study 1 participants had a complex relationship with mental health services was because they recognised that involvement with mental health services carried social stigma, which negatively impacted upon them (see Clue and Josh as examples). When discussing their experience of limited connections to social structures, the study 1 participants described the stigma of mental illness and the stigma of involvement in mental health services as contributing to their isolation in society.

Most of the study 1 participants felt a sense of loss and sorrow because of their involvement with mental health services and believed that this involvement had negatively impacted on their relationship with their local community. Although they did not talk about the issues they faced in life using the same terminology as the professionals in study 2, they nonetheless expressed awareness and anxiety about the impact their involvement with mental health services had on their role and identity in society. Part of the complexity of involvement with mental health services was the study 1 participants felt unable to associate with people in the community as they would wish. There was awareness amongst the study 1 participants that people in the broader community had little understanding of mental health issues and because mental illness was not visible it was not always recognised. This understanding further contributes to the sense of isolation from the local community and is another example of how involvement with mental health services impacts upon the relationship the study 1 participants had with their families and communities.

Previous literature has suggested that people with SMHP are aware of the public stigma that surrounds mental illness, and may in time come to agree with that stigma and believe that those public stereotypes apply to them (Knight et al., 2003). This awareness of public stereotypes and stigma may start to erode the person's identity, self-esteem and their ability to efficiently manage their illness (Fung et al., 2008). The relationship between the erosion of the person's original identity, self-esteem and their ability to efficiently manage their illness then becomes a barrier to the person's on-going recovery (Hasson-Ohayon et al., 2013). As discussed in the findings, some of the study 1 participants attribute illness, misfortune and negative social dynamics to themselves, perpetuating a pattern of negative self-identity (Fung et al., 2008). Whilst these negative thought patterns could be interpreted as a symptom of SMHP, they could also be interpreted as expressions of learned helplessness and social defeat. In relation to this study, the participants in study 1 and 2 were aware of the negative stereotypes that are attributed to people with mental illness. The awareness and sense of shame are important factors in on-going disengagement for the participants and other service users (Cooper et al., 2003; Fung et al., 2008).

Supporting the findings of this study and strengthening the suggested link between disengagement and perceived stigma, Howerton et al. (2007) examined the reasons why male

offenders with mental distress did not seek help. The majority of offenders would not seek help for their mental distress and one of the reasons for this was the fear that they would be given a formal mental illness diagnosis and the men feared the stigma that was associated with such a diagnosis. Furthermore, Howerton et al. (2007) suggest that their participants viewed healthcare professionals as authority figures who were not to be trusted and would not listen to them, similar to the findings of this study. The study by Prior et al. (2003) sought to investigate whether societal stigma of involvement with mental health services stopped people from accessing help. The conclusions of the study were that it did not. The reason for people experiencing mental distress not disclosing this to mental health services was that people have different ideas about the role of mental health professionals. As a consequence, Prior et al. (2003) proposed that non-disclosure of mental distress to professionals may be more related to alternative understandings of the role of mental health professionals as opposed to the stigma attached to services.

Using an IPA methodology, Knight et al. (2003) investigated how people diagnosed with schizophrenia felt their social contacts were altered and how they were viewed by society as a consequence of that diagnosis. The findings of that study suggest there are social ramifications as a consequence of being diagnosed with schizophrenia, both on a personal level and in relationships with others. Findings of both this study and Knight et al. (2003) suggested that people with SMHP experience discrimination from wider society, mental health services and, in some cases, from their family. Furthermore, both this study and Knight et al. (2003) propose that perceived discrimination and lack of acceptance by their families, and 'social cliques', can lead to the lowering of people's self-esteem.

Corrigan et al.'s (2009) notion of 'why try?' is salient when discussing the experience of stigma amongst the study 1 participants. As previously discussed, the findings of study 1 indicate that the participants were aware of the stigmatising attitudes towards them. They felt powerless in their relationship with mental health services and the participants in study 2 also saw their service users' responses to stigma as important in the experience of disengagement for their patients. Corrigan et al.'s study (2009) reported that as a consequence of internalising the stigma generated by public stereotypes about mental illness, patients lose the empowerment to pursue their life goals, hence adopt a 'why try?' attitude. As outlined in the

findings, some study 1 participants had stopped resisting mental health services and this could be interpreted as learned helplessness.

5.1.5.2 Disengagement and racial identity

The first four participants recruited to the study were men, all of whom used the term 'black' to describe their racial identity. Consequently, a decision was taken to only recruit 'black' male participants. The term 'black' refers to people of African descent and origin, communities that may also be referred to as African-Caribbean or BME communities.

Aspinall (2002) claimed that the use of the term 'black' had a precise meaning when the term was used by individuals as a 'self-identifier'. However, the term becomes 'imprecise' when it is used as a collective term to describe groups of people. In Britain, for research purposes, the term 'black' is often used to refer to people from African-Caribbean descent, see Keating and Robertson (2004), for example. Agyemang et al. (2005) calls for the term 'black' to be phased out (except when studying racism) and replaced by "African" with an appropriate suffix, for example "African Caribbean" or "African British". Such practice would help to differentiate between diverse ethnic populations (Agyemang et al., 2005). According to Maylor (2009) using the term 'black' is contentious because of the ethnic diversity within the African-Caribbean population (Maylor, 2009) or even offensive and inaccurate (Agyemang et al., 2005). Maylor (2009) continued the debate about using the term 'black' as a research term, highlighting that the word carries both political and historical connotations. Maylor (2009) concluded that the term 'black' remains problematic.

Studies have highlighted the challenges faced by ethnic minority communities when engaging with mental health services (e.g. Robinson, Keating & Robertson, 2011) and at policy level (DoH, 2014a). Fung et al. (2006) and Fearon et al. (2006) both highlighted that people of African-Caribbean descent are the most over represented ethnic group within UK mental health services and also overrepresented on the caseloads of AOTs (SCMH, 1998; Priebe et al., 2003; Keating, 2007). Additionally, there are a disproportionate number of people from BME groups who are subject to CTOs (CQC, 2010). The National Mental Health Development Unit (2011) highlighted that people from BME backgrounds were more likely to have a negative experience of NHS mental health services. Morgan et al. (2004), the

Mental Health Act Commission (2006) and Rabiee and Smith (2007) all report on the dissatisfaction experienced by people of African-Caribbean descent in the UK with mental health services. Additionally, people of African-Caribbean descent in the UK also report a worse experience of services relative to other ethnic groups (Fearon et al., 2006; Fung et al., 2006; NICE, 2010). Boydell et al. (2010) report that the research into the experiences of mental health services from the perspective of black service users is limited.

Bowl (2007) used thematic analysis of focus groups and individual interviews with South Asian and African-Caribbean mental health service users. The study examined whether the *Delivering Race Equality* initiative was likely to improve mental health services for black service users. Two of the findings of Bowl (2007) support the findings of this study. Firstly, Bowl (2007) suggested that "economic exclusion" has a considerable impact on the mental health of service users of African-Caribbean descent. Secondly, Bowl (2007) also found that only a few participants reported experiencing racial insensitivity. However, there were only 12 participants in Bowl's study (2007) so it may be hard to generalise the results. Bowl (2007) concluded that without thorough consultation with service users of African-Caribbean descent, it is unlikely that services would improve. Pierre (2000), Secker and Harding (2002) and Karlsen et al. (2005) all suggest that after allowing for gender, age and socioeconomic factors, the participants in their studies experienced overt and implicit racism during their contact with mental health services. Both Littlewood (1997) and Mclean et al. (2003) suggest that, because of the anticipation of racist treatment by healthcare professionals, people of African-Caribbean descent have been deterred from accessing mental health services. Consequently, when people of African-Caribbean descent do access services it is more likely that it will be at a time of crisis and will lead to more restrictive and custodial care (Mclean et al., 2003). With reference to the David 'Rocky' Bennett inquiry, Jones et al. (2010) suggest that some service users are verbally insulted because of their ethnic background. Keating et al. (2002) reported that stereotypical views, racism, cultural ignorance, stigma and anxiety associated with mental illness often combine to have a negative influence on how mental health services assess and respond to the needs of people of African-Caribbean descent. Chakraborty et al. (2011) report that some people of African-Caribbean descent have developed a mistrusting attitude towards mental health professionals and there are consistent findings that people of African-Caribbean descent perceive themselves as being treated in a

racist manner by mental health professionals. It is noteworthy that in Selten and Cantor-Graae's (2005) model it is perceived that discrimination contributes to a person's sense of social defeat whereas Janssen et al. (2003) perceives racism as a precursor to psychosis.

The study 2 participants appeared to be aware of unique dynamics affecting the relationship between the black community and mental health services. The participants in FG1 were cognisant of the unique social dynamics within the community that they worked with. Accordingly, they proposed a model of disengagement for black male patients who are proud to be independent and are deeply affected by the social shame they feel by having mental health services involved in their lives. The shame felt as a consequence of this perceived stigma from the involvement of mental health services becomes a driving force behind continued disengagement.

A finding of Keating and Robertson (2004) that the stigma associated with mental illness within the black community has a great impact on the working relationship between services and individuals is one of the driving forces behind continued disengagement, supporting the model suggested by focus group 1. Both Biddle et al. (2007) and Davies et al. (2014) expressed similar ideas to this, that people (regardless of ethnic background) will reject or avoid mental health services because of the stigma and changes to identity that are associated with being involved with mental health services. Another finding of Keating and Robertson (2004) was that professionals are often wary of the black community, fearing criticism, not knowing how to respond, and are fearful of young black men. Analysis of the focus group texts did not show any fear or wariness of the black community.

Whilst there are different social contexts, the findings of Arthur et al. (2010) lend support to findings of high levels of stigma towards people with SMHP. Arthur et al. (2010) was a qualitative study based on focus groups examining attitudes towards people with mental illness in Jamaica (three of the study 1 participants were born in the Caribbean and the parents of a fourth came to England shortly before he was born). The findings of the study were that there are high levels of stigma towards people who were mentally ill in Jamaica, characterised by fear and specifically the fear of danger. As a consequence of this perceived threat, the

participants in Arthur et al.'s (2010) study said they avoided people who were mentally ill and also described discrimination, abuse and exploitation of people who were mentally ill.

5.1.5.3 Perception of disengagement

Interpretative analysis of the data is suggestive that the study 1 participants did not perceive themselves as disengaged from mental health services. All the study 1 participants had been described by professionals as having a history of disengagement from mental health services. The participants did not recognise this description of themselves. Whilst one of the younger study 1 participants was excited to be described as disengaged, the participants denied that they had ever disengaged from services. The study 1 participants (supported by the professionals in study 2) appeared to prioritise certain functions provided by mental health services. From the perspective of the study 1 participants, if they appeared to reject some aspects of services that did not mean that they were 'disengaged'.

These findings are supported by Davies et al. (2014) and Farrelly and Lester (2014). Farrelly and Lester (2014) was a critical interpretive synthesis of the literature. The paper discussed the impact of therapeutic relationships between clinicians and people with a psychosis. They concluded that therapeutic relationships break down when there is a perceived difference in priority between the clinician and the patient. Davies et al. (2014) concluded that whilst it is hard to sustain engagement with some people, it does not necessarily mean they want to disengage, rather that they have different priorities from mental health services. Furthermore, in a similar vein to this study, Davies et al. (2014) also suggested that services should reconsider what they mean by 'hard to engage' and 'disengage'.

5.1.6 Identity

Interpretative analysis of study 1 demonstrates that, as a consequence of their limited connections to social structures, the study 1 participants largely held a negative view of themselves, which applied to different aspects of their life. The participants in study 1 felt their association with mental health services had a detrimental effect on their identity. The impact of this negative identity would appear to affect the study 1 participants' relationship with wider society, their position in the local community, within their families, in their relationship with mental health services and the judiciary, and, for some of the participants, in

relation to their racial identity. However, Theme B of the findings of this study suggests that the study 1 participants had developed strategies to assert a more positive identity.

The phenomenon of wanting to be independent and wanting to help yourself was evident amongst the study 1 participants and lies in parallel with other themes: the sense of disempowerment and learned helplessness. After years of experience, the older participants had developed a belief that they could not stop mental health services from being involved in their life nor were they able to stop mental health services from giving them medication that they did not want. In this context the participants were striving to help themselves and attempting to assert their identity and their independence. The participants showed a desire to actively try to help them, reassert their identity and reinforce their resilience. Or to phrase that differently, participants believed that if they were to be more than a passive recipient of care, then they had to help themselves (Watts & Priebe, 2002).

The negative identity associated with mental health is another way the COA model (Biddle et al., 2007) supports this study. In the COA model one of the greatest inhibitors for staying involved with mental health services was that the social consequences of being perceived as having long-term, irreversible, 'real' distress was that the participants would experience a change of identity (both public and private). For the participants in the Biddle et al. (2007) study, having a mental health identity meant having a record of treatment that stayed with them and as a consequence they believed this would invariably lead to them becoming victims of the stigma of mental illness. Furthermore, just as the study 1 participants developed strategies to reassert their personal identity and to reinforce their personal resilience to compensate for their limited connections within social structures, the COA model participants developed a range of coping skills to avoid crossing the threshold into 'real distress'.

Kessler et al. (2001) reported that the most common reason for people with SMHP both failing to seek treatment and dropping out of treatment was that they wanted to solve their problems themselves. The experience of AOT patients feeling powerless to influence decisions about treatment, whilst still believing that they should help themselves was a theme of Priebe et al. (2005). Priebe et al. (2005) highlighted that "lack of active participation and poor therapeutic relationships" and "loss of control due to medication and its effects" are

important components of the experience of disengagement. These two themes contribute to a sense of losing personal agency as a result of being involved with mental health services (Priebe et al., 2005). Priebe et al. (2005) and Chase et al. (2010) highlighted that understanding a person's need to have both individual agency and identity were crucial in understanding the experience of disengagement and re-engagement. Herein lies a correlation between study 1 and 2. The study 1 participants appeared to experience multiple threats to their identity through their involvement with mental health services and their lack of choice. Simultaneously, the professionals were attempting to address these concerns by trying to provide highly individualised care.

5.1.7 Belonging to and exclusion from community and society

The findings of study 1 suggest a consequence of having limited connections to social structures is that participants experience both 'belonging' and 'exclusion' within society. Whilst none of the study 1 participants believed themselves to be part of wider society, the participants' relationship with their local communities was not wholly negative – some of the participants felt that they were part of their community.

The study 1 participants all lived in the inner city; were all chronically unemployed, with no realistic opportunity of employment; all had very limited social networks; all frequently moved home; and all felt limited connection to social structures. The five older study 1 participants had left school with no qualifications, one younger participant had achieved a BTec in sound engineering and the other had started university before dropping out. Also, another finding of study 1 was that the participants appeared to have had fractured relations with their families. Throughout the interviews the participants in study 1 talked about their struggles to feel part of a wider society. The study 2 participants were aware of this dynamic, highlighting both the over-representation of black men in mental health services and also that an awareness of the stigma of involvement with mental health services could be a driving force behind continued disengagement.

These are similar social characteristics to the ones described in the O'Brien et al. (2009) review of people who were more likely to disengage from mental health services – people living in the inner city, unemployed, with poor social networks and low educational

achievement. Similar to the study 1 participants, the literature highlights that BME communities in the UK have experienced a long history of inequality and disadvantage. According to Keating et al. (2002), the history of inequality and disadvantage would appear to be a result of racism and discrimination and this experience of inequality and disadvantage applies to many different aspects of people's lives, education, housing and employment, as examples. Keating and Robertson (2004) concluded that, "Black communities also face challenges in responding to those with MH [mental health] problems. There is a pressing need to tackle stigma and to disseminate greater knowledge about MH problems. Education and information can help to ... reduce the fears and stigma associated with mental illness." (p. 446).

Fung et al. (2006) stated that reduced participation and isolation within society may be a potential reason for the higher levels of schizophrenia in people of African-Caribbean descent in the UK and are a reflection of the multiple risk factors which are evident in the African-Caribbean community. Hargraves, Cunningham and Hughes (2001) attributed the health disparities experienced by different ethnic groups' experience to both low socioeconomic status and to reduced access to healthcare, which are often experienced by people from ethnic minority groups (see also Karlsen & Nazroo, 2002). Karlsen and Nazroo (2002) used regression analysis on census data to explore the impact of racism and social class on the health of the ethnic minority populations in England and Wales. They concluded that despite the different ways in which racism manifests itself (e.g. interpersonal violence, institutional discrimination and socioeconomic disadvantage) all forms of racism have detrimental effects on people's health. Mclean et al. (2003) focused on social exclusion and highlighted that one of the greatest barriers to improving mental health and accessing mental health services for people of African-Caribbean descent was the on-going financial and socially disadvantaged situation in which many in the African-Caribbean community found themselves. Further, Hickling (2005) questioned whether social alienation, racism or misdiagnosis can explain the increased rates of diagnosis.

Rogers and Pilgrim (2014) sought to explain why there was the elevated rate of diagnosis of schizophrenia in the African-Caribbean community in the UK. The conclusion of Rogers and Pilgrim (2014) was that neither genetic explanations, misdiagnosis nor faults in psychiatric

theory and practice could adequately explain the disparities. Rogers and Pilgrim (2014) suggested that factors such as long-standing external pressure (housing, education and wealth) combined with perceived institutional and personalised racism contribute to the experience of mental health services and possibly poorer mental health outcomes. Wong et al. (2014) examined the experience of social inclusion for people recovering from SMHP. They suggested that people with SMHP were capable of being included in society and experiencing a sense of inter-connectedness. Most of the participants in Wong et al.'s study believed that through proactive engagement, meaningful relationships were an achievable goal in their recovery.

5.1.7.1 Fear of assault

Further to the study 1 participants' experience of belonging and exclusion in community and society, there was an underlying fear of assault or "*being got*". Individually, the study 1 participants had experienced this threat and the fear of assault was very real for them. This interpretative finding, whether as a consequence of mental illness, racial identity or both, is supported by the literature.

The findings of Karlsen et al. (2005) suggest British society is inherently racist and in that context the experience of both verbal abuse and physical assault are associated with the prevalence of mental illness and a risk of developing psychosis. Williams et al. (2009) used a focus group format to investigate the experiences of African-Caribbean fathers, coincidentally recruited from the same geographic area as some of the study 1 participants. Williams et al. (2009) report on a "hard social world"; African-Caribbean fatherhood took place in communities that participants characterised as a "hard" social world. The experience of a "hard" social world echoes themes from both stages of the study.

An Australian study by Chapple et al. (2004) used logical regression to examine the rates of victimisation amongst people with psychosis. The study found that one in every six people with a psychosis will be a victim of violence in a 12-month period. Furthermore, Hiday et al. (1999) collected their data via extensive individual interviews with people who were recently discharged psychiatric inpatients. Hiday et al. (1999) found that the rate of criminal victimisation was 2.5 times higher amongst people with SMHP relative to the general

population. Kamperman et al. (2014) was a multi-site Dutch study looking at the rates of victimisation of severely mentally ill people across the Netherlands. Of the respondents in that study, 47% reported that they had been victims of crime in the previous 12 months, which is 14 times higher than the general population.

A US study, Teplin et al. (2006), set out to test the hypothesis that, since the closure of large psychiatric institutions with the majority of mental health care being delivered in the community, people with SMHP were more likely to be victims of crime. The rates of crime victimisation for the SMHP population were compared to the general population as recorded on the National Crime Victimization Survey. More than a quarter of the SMHP people surveyed had been victims of violent crime in the previous 12 months, a rate that was 11 times greater than the general population. Similar figures were reported in a British study (Walsh et al., 2003); 691 people with an established diagnosis of a psychotic disorder were interviewed regarding violent victimisation in the previous 12 months and these figures were compared against the general population figures. The figures were slightly less than the US figures of Teplin et al. (2006), but 16% had been violently victimised in the previous 12 months.

The two study 1 participants who were the most concerned about the physical dangers had a history of substance abuse and homelessness, had poor social and organisational skills, had a dishevelled appearance at the time of the interviews and both expressed odd ideas in the interviews which could be interpreted as formal thought disorder. Hiday et al. (1999) highlighted that positive symptoms such as talking to oneself and formal thought disorder, as well as having a dishevelled appearance, increased the chances of becoming the victim of violence. The results of Walsh et al. (2003) support the characteristics of the study 1 participants; the victims of violence were more likely to have psychotic symptoms and a history of homelessness, substance misuse and violent behaviour. Chapple et al. (2004) highlighted that substance abuse, homelessness and poorer social and organisational skills appeared to increase the chances of someone with a psychosis being a victim of violence. Hodgins et al. (2009) followed up 225 men with schizophrenia for two years post-discharge and set out to examine the "real life functioning" of these men who experienced numerous social difficulties. A finding of Hodgins et al. (2009) proposed that the two variables that

increase the chances of men with schizophrenia being victims of violence were having a history of substance abuse and having a low level of education. As stated previously, the five older study 1 participants had no formal qualifications. Therefore, in relation to the literature the study 1 participants fitted the profiles of men who were more likely to be victims of violence as highlighted by previous literature.

5.1.8 Disengagement, family and social support

As stated, experiences of disengagement from mental health services for the study 1 participants should be understood in the context of wider limited connections with a range of different social structures. A component of this experience is that the study 1 participants had a lack of support networks and intimate relationships, in addition to fractured family ties. Within their fractured family relationships, the study 1 participants had not had a relationship with their fathers and subsequently, for those who had become fathers themselves, they did not have a relationship with their children. Some study 1 participants had chosen to live solitary lifestyles, whilst other perceived themselves as having only limited support. This point was recognised by the study 2 participants who suggested that AOTs act as a support structure for their service users, which would not otherwise exist, describing themselves as both a 'safety net' and 'family'.

Macdonald et al. (2004), Wagstaff (2007) and Sapra et al. (2013) all support some of the findings of this current study. The study 1 participants used drugs on a regular basis, had a pervasive sense of sorrow, found it difficult to engage with mental health services and they perceived themselves as having limited support structures. Macdonald et al. (2004) found that dual diagnosis patients who were more progressed in their recovery were more likely to access support from non-drug using social circles or professionals, compared to dual diagnosis patients who were less progressed in their recovery. Wagstaff (2007), in a small-scale qualitative study, found that people with SMHP, who used drugs and had a history of disengagement from mental health services, also had few or no social networks. Sapra et al. (2013) assessed the role support networks had on engagement with mental health services and concluded that "drug-users" who were given "informational support" were more likely to access mental health services during a depressive episode than those people who had no support. A finding of the secondary analysis of the EMPIRIC study (King et al., 2005) by

Chakraborty et al. (2010) proposed that people from the Black-Caribbean community in the UK with a mental illness were less likely to have a person close to them relative to other ethnic groups.

On the subject of absent fathers, in The Role of Fathers in Childhood Development (2004) Lamb summarised that evidence suggests that a father's absence may be harmful because many paternal roles – economic, social, emotional – go unfilled or inappropriately filled. This in turn recognises that fathers have multiple roles; for example, breadwinner, parent and emotional partner, which demonstrates the multiple ways in which fathers influence children's development. Additionally, Lamb (2007) highlighted that fathers have an impact on their children that lasts a lifetime, even if they're dead or otherwise entirely 'out of the picture'. This idea is developed by Blanden (2006) who highlighted that low, or no, involvement by fathers is strongly linked with delinquent behaviour in teenagers and school failure in boys. It is of note that some of the study 1 participants first came into contact with mental health services whilst they were still teenagers, and the five older participants left school without any qualifications.

Using grounded theory and a constant comparative method, Fägerskiöld (2008) highlighted that fatherhood can be a life changing experience for men, but there can also be a link with 'negative behaviours', such as drug and alcohol use. The five study 1 participants who were fathers highlighted that not being involved with their children as they were growing up had had a negative impact upon them. Fägerskiöld's (2008) research would also potentially suggest that had they been involved with their children this may have influenced their drug use, though none of the participants suggested this connection.

Both Aldridge (2006) and the Le Francois review (2010) highlighted that children of fathers with poor mental health experience a wide range of negative outcomes, including poorer mental health themselves. Fathers who have mental health problems are also more likely to experience poverty and other forms of socioeconomic disadvantage, especially if they are from BME backgrounds. There was no information available about the mental health of the fathers of the seven participants in study 1, so no inferences can be drawn as to whether their mental health influenced the development of schizophrenia and position of social

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disadvantage in their sons. As stated, Bubbles' son met the inclusion criteria for this study and was approached but declined to participate. It should be noted that Bubbles' son had a diagnosis of schizophrenia, was first detained under the Mental Health Act as a teenager, was under the care of an AOT and had a history of substance use, which is in keeping with Aldridge's (2006) study. Laumann-Billings and Emery (2000) and Fortin et al. (2006) found that when boys grow up not knowing their father this leads to substantial distress, anger and self-doubt, all of which can persist into adulthood. Again, it is very difficult to determine what impact the absence of their fathers had upon the social and psychological development of the study 1 participants

A recommendation of the Fatherhood Institute (2015) is that services should identify the parental status of every male service user and his connections with his children – and seek to develop strategies to ensure that these connections remain fruitful. The Fatherhood Institute (2015) also recommended that drug and alcohol services should also consider using men's fatherhood as a motivating factor to help them change their behaviour. Why the relationships between the study 1 participants and their children broke down is unclear. Rebel said that he and his girlfriend were forced to give their child up for adoption; Clue believed that his children stayed away from him because he 'wore the dread' {p. 42} and it was his children's responsibility to seek him out now they were adults; Bubbles' ex-partner had taken a restraining order out against him when the children were younger. One of the service user reviewers was of the opinion that the families of the mothers would have encouraged them to keep the children away from their fathers because the fathers were mentally ill. Another factor that could have impacted the relationship between the study 1 participants and their children was that they had all spent time removed from society, whether that be detained under the Mental Health Act, detained in a Special House or detained in prison.

Using a focus group methodology, Williams et al. (2009) found that participants had to work hard as fathers to enable good mental health in their children, emphasising instilling self-esteem, love and good communication as hallmarks of fatherhood. Therefore, relating Williams et al.'s (2009) findings to this study it could be said that the fact that the study 1 participants grew up in a 'hard' social world without the input from their fathers to help them develop good mental health as adults played a role in them developing SMHPs.

Similar to study 2, the participants in Wright et al.'s (2011) study were clinicians who described themselves as being a safety net for their patients, as their patients went through transformations. The analogy of a 'safety net' was also used in Petterson et al. (2014); however, in this instance it was the clients using the analogy to describe their relationship with their AOT. Petterson et al.'s (2014) study examined the views of 11 people diagnosed with severe mental illness in Norway recruited to assertive community treatment and focused on how previously disengaged clients understood their relationship with AOTs.

Addis and Gamble's (2004) qualitative paper examined how a small number of nurses working in AOTs experienced engagement with patients on their caseload. The paper highlighted seven themes; the themes on which the participants put the most emphasis were: caring, timing, consistency, humanness and "teamness". The participants in study 2 spoke of their appreciation that they worked with their patients over an extended period of time, a finding supported by Addis and Gamble (2004). Hitch (2009) examined the experience of engagement for professionals and service users in AOTs. Again, one of the findings of that study was that one of the features of engagement with AOTs was that both professionals and service users liked that the engagement lasted for significant periods of time. The nurses in Addis and Gamble's (2004) study were aware that they would experience dejection when interventions were unsuccessful and also that working with this client group could be psychologically exhausting. While the clinicians in study 2 were seemingly happy in their jobs, they were also aware that they were doing a difficult job and that many of the interventions that they tried would be unsuccessful.

5.1.9 Implications for future practice

Literature (e.g. SCMH, 1998; Taylor & Kearney, 2005; Kreyenbuhl et al., 2009; O'Brien et al., 2009; Rooney et al., 2012) suggests that the participants who were recruited onto study 1 should be difficult to engage clinically and in research. However, the participants were willing to engage in the research and wanted to talk. An implication for future practice is that there needs to be an on-going awareness from clinicians that even though service users may have a history of disengagement this does not necessarily mean that there are not issues that they want and need to talk through with mental health professionals.

The findings of this study indicate that disengagement from mental health services should be viewed as a component of a broader experience of having limited connection with social structures, evidenced in the findings of study 1 and 2. A consequent implication for practice is that clinicians need to engage in discussions with service users to develop a broader understanding of a range of factors that contribute to their experiences of disengagement from mental health services.

The interpretative findings suggest that the study 1 participants had a complicated and largely negative relationship with mental health services. The study 1 participants did not always understand the role or actions of mental health services and they did not feel listened to. Whilst the study 2 participants appeared to be striving to provide individualised care and were genuinely concerned for the well-being of their service users, the study 1 participants appeared to not be wholly aware of this. Given the levels of apparent distress the participants experienced in relation to not understanding aspects of care, the placing of greater emphasis on writing care plans in a collaborative fashion and staff investing more time in making sure service users understand the treatment they are receiving may prove beneficial.

A finding of study 1 was that the participants were clear in their dislike of medication, particularly the use of depot. Whilst DoH (2014a) emphasised that people from the BME communities needed greater access to talking therapies, the findings of this study suggest that there was a continuing perception amongst the study 1 participants that medication was the main treatment option. The study 1 participants felt that they had little choice but to take medication regardless of their wishes. Secker and Harding (2002), Priebe et al. (2005), Davies et al. (2014) and this study all say that one of the most disengaging features of mental health care was the loss of control of medication. The study 2 participants knew that their service users preferred oral medication, but were suspicious of their motives. Whilst oral medication may return personal choice to the respective service users, the clinicians believed that service users preferred oral medication so that they had the option to stop whenever they wanted. A recommendation from Davies et al. (2014) was that services should work collaboratively with service users to devise advanced directives so that at times of crisis service users may be able to influence some control over the medication given to them.

Additionally, NICE guidelines consider CBT and family interventions as effective forms of treatment alongside psychotropic medication in the treatment of schizophrenia (NICE, 2014). Furthermore, Morrison et al. (2012) in the British Journal of Psychiatry said that it is time, "to reappraise the assumption that antipsychotics must always be the first line of treatment for people with psychosis" (p. 84). Chase et al. (2010) and Priebe et al. (2005) both concluded that to promote engagement and minimise historic disengagement a partnership model needs to be adopted. A partnership model that incorporates the employment of peer support workers, collaborative care planning, skills such as the study 2 participants' flexible use of language, listening to the concerns of service users and investing more time explaining to service users what medication they are on and why they are taking it could all help address the difficult issue of medication in contemporary mental health care.

Regardless, the interpretative findings of this study suggest that the study 1 participants did not have a wholly negative relationship with services. All the study 1 participants were able to highlight positive aspects to their relationship with services and services should acknowledge these positive aspects and focus on how to develop these further. It would appear that there are already aspects of this happening, for example the focus groups joking that all their service users want from them is "*housing and benefits*" {FG2: p. 5}. Norman and Ryrie (2013) proposed that if service users are to develop a more positive attitude towards services then believing that services are empowering and accessible would provide a greater incentive to engage with services.

All the study 1 participants described their racial identity as 'black'. Literature suggests that many people of African-Caribbean descent in the UK have a negative experience of mental health services (e.g. Rabiee & Smith, 2007; Chakraborty et al., 2011). The reasons are complex and the negative experience has an impact across the spectrum of the services provided (e.g. SCMH, 1998; Priebe et al., 2003; Morgan et al., 2004; Mental Health Act Commission, 2006; Fung et al., 2006; Fearon et al., 2006; Keating, 2007; CQC, 2010; Robinson, Keating & Robertson, 2011; The National Mental Health Development Unit, 2011; DoH, 2014a). Drawing on Keating and Robertson (2004), an implication for practice from this study is that any initiative designed to address the difficulties that the African-Caribbean community have in accessing mental health services cannot be done in isolation, but needs to

be a component part of a wider programme which also tackles wider social issues such as education, housing and employment. Regardless of racial identity, Kidd et al. (2015) also highlighted that people with SMHP needed greater access to employment opportunities in order to enable their on-going recovery.

The study 1 participants perceived themselves to have been stigmatised within society and their communities. The study 2 participants suggested a model of disengagement wherein the awareness of stigma was a driving force for continued disengagement from mental health services. Another implication for future practice is that work needs to be done by mental health professionals to highlight both the benefits of continued involvement with mental health services for individuals and also to become involved in a concerted public campaign to reduce the stigma of involvement with mental health services. Locally, nationally and internationally work needs to be done to reduce stigma (Thornicroft et al., 2008). Recent government policy, *Closing the Gap: Priorities for essential change in mental health* (DoH, 2014a), acknowledges that many people with mental health issues experience disproportionate discrimination and it is clear that stigma attached to mental illness is an area that needs to be tackled. Both media campaigns (such as the time to change campaign (time-change-change.org.uk)) and targeted interventions with specific groups have been shown to impact positively on mental health stigma (Wright et al., 2006; Thornicroft et al., 2008). Thornicroft et al. (2008) was an influential paper examining how the stigma associated with mental illness could be addressed. Two strategies suggested by Thornicroft et al. (2008) which could significantly improve the working relationship between service users like the study 1 participants and mental health services were having a greater emphasis on jointly formulated care plans and further promotion of peer support workers.

An important point for future public health initiatives and clinical practice revolves around addressing the fear of assault theme that emerged from study 1. This study, supported by international literature (Walsh et al., 2003; Teplin et al., 2006; Kamperman et al., 2014), demonstrates that violence against people with SMHP is a real concern. The 2014 guidelines published by the Crown Prosecution Service define disability hate crime as, "Any criminal offence which is perceived, by the victim or any other person, to be motivated by a hostility or prejudice based on a person's disability or perceived disability" (CPS, 2014). Whilst it is

unclear whether it was mental health status, racial identity, social position or appearance that led to the participants either being attacked, or being fearful of the imminent possibility, there nevertheless needs to be a concerted public health effort to address this issue.

The interpretative finding of social exclusion experienced by the study 1 participants has been highlighted in previous literature. Shetty (2010) proposed that after engagement, the focus of AOT care should become 'recovery' and social inclusion. This change in emphasis would address concerns raised by this study and also by Claassen and Priebe (2006) and Spindel and Nugent (2000) about marginalisation and stigmatisation of people under AOT care.

Another implication for practice is understanding what is meant by clinicians when describing a service user as 'disengaged'. The findings of this study suggest that this is a professional perspective and not a service user description of their relationship with services. Consequently, clinicians need to question what is meant when they describe someone as 'disengaged'. Questions such as "What does disengagement mean?", "To what extent is the person disengaged?" and "Are they disengaged from all aspects of the service?" could illuminate the design care packages, promoting better engagement.

Finally, as previously stated, the experiences of disengagement for the study 1 participants need to be understood in the context of the participants having limited connections to social structures. This includes having a lack of support networks, intimate relationships and also fractured family ties. Josh highlighted that he had never been offered any form of talking therapy to address the loss of his mother. Similarly, other participants felt great sadness at not being involved with raising their children. An implication for practice is that the study 1 participants at least could have benefitted greatly from the opportunity to talk these issues through. Additionally, there may have been benefit in providing education about the nature of SMHP to the families during the early stages of the participants' illness, before the relationships became too fractured.

5.1.10 What are the experiences of people with a diagnosis of severe mental health problems and a history of disengagement from mental health services? Conclusion

Despite meeting the demographics for those people who were the most likely to disengage from services, the study 1 participants were recruited onto the study and appeared to participate in an open and honest manner. This serves to highlight both that the participants were keen to talk about their experiences and as a reminder that it is imperative that service users' experiences are listened to in order to improve services (Van Den Tilaart et al., 2009).

The interpretative findings indicate that from the experiences of the participants, disengagement needs to be understood as a multi-faceted phenomenon. Disengagement from mental health services should be viewed as a component of a broader experience of having limited connection with social structures, evidenced in the findings of study 1 and 2. The study 1 participants had a complex and ambivalent relationship with mental health services and this complexity has been previously noted in the literature (e.g. Priebe et al., 2005). The findings of study 2 add extra context to this complex relationship. A noteworthy finding was that the study 1 participants did not regard themselves as having a history of disengagement from services, and that such terminology was a professional description of the relationship between services and service users, as opposed to one used by the participants. A finding of study 1, recognised in study 2, was that if mental health services really wanted to help the participants, then the most helpful thing they could do was to leave the participants alone. Due to historic and on-going risk factors this was not possible; however, the study 1 participants acknowledged positive experiences of mental health services, particularly when addressing practical concerns. It remains an unresolved point as to whether the study 1 participants really did want to be left alone or rather that they wanted to access services on their own terms.

Whilst the participants of study 2 largely supported the findings of study 1, there were points of disagreement. For example, the study 1 participants' experience of mental health services was characterised by a sense of powerlessness and lack of choice whereas the study 2 participants reported that their efforts to deliver care were holistic, individualised and, where possible, provided choice for service users. Evidence of these individualised attitudes were the participants' attitudes towards cannabis use, medication, spirituality and their own use of

language. Interestingly, literature (e.g. Claassen & Priebe, 2006; Killaspy et al., 2009a) highlights opposing views about the primary role of AOTs; the findings of this study reflect that divergence of opinion. FG2 viewed their primary responsibility as risk management and that all other considerations were secondary to that whereas as FG1 perceived their primary role as the promotion of the well-being of service users.

The stigma of mental illness and involvement with mental health services were important components in the complex relationship that the study 1 participants had with both society and mental health services. The participants' perception of stigmatisation impacted on their identity and also on their perception of their position within society. The interpretative findings of study 1 suggest that the fear of assault contributes to the participants' perception that they are excluded from society. Previous research (Hiday et al., 1999; Chapple et al., 2004; Teplin et al., 2006; Hodgins et al., 2009; Williams et al., 2009) has highlighted that violence and the fear of violence are a concerning reality for many people with SMHP, both nationally and internationally. However, despite the fear of assault and the stigma of being involved with mental health services, the majority of the participants felt comfortable in their immediate community. The lack of support networks, intimate relationships and fractured family ties were all important experiences for the study 1 participants. Additionally, not being involved with the upbringing of their children was a source of great sadness for the participants.

This thesis does not propose a model which explains disengagement from mental health services. The current study suggests that participants had their own personal and sociological motivations for disengaging from mental health services. If a functional model of disengagement from mental health services were to be devised, then it would need to be multi-dimensional, inclusive and complex. The complexity of the model would be a reflection of service users' idiosyncratic social, cultural and psychological experiences. For the study 1 participants a model of disengagement would need to reflect their ambivalent relationship with mental health services: that the participants believed they had schizophrenia, wanted to talk about their experiences, wanted mental health services to leave them alone (and felt hounded by services) whilst simultaneously valuing the pragmatic support that services provided. Furthermore this ambivalent relationship would need to be understood as

part of a wider social picture in which the participants had only limited connections to social structures. Models of disengagement have been proposed previously (for example Chakraborty et al., 2011) which partly address the experience of the study 1 participants. Writers, including Priebe et al. (2005), have suggested that individual agency and identity are crucial in understanding the experience of disengagement/re-engagement. Additionally, Keating and Robertson (2004) suggested that for black service users, involvement with mental health services reflects their experiences in society; they found the involvement to be alienating and degrading, and therefore was considered to be a last resort. A finding of study 2 suggests that one of the driving forces for continued disengagement from mental health services was that young black men, in particular, were proud of their independence and therefore did not wish to be associated with the stigma, and 'shame', of involvement with mental health services. Such a model overlaps with Keating and Robertson (2004).

5.2   How do the Research Participants Understand their own Health, Well-being and Illness?

The study 1 participants appeared to not understand their mental distress in the same terms as professionals. They had developed their own idiosyncratic understanding of their mental distress. Additionally, they did not always understand the decisions made by mental health services. The study 1 participants were not denying that they had schizophrenia, it was more the case that they did not understand the diagnosis given to them and they did not have the same understanding of their mental distress as professionals. In the following section the study 1 participants' perceptions of their health, well-being and illness and the phenomenon of them developing their own idiosyncratic understanding of their mental distress and treatment is discussed with reference to literature. Furthermore, the study 2 finding that the language used by professionals to describe a person's diagnosis and symptoms is both important and flexible will also be discussed.

It is not accurate to say that the study 1 participants lacked insight into their mental illness. A more accurate description of their experience would be that whilst they knew their diagnosis, they did not understand what that diagnosis meant. Consequently, they had developed their own idiosyncratic understanding of their mental health. One study 1 participant did deny he

had a mental illness; however, even he acknowledged that he had been "*crazy*" when he first came into contact with mental health services.

The experience of the study 1 participants, combined with the model proposed in study 2, suggest that mental illness, stigma and disengagement are experienced together within a social context. As stated, the study 1 participants appeared not to reject their diagnosis but rather not understand it. However, the participants were aware of the negative social impact that the diagnosis and contact with mental health services entailed. Without an explanatory model to provide a meaningful context for their mental distress, the study 1 participants were living with uncertainty about the meaning of their diagnosis. This led them to question the value of mental health services and to question the decisions made by mental health services. This finding is supported by McCabe and Priebe (2004a) who proposed that explanatory models of mental illness differ between cultures and ethnic groups. McCabe and Priebe (2004a) also suggested that whilst explanatory models of mental illness do not impact upon compliance with treatment, they do impact upon satisfaction with treatment. However, a cautionary point suggested by McCabe and Priebe (2004b) was that explanatory models of mental illness are not stable across time and therefore their value is questionable.

A component of the process of the participants developing their own idiosyncratic understanding of their mental distress was that they did not readily consider some symptoms that professionals would see as pathological as symptoms of a psychiatric disorder, for example Arthur and his "*signals*". Similar to the study 1 participants, the participants in Biddle et al. (2007) assessed whether the mental distress they were experiencing fell into either a 'real' or a 'normal' category. The process of self-diagnosis is central to Biddle et al.'s (2007) COA model. The participants in Biddle et al. (2007) found this process to be complex and they developed a link between how they defined distress and their own perceptions about the circumstances under which people should seek help for distress. Both McCabe and Priebe (2004b) and Biddle et al. (2007), combined with this study, all serve to highlight that people generate their own definitions of mental distress and illness, which may be flexible across time.

In part, Phillips et al. (2006), a UK study into the identity and cause of problems for 17 people with schizophrenia, contradicts the findings of study 1. In study 1 the participants were not primarily distressed by the symptoms of their mental distress; what concerned them were the consequences of the diagnosis and contact with mental health services. In contrast, Phillips et al. (2006) suggested that the main reported difficulty for their participants was either psychiatric or psychological.

Whilst some findings of both Johnson and Orrell (1996) and White et al. (2000) are in line with the findings of study 1 and 2, the findings of those studies also serve to explain disparities in the perspectives of the study 1 and 2 participants. Johnson and Orrell (1996) set out to investigate whether there was an association between a patient's ethnicity and a psychiatrist's assessment of their level of insight. Johnson and Orrell (1996) suggested that a psychiatrist's assessment of a patient's insight is influenced by the patient's ethnicity. A potential explanation for this is that patients form their lay views of mental illness on the beliefs of their social group. Also, as with this study, Johnson and Orrell (1996) highlighted that belief about mental illness are informed by the stigma associated with mental illness and the cultural suspicions around the necessity and purpose of medication. Johnson and Orrell (1996) suggested the possibility that both the psychiatrist and the patient are equally influenced by the social and cultural beliefs about mental illness of their own ethnic group. Additionally, one of the findings of White et al. (2000) was that patients adopt an attitude towards their illness that is congruent with the beliefs of their social group.

Interpretative analyses of the study 1 participants' experience propose that disengagement from mental health services was not influenced by their interpretation of their SMHP. This finding is supported by Watts and Priebe (2002), who suggested that disengagement is related to cultural and historical factors rather than insight. But these findings run contrary to the O'Brien et al. (2009) review into disengagement. When asserting that intuitively the lack of insight would be relevant when considering disengagement, O'Brien et al.'s review referenced Priebe et al. (2005). Priebe et al. (2005) stated that one of the main reasons for peoples' relationships with mental health services breaking down was a difficulty accepting a mental illness diagnosis. Moreover, Priebe et al. (2005) also suggested that denial of the need for treatment was a mechanism to cope with the stigma associated with the diagnosis of

psychosis (see also Moore et al., 1999). This finding complements the model of disengagement suggested in study 2: the desire to avoid the stigma of involvement with mental health services is a driving force behind continued disengagement. Kreyenbuhl et al. (2009) stated that one reason why patients disengage from mental health services was that from their perspective they did not perceive the need for treatment. Not always perceiving a need for treatment, regardless of diagnosis, is a fitting description of the attitude of most of the study 1 participants.

Saravanan et al. (2004, 2007) stressed that insight should not be seen as fixed, nor should it be seen as a singular entity. Saravanan et al. (2007) used a cohort of 125 people with psychosis having their first contact with mental health services in south India. The aim of the study was to try to reconcile Indian and UK ideas about psychosis and insight. Saravanan et al. (2007) suggested that professionals need to think carefully about the cultural context of the person's explanation of mental distress before judging a person as having a 'lack of insight'. Both Priebe et al. (2005) and Saravanan et al. (2007) argued that the relative lack of insight in people with schizophrenia was a means by which to cope with the stigma and negative social views associated with the condition.

Moore et al. (1999) approached the phenomenon from a different perspective. Their sample group of 46 patients with schizophrenia were evaluated for their level of insight, depression and levels of self-deception. The conclusion of Moore et al. (1999) was that those patients with less insight were also less likely to be depressed. They theorised that lack of insight is not a defence mechanism against the stigma and negative social views associated with schizophrenia but rather a defence mechanism against depressive symptomology. However, it should be noted that those participants in Moore et al. (1999) with lower levels of insight also had less awareness of the social consequences of being diagnosed with schizophrenia. This finding differs from the findings of this study as the participants of both study 1 and 2 were aware of the social consequences of the diagnosis of schizophrenia, and also the study 1 participants did not wholly reject their diagnosis.

Furthermore, Cooke et al. (2007) provided useful perspective on the relationship between disengagement and 'insight'. Cooke et al.'s study explored the relationship between the

coping styles and denial of illness in 65 outpatients with schizophrenia in the UK. Cooke et al. (2007) concluded that there was a correlation between awareness of symptoms and high levels of distress for many people with schizophrenia. To cope with the high levels of distress, people sought social support and looked for both personal growth and mental disengagement as means of coping with the symptoms of their condition. Cooke et al. (2007) saw these strategies as a means of lowering distress and helping to cope with the impact of the condition rather than denial of the illness. Similar to Cooke et al.'s idea that people seek social support and personal growth as means to cope with the impact of their condition, an interpretative finding of study 1 was that the participants viewed the social benefits of cannabis use and an awareness of personal development as beneficial in assisting them in reinforcing their personal resilience and reasserting their personal identity.

Charmaz (1994) was a large-scale US qualitative study into identifying dilemmas of chronically ill men. The paper discussed how men manage their identity when they have a chronic illness. The participants in Charmaz (1994) felt disadvantaged within a hierarchy of men. The study 1 participants perceived themselves as being disadvantaged and had a prevailing sense of sorrow, which informed their identity and world view. Whilst the study 1 participants did not directly understand their diagnosis as an affront to their masculine identity, on an interpretative level it should be noted that they stressed that being able to help themselves was important in maintaining a positive identity. The participants in Charmaz (1994) strove to minimise the significance of their condition. As discussed the study 1, participants had developed their own understanding of their mental distress. An interpretation of this phenomenon would be, with reference to Charmaz (1994), that the study 1 participants minimised the significance of their condition in order to reinforce their personal identity. However, bar Arthur, this model does not apply to the study 1 participants' understanding of their physical health. Whilst Arthur had his own interpretation of his physical health, the other participants had an understanding of their health that was broadly similar to the professionals.

A finding of study 2 was that the participants changed the words they used to describe diagnosis and symptoms based on both the person and circumstances, in order to facilitate better engagement. The participants were aware that there was flexibility in the

understanding and language of diagnosis and used this thoughtfully when engaging with service users. The study 2 participants were not fixed in the language they used to describe mental illness. They reported that their service users are implicitly aware of, and are happy with, this arrangement. Indeed FG2 highlighted that their service users are also comfortable changing the language used to describe their mental illness depending on the situation.

The flexibility in the use of language in study 2 is also supported by Hamilton and Roper (2006). Hamilton and Roper's study (2006) critiqued how professionals conceptualise and use a service user's apparent lack of insight. The critique challenged mental health professionals to be more culturally aware. The critique advocated for professionals to have greater awareness of an individual's differences in understanding mental distress and subsequently have more flexibility of language in describing symptoms and diagnosis. Furthermore, Hamilton and Roper (2006) deconstructed the notion of insight and encouraged professionals to move towards a model where professionals acknowledge each individual's right to interpret their own experience. Just as the professionals in study 2 modified their language depending on the person and the circumstance, a review by Forbes (2010) concluded that mental health nurses should be developing their own language. The language nuance that Forbes (2010) recommended was moving away from using terms like 'poor insight' towards thinking of 'unawareness' in schizophrenia as 'neurological disturbance' and to subsequently change their language accordingly.

5.2.1   Future practice

Both Phillips et al. (2006) and Biddle et al. (2007) suggested that because individuals have such a range of subjective beliefs about their own difficulties and the causes of those difficulties, traditional insight scales fail to capture this complexity and diversity. Indeed, these findings are supportive of interpretative findings of study 1; the lack of explanation from clinicians had led the participants to either develop their own idiosyncratic understandings of their mental distress or alternatively not to understand what their diagnosis meant. Whilst these idiosyncratic interpretations encompassed the causes and the symptoms of the illness and the purpose of treatment, these beliefs did not directly impact upon the participants' engagement. In developing future practice, clinicians need to understand the service users' perspective of their mental distress and where possible tailor treatment

interventions to reflect these personalised interpretations. With further reference to Biddle et al. (2007), there is always a concern that service users will develop coping strategies in response to their idiosyncratic understanding of their mental distress that are counterproductive and worsen the symptoms of their condition. Therefore, it is important that professionals talk to service users about how they as professionals view and understand the service users' mental distress. A recommendation for future practice for clinicians working with service users who do not hold conventional beliefs about their mental distress is that they should strive to cultivate an understanding of the service user's perspective (Hamilton & Roper, 2006). The creation of a dialogue creates the opportunity for greater understanding for both parties. Further, as previously suggested by Godfrey and Wistow (1997), whilst professionals do need to keep service users informed of the treatment options available to them, this has to be done in the context of seeking the service user's perspective of their illness and taking that into consideration when making decisions.

5.2.2 How do the research participants understand their own health, well-being and illness? Conclusion

The findings of study 1 indicate that the participants were aware of what their diagnosis was, though not what the diagnosis meant. Previous literature support this finding in suggesting that in the absence of having a meaningful explanatory model, the study 1 participants developed their own idiosyncratic understanding of their SMHP and mental distress (e.g. McCabe & Priebe, 2004b and Biddle et al., 2007). Literature shows that lack of awareness and lack of insight, as well as the male tendency to minimise the impact of illness, are explanations of why clinicians and service users have different understandings of mental distress. Interpretative analyses of the study 1 participants' experience suggest that the participants' disengagement from mental health services was not influenced by their interpretation of their SMHP, a finding supported by Watts and Priebe (2002).

This study contributes an alternative explanation for service users presenting different perceptions and understanding of their mental distress based on the participants knowing their diagnosis but not understanding what the diagnosis means. Furthermore, this lack of understanding by the study 1 participants contributed to their experiences of mental health services in so far as they did not understand aspects of their treatment, leading to confusion

and frustration. In order to facilitate better future engagement clinicians need to cultivate an understanding of service users' perspectives of their mental distress. Such an understanding needs to take into consideration both what impact a service user's culture has had on their perspective and also what impact that idiosyncratic perspective of their mental distress has had upon their identity.

5.3 How do the Research Participants Perceive their Needs in Relation to Statutory Mental Health Services?

The final research question examined how participants perceived their needs in relation to statutory mental health services. However, the study 1 participants did not directly answer this research question, despite being questioned during the research interview. Through the interpretative process the question was indirectly answered and the answer lies in the study 1 participants' attitude towards mental health services.

For the study 1 participants, there are three components to their attitude towards mental health services:

• They did not fully understand the decision-making process of mental health services (see Rebel, for example) and did not conceptualise mental health services as intrinsically trying to help them.

• The participants were more comfortable keeping mental health services at a distance and generally viewed services as intrusive and hounding them (see Bubbles and Arthur).

• The services provided by mental health services that the participants valued the most were help with housing, benefits and the supply of oral medication (again see Rebel, for example).

It is of note that when the professionals in study 2 were asked which services their patients appreciated the most they responded "*housing and benefits*" {Greg, FG2 p. 11/12}. This perception that the practical support that mental health services can offer is the most important aspect of care is also one of the findings of Davies et al. (2014).

However, to address this research question, the strategies that the study 1 participants developed to reinforce their personal resilience and personal identity in light of the

psychological, social and emotional consequences of their limited connection to social structures need to be examined. An alternative explanation of Theme B is, with reference to both Priebe et al. (2005) and Chase et al. (2010), the study 1 participants appeared to be determined not to lose their agency and have their identity subsumed into mental health services. Hence they used the four highlighted strategies to reassert their personal agency and identity to try and have more control in their lives. These strategies were developed, for the most part, independently of mental health services, reflecting the participants as active agents in promoting their own well-being as opposed to being passive recipients of care and treatment. As highlighted in the Findings chapter these strategies are:

I.   Medication

II.   *"Drugs make you the man you are"*

II.   Faith, spirituality and solace

III.   Age, experience and maturation

The research theme of "*Drugs make you the man you ar*e" is addressed separately in the next section of this Discussion chapter. The other three themes are discussed in the following section of the chapter, as these strategies address the needs of the service users which were not necessarily addressed by statutory mental health services.

A component of both the complex relationship with mental health services and the dislike of psychotropic medication was the sense of lack of control that the study 1 participants had with regards to medication. There was genuine anger at this lack of control. However, the older study 1 participants were able to acknowledge that they had developed as people over the years. This personal development had happened within the context of being patients in the mental health system. The acknowledgement was interpreted as a strategy which reinforced their personal identity and resilience. However, this theme was not evident for the two younger service users. The focus groups were aware that medication was an obstacle to be negotiated in the complex relationship they had with their service users.

5.3.1   Perspectives on medication

This study suggests that medication is a highly emotive issue and the study 1 participants were able to articulate their ambivalent relationship with medication. As has been reflected in

4.3.1.1.iii, there was particular dislike for depot medication. Not only was it seen as symbolic of the violence between mental health services and the study 1 participants, it was also described as "*poison*", to which they felt "*allergic*". But prescribed medication, particularly oral medication, was a strategy with which the study 1 participants helped to maintain their personal resilience and assert a more positive identity.

In contradiction of other studies but supporting the perspectives on the medication theme in this study, Rethink (2008) reported that 76% of their sample group saw benefits to taking psychotropic medication. Aldebot and Weisman de Mamani (2009) investigated whether there was any correlation between the coping style of 40 people with schizophrenia and their adherence to medication. The study proved their hypothesis that a "denying coping strategy" was inversely related to problems with medication adherence. But, interestingly, an "acceptance coping style" was not necessarily related to medication adherence. What these research finding suggest is that there are many factors involved in the decision to take psychotropic medication. Just because someone accepts that they need medication does not necessarily mean that they will take the medication prescribed.

5.3.2   Changing perceptions with age

A strategy that the older study 1 participants described as reinforcing their reliance and identity was awareness that their perspective had changed over time and as they got older they felt less hostility and less inclination to resist mental health services. Accordingly, the two study 1 participants who were the most disengaged at the time of the research interview were also the two youngest. However, the study 2 participants did not all recognise the transformations as inherent in the study 1 age, experience and maturation theme. As Bernard pointed out, "*The person that we see most frequently on a long-term scale is in his 80s. ... And if we didn't see him, they could be well doing heinous things, I kid you not*" {FG1 p. 29}. In FG2 Greg recognised the point that was being made but was unable to determine whether people changed their attitude as they got older or changed their attitude because they were now experiencing a less restrictive form of service delivery. The professionals in both groups were sceptical, additionally expressing disappointment that mental health services had in effect, "*beaten the service users into submission*" {Martha, FG1: p. 28}.

Keys to Engagement (SCMH, 1998), Parkman et al. (1997), Chakraborty et al. (2010) and Petterson et al. (2014) all support the theme of service users changing their perception of mental health services over time. Parkman et al.'s (1997) study sought to measure the satisfaction of mental health services for UK-born Black Caribbean people compared to white people in London. That study proposed that the older Black Caribbean participants in their study were less dissatisfied than their younger counterparts. Similarly, one of the findings of Chakraborty et al. (2010) was that because people perceived themselves to be powerless, over time they develop a more collaborative attitude towards mental health services. The focus of Petterson et al. (2014) was on how the clients understood their relationship with AOTs. One of their findings was that after initial difficulties in engaging with their AOT, the clients changed their perception about the value of AOT over time. Whilst *Keys to Engagement* (SCMH, 1998) put the time frame for this to happen at 18 months, Petterson et al. (2014) said the mean time for clients to engage and see the value in working with AOT was 22 months.

The idea of AOT service users changing over time and this change impacting upon engagement has been raised in literature before. A theme that Wright et al. (2011) highlighted as important for engagement was "transformation". Wright et al. (2011) described their participants as seeing mental illness as being transformational in itself and that the participants were aware that the cycle of illness and wellness altered their personality and perception. Some of the participants in Wright et al. (2011) disengaged from mental health services in order to reject these transformative effects of mental illness. Kidd et al. (2015) was an Australian action research study which aimed to develop a collaborative understanding of the nature of recovery. The findings of that study highlighted that, amongst other criteria, both the passage of time and the need for greater connection are important components of recovery.

There are different ways in which the participants' perceptions changing over time can be interpreted. One interpretation of this phenomenon could be that it reflects AOTs fulfilling their role over time and positively impacting on service users' engagement (SCMH, 1998). Relatedly, the change in attitudes that was noticeable in the older study 1 participants can be framed as part of a recovery process, which through the passage of time enabled the participants to progress further with their recovery (see Kidd et al., 2015). Another

interpretation from FG1 is that services have worn down the resistance of service users and they have realised they have only very limited control; therefore, they have become much more passive towards services (see also Selten & Cantor-Graae, 2005 and Chakraborty et al., 2011). A final interpretation from FG2 would be that as service users get older they move towards less restrictive forms of care; for example, the younger participants were in hospital more frequently than the older participants. Therefore, it is easier for older participants to engage with the less restrictive forms of care currently being delivered to them.

5.3.3 Faith, spirituality and solace

The third strategy that appeared to strengthen the study 1 participants' resilience and reasserted a more positive identity was the solace found in faith and spirituality. One of the unexpected findings of study 2 was that the professionals initially said that they did not see that caring for their patients' spiritual needs was a part of their job. However, as the focus groups progressed it was clear that they did indeed care for the spiritual well-being of their patients. The study 2 participants were aware of the importance of 'spirituality' to their patients to the extent that part of promoting individualised care means facilitating 'spirituality' as part of the patient's recovery. In practice, nursing care focuses on treating the person in four domains: physical, social, mental and spiritual. Frequently it is the spiritual side of care which is neglected (Chan, 2010). Furthermore, Nolan and Crawford (1997) not only said that the spiritual aspects of care were frequently the most forgotten but also that those patients with mental illness were often the patients most in need of spiritual care.

Erdner et al.'s (2009) study examined the views of 11 people diagnosed with mental illness in Sweden. The findings both support those of this study whilst also offering a counterpoint. Whilst the study 1 participants found solace in their relationship with God and their spiritual beliefs, the participants in Erdner et al. (2009) had difficulties relating to God. The study 1 participants felt estrangement from other people but the participants in Erdner et al. (2009) were estranged from both other people and God. The participants in Erdner et al. (2009) yearned for lasting relationships with people which is also partially true of the study 1 participants who wanted greater acceptance in society and were profoundly upset that they were not involved with their respective children whilst they were growing up. Whilst both Erdner et al. (2009) and the current study 1 the participants found that faith gave them

comfort, Erdner et al. described this as giving the participants a healthier life; whilst the study 1 participants valued their health, they did not connect it to their spirituality.

Most of the study 1 participants did not understand their mental distress, its treatment or their recovery in the same terms as professionals, but they saw spirituality as a means of support. With reference to the earlier discussion regarding the understanding of diagnosis, Barker and Buchanan-Barker (2008) state that part of the attraction of spirituality in relation to people attempting to understand their mental distress is framing an idiosyncratic understanding around spirituality "sidesteps the lunacy of diagnosis" (Barker & Buchanan-Barker, 2008, p. 63). Another potential point of misunderstanding was that the study 1 participants wanted the spiritual care that was delivered to them to be more of a spoken nature, whereas the study 2 participants felt unable to provide this but did feel able to facilitate opportunities for spiritual support to be delivered.

Moreno and Cardemil's (2013) qualitative study examined religiosity amongst 20 Latino people who were facing adversity and were seeking help from mental health services in the US. Similar to this study, the conclusion of Moreno and Cardemil (2013) was that the majority of the participants viewed both organised and informal religious and spiritual practices as a preferable coping strategy. However, in divergence from this study, when problems were viewed as either more serious or as biological in origin, the participants of Moreno and Cardemil (2013) thought it appropriate to access mental health services.

5.3.4 Future practice

As highlighted by Knight et al. (2003), an implication for practice from this study is that it is not only the responsibility of service users to strive to establish a positive identity but it is also the responsibility of professionals and the person's immediate community. As reflected elsewhere, there is a need for clinicians to listen to service users and develop an understanding of their perspective, which may engender greater trust on both parts.

In Theme A of study 1 the participants spoke in detail of their dislike of medication, in particular depot medication. However, in Theme B the participants spoke of either how they had benefitted from taking oral medication or their desire to be switched from depot

medication to oral. This is indicative of a wider implication for future practice that there should be more negotiation between clinicians and service users over medication which may facilitate improved engagement. Another implication for practice is that clinicians should question the use, value and purpose of medication and be aware of policy guidelines encouraging a greater emphasis on talking therapies (DoH, 2014a).

Another interpretative finding in Theme B of study 1 was that the older participants changed their perception of the value of mental health services over time. An implication for future practice regarding the change in perception towards services would be an acknowledgement of this maturation and transformative process and, if it was not happening already, changing the nature of service delivery to reflect this.

The other interpretative finding that contributed to Theme B was that spirituality was important to the participants and greater emphasis on their spiritual well-being would have potentially improved their engagement with mental health services. This idea was raised with the focus groups in study 2. An interesting finding which was not anticipated was that the clinicians in the focus groups initially denied having input into the spiritual welfare of service users. However, subsequently, they explained how they facilitated interventions to promote service users' spiritual well-being. In relation to the study 1 participants' perceived needs from mental health services and an implication for future practice is that there needs to be greater awareness on the part of clinicians on the role they currently perform and the expectation some service users have in regards to the provision of spiritual care. Potentially there was a misunderstanding in what the study 1 participants could reasonably expect in terms of spiritual care from mental health services compared to what mental health services, and the study 2 participants, are able to deliver.

5.3.5   Conclusion

Despite the ambivalent relationship with mental health services, the limited connections to social structures and the pervasive sense of sorrow described in Theme A, the strategies in Theme B would appear to offer a counterpoint for the study 1 participants, strategies that the study 1 participants had developed to reinforce their resilience and reassert their identity. The participants in study 2 recognised, without wholly endorsing, these strategies.

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The findings of this study suggest that the use of medication in the treatment of SMHP is a difficult issue and most study 1 participants were able to articulate their ambivalent relationship with medication. Whilst there was particular dislike for depot medication, there was a different attitude towards oral medication. Taking Rebel as an example, he was able to articulate how tablets had helped lessen some of the symptoms of his SMHP. Contradicting the negative experiences of depot medication, oral medication has been interpreted as a strategy whereby the study 1 participants helped to maintain their personal resilience and assert a more positive identity. Whilst oral medication may return some control to the respective service users, the clinicians believed that service users preferred oral medication so they were able to choose not to take the medication.

An interpretative finding of study 1 was that the older participants were more comfortable with their relationship with mental health services. The two study 1 participants who were the most disengaged and the most angry with services at the time of the research interview were also the two youngest. This was coupled with awareness that services may have been responsible for older services users developing a sense of learned helplessness. *Keys to Engagement* (SCMH, 1998), Chakraborty et al. (2010) and Petterson et al. (2014) have all reflected that AOT service users change their perception and attitude towards services over time but interestingly, the study 2 participants were sceptical and did not wholly recognise this interpretative theme. FG1 interpreted this as the participants may have been 'worn down' by the persistent nature of the mental health services, whereas FG2 highlighted that as people get older they often receive less restrictive forms of care, which may explain the progression of attitudes. The study 1 participants found solace in their spirituality and the findings of study 2 indicate that the clinicians were not immediately aware of the work they did to provide spiritual support to the service users. However, upon exploring the issue further it transpired that the clinicians did work to facilitate the spiritual welfare of service users.

5.4   What are the Research Participants' Understandings of the Role of Drugs and Alcohol within their Lived Experience?

A finding of study 1 was that the participants viewed cannabis as being beneficial to them. The benefits of cannabis ranged from being able to bring people closer to God to helping form

their identity. All the study 1 participants praised the use of cannabis. Equally, the study 2 participants understood that drugs are a significant part of life for their service users. Whilst not encouraging the use, the study 2 participants took the pragmatic approach that cannabis use was prevalent in the community that they served. The study 1 participants did not hold the same degree of reverence for crack cocaine as they did for cannabis; the study 2 participants were also aware of the increased risks associated with crack-cocaine use.

Whilst the study 1 participants all spoke positively of cannabis use, such sentiments run contrary to research evidence on the subject. The issue of substance use amongst the SMHT population is well-established. The prevalence of cannabis use amongst people with schizophrenia was examined in the meta-analysis of Koskinen et al. (2009). After reviewing 35 studies, their conclusion was that approximately 25% of patients with schizophrenia in their studies met the criteria for cannabis use disorder. Koskinen et al. (2009) did not examine whether there was a causal link in either direction between cannabis use and schizophrenia but did note that younger men who were having their first episode of psychosis were the most likely to also have cannabis use disorder. Kalant (2004), in a review of the post-1996 literature on the effects of cannabis, summarised that there was a causal link between cannabis smoking and upper airways cancer and that cannabis use contributes to a variety of different psychiatric disorders (as opposed to visa-versa). Additionally, Kalant (2004) concluded that regular cannabis use contributes to poorer psychosocial outcomes. The Kalant (2004) review highlighted that there is strong evidence to suggest that there are cannabis dependence disorders (including withdrawal symptoms), an increased risk of cardio-vascular disorders and subtle developmental problems in the children of mothers who smoked cannabis during pregnancy. The review by Moore et al. (2007) examined longitudinal studies into the risk of developing psychosis and concluded that there was sufficient evidence to say that cannabis increases the risk of developing a psychosis, independent of transient intoxication states, but the evidence of cannabis impacting on mood disorders was less certain. The Moore review did not find sufficient evidence to claim that cannabis causes psychosis rather there was sufficient evidence to suggest that using cannabis increases the risk of developing a psychosis later in life.

Cantor-Graae et al. (2000) investigated whether substance abuse was an independent risk factor for people with schizophrenia and also tried to gauge the impact of substance abuse through the life course of the illness. Taking a sample of 87 patients attending a clinic in Sweden the study found that men, with a family history of substance use, with higher rates of hospitalisation and criminality were the participants who were the most likely to abuse substances and were also the people who had the worse clinical outcomes. The study suggested that there may be links between substance abuse and the poorer clinical outcomes are frequently seen in male patients. Mueser et al. (2000) recruited 325 inpatients in New Hampshire in the US to look at the prevalence and demographics of substance abuse disorders across the lifetime of people who were currently psychiatric inpatients. The study established that males, the younger end of the age spectrum, low levels of education, never been married, a number of previous hospital admissions and having spent time in jail were strong predictors of psychiatric inpatients also developing a substance abuse disorder across their lifetime. However, an interesting point from Mueser et al. (2000) is that these characteristics for developing a substance abuse disorder amongst psychiatric inpatients are the same predictive characteristics for the development of a substance abuse disorder in the general population. These results are suggestive that the same social dynamics impact on individuals regardless of their mental health status.

Swartz et al. (2006) add further information to the emergent clinical picture of those people with schizophrenia who use substances. Swartz et al. (2006) examined the baseline correlates of a study into the cost effectiveness of antipsychotic drugs to develop a detailed picture of substance use amongst people with schizophrenia in the US. The study used 57 different sites and had 1460 participants. They found that 60% of the participants used substances and 37% had substance abuse disorders. Several studies cited above highlighted that men, with low levels of education, histories of homelessness and higher levels of symptomology were more likely to use substances. Swartz et al. (2006) additionally found that people with schizophrenia who had had a recent depressive episode, a childhood conduct disorder and were African-American were more likely to use substances. These demographics are similar to the demographics of the study 1 participants.

Bahorik et al.'s (2013) US study examined the long-term substance use of over 1000 SMHP patients in the year following discharge from a psychiatric hospital. The study established that substance use amongst people with SMHP is a frequent and long-term problem, which interferes with the individual's potential recovery. Fowler et al. (1998) examined the substance use patterns of 194 outpatients in Australia, all with a diagnosis of schizophrenia. Both the patients and their key workers were asked to complete questionnaires about the patients' patterns of substance use and there was a high degree of correlation between the patient and key worker reports. The reasons for substance use given by Fowler et al. (1998) were intoxication effects, dysphoria relief, social effects and symptom/side effect relief, which support the findings of this study. Graham (1998) highlighted that cannabis was relatively cheap, was socially acceptable and that people with SMHP using cannabis perceived it to be beneficial.

Graham and Maslin's (2002) study was designed to assess the prevalence of cannabis use amongst the SMHP population in a UK inner city. The study reported on 159 CMHT key workers' completed questionnaires on 1369 clients. A finding of the study was that key workers believed pleasure enhancement and coping strategies were the primary reasons for cannabis use. Gregg et al.'s (2007) review of the self-report literature examined the reasons why there was such a high prevalence of substance use amongst SMHP patients despite the poorer outcomes. Aside from demographic factors and contextual factors, such as a family history of substance use, the strongest theory for why a substance misuse co-morbidity develops in people with schizophrenia according to Gregg et al. (2007) was self-medication; patients were using substances to mitigate against the unpleasant mood effects of schizophrenia, and for the "alleviation of dysphoria" (see also Fowler et al., 1998). Mueser (1999) found that people with SMHP who used cannabis in a problematic way cited recreational and coping reasons. This is a finding reinforced by Phillips and Johnson (2001).

Phillips and Johnson (2001) carried out a wide-ranging review examining different aspects of dual diagnosis and suggested that there is some evidence that people with schizophrenia use cannabis to reduce general dysphoria, and possibly negative symptoms. It is unclear whether these findings match the experiences of the study 1 participants who tended to frame their experiences positively, smoking cannabis to bring happiness, relaxation and to feel normal.

That is not to say that if the study 1 participants had been asked they would have responded that without cannabis they would have felt greater levels of sadness, anxiety and isolation from society. The Phillips and Johnson review also tentatively suggested that the social environment had an impact on the development of problematic substance use with the SMHP population but highlighted the lack of empirical evidence in relation to all aspects of dual diagnosis.

The study 1 participants had been using cannabis for a long time. Given the age of the participants and the absence of early clinical notes, some details are unclear. One participant was 64 at the time of the interview and said he had started smoking cannabis before he left Jamaica aged 13. Another participant was in his 50s and had been using cannabis since his late teens. There is limited research on the experiences of people with schizophrenia who have used cannabis over an extended period of time. But research by Drake et al. (2006) examined the recovery outcomes for people with co-occurring schizophrenia and substance use disorders over a ten-year period. Just as the five older participants in study 1 had achieved some stability, similarly the findings of Drake et al. (2006) indicated that the 130 patients in New Hampshire in the US showed improvements relative to six recovery outcomes over a ten-year period. As a group the participants in Drake et al. (2006) felt that they had more control over the symptoms of their schizophrenia, their substance abuse was in remission, the majority were living independently, some were employed, some had regular contact with non-substance users and the majority had overall life satisfaction. Whilst the study 1 participants were not doing as well as the participants in Drake et al. (2006), the older participants were being admitted to hospital less frequently, were not committing violent crimes or serving prison terms, had accommodation and were able to give perspective on their life course. Drake et al. (2006) also potentially supports the theme of participants changing their perspective over time meaning that it becomes easier for them to work with mental health services.

Childs et al. (2011) carried out an IPA study into the experiences of people with psychosis who used cannabis. The participants were under 30, were experiencing psychotic symptoms and were under the care of an early intervention team. The results of Childs et al. (2011) support this study in so far as the participants reported positive benefits to cannabis.

However, there are differences. For instance, the main finding of Childs et al. (2011) was that cannabis use was a journey where experiences of cannabis changed across time and this journey also included negative experiences. Whilst the themes in Childs et al. (2011) of using cannabis to enhance enjoyment and creativity echo the experiences of the study 1 participants, the theme of losing all motivation as a consequence of smoking cannabis was not reflected in this study.

The focus of Pederson and Standberg's (2012) study is different from this one but provides further context for it. Pederson and Standberg's (2012) large-scale qualitative study looked at the experiences of Norwegians who smoked cannabis for medical reasons. The study found that not only did the participants smoke cannabis to alleviate medical conditions but also for issues such as sleep difficulties, relaxation and general well-being. Interestingly, one of the main findings of Pedersen and Sandberg (2012) was that the participants wanted an ally within the healthcare system to sanction their use of cannabis, from the perspective that it was medically useful to them. One study 1 participant was using cannabis because of the perceived health benefits (Arthur believed cannabis was good for his lungs) and the rest were not using cannabis for any medical benefit other than their mental well-being. The study 1 participants neither attempted to hide their drug use nor showed any desire to have their use sanctioned by healthcare professionals. It appeared that the study 1 participants were going to continue to use cannabis regardless of the opinion of professionals. The findings of study 2 demonstrate that clinicians were aware of these attitudes and their clinical practice reflected this reality.

5.4.1   Future practice

This study supports a conclusion of Barnes et al. (2006): given both the prevalence of substance use and the poorer long-term outcomes (see Cantor-Graae, 2000) for people with schizophrenia who use substances, clinicians should routinely assess for substance use and consider specific interventions throughout a person's involvement with mental health services. However, the role that cannabis plays needs also to be seen in different contexts. Whilst there is no denying the potential dangers that exist with cannabis use (e.g. Kalant, 2004; Moore et al., 2007; Bahorik et al., 2013), simultaneously this study highlights personalised benefits which perpetuated the participants' use. Graham and Maslin (2002)

stated that it is easy for clinicians to underestimate the impact that cannabis has on people with SMHP. Similar to the clinical need to actively seek out how service users interpret their mental distress in order to facilitate closer working relationships, there is also a need to understand what service users perceive to be the benefits of their substance use and the context of their use.

5.4.2   Conclusion

The study 1 participants held cannabis in a degree of reverence which was not given to crack cocaine or alcohol. In conjunction with this finding, the clinicians in study 2 accepted that cannabis use was significant in the life of service users and also took a more pessimistic view of crack-cocaine use. It is important to note that none of the study 1 participants viewed cannabis use as problematic and the study 2 participants had adapted their working practice to reflect this reality.

In relation to policy, developing better services for people with co-morbid mental health and substance use has been a national priority in the UK since 2005 (DoH, 2005). Despite this, there is evidence that people with schizophrenia who use cannabis have worse clinical outcomes relative to those who do not (Cantor-Graae, 2000); all the study 1 participants spoke in reverential terms about cannabis use. Research has also highlighted that there is a correlation between being male, never being married, having low educational attainment and having a criminal record amongst people with schizophrenia who use cannabis (Swartz et al., 2006). In these respects the participants in study 1 conform to previous literature on the subject. This study does add different dimensions to the available literature in providing greater depth to the reasons why people in the SMHP population use substances, in particular cannabis. Indeed the participants perceived cannabis use as beneficial and a means by which they could re-establish their identity that had been damaged as a result of diagnosis and the social consequences of diagnosis.

5.5   Critique of Study/ Limitations of Study

This study has several limitations. The sample sizes in both study 1 and 2 are small. It is possible that if a larger cohort had been used in study 1 then the themes generated would have

been different, but that consideration needs to be balanced against the benefits that having seven participants allows for greater focus on the individual experience.

The research was designed with unique features which were intended to combine to create a robust research method. Whilst the engagement phase, the clarifying interview and the service user reviewers all improved the quality of the study, the post-interview meeting was not as successful. It may have been interesting for the participants to have been told of the interpretative findings of study 1 in the post-interview meeting, it provided little to the principal researcher in terms of progressing or expanding thinking about those emergent themes. In retrospect it may have been more beneficial to hold these meetings once the two studies had been completed so that the participants had feedback on the findings of both study 1 and study 2.

Theoretically using IPA to analyse the data generated by focus groups should generate a singular socially constructed narrative. In part this did indeed happen. However, IPA for focus groups does not allow for disconfirming evidence – people who did not agree with the majority view but did not say anything. In both focus groups the team leaders participated in the groups and power dynamics of the relationship between the participants may have resulted in some participants being reluctant to express a view that they believed their line manager may have disapproved of (Liamputtong, 2011). So, whilst the socially constructed narrative based in human experience developed is interesting and useful, it is not reflective of any dissenting voices. This critique can be neither proved nor disproved. However, the clinicians gave the impression of talking openly and freely, no-one contradicted themselves nor was there incongruent body language.

Although the service users gave the impression that they were talking in an open, honest and unguarded manner, a persistent question that can be raised against the study is that there was a possibility that if the researcher had been from the same ethnic background then the responses given by the service users may have been different. However, this could also be true had there been a difference in gender between the researcher and the participants. Ultimately, the validity of the research lies in whether at the time of the interview the participants gave the impression that they were discussing the material in an honest and unguarded manner.

5.6   Publication

To date there have been three papers published in peer reviewed journals and papers delivered at six international conferences from this thesis. That the work has been published and accepted at conferences highlights that the research method is considered to be of a suitable quality and the findings of the study were considered to be reliable and dependable by academic peers.

Wagstaff, C., Williams, R. & Farrell, D.P. (2011) Disengagement of clients from mental health services, *Mental Health Practice*, 14 (8), pp.20-22.

This paper laid out the need for the research, the research aims and objectives, and the intended research method.

Wagstaff, C. & Williams, R. (2014) Specific design features of an interpretative phenomenological analysis study, *Nurse Researcher*, 21 (3), pp. 8-12.

This paper highlighted the specific design features of study 1, and explained the research method and analysis process in detail.

Wagstaff, C., Jeong, H., Nolan, M. et al. (2014) The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology, *The Qualitative Report*, 19 (24), pp. 62-70.

This paper collected the reflections of eight relatively novice researchers' experience of using IPA as a research method. Reflections on carrying out study 1 were drawn upon in this paper.

Conferences
2010: Conference paper: An Interpretative Phenomenological Analysis exploring the relationship between self-concept and disengagement from mental health services for people with severe and enduring mental illness, at the *16th International Network for Psychiatric Nursing Research Conference*, Oxford University.

This conference paper laid out the intention of the study, the rationale for why the study was important and also the aims and research questions.

2011: Conference paper: Methodological issues arising from an Interpretative Phenomenological Analysis study of service user's experiences of disengagement from mental health services, *17th International Network for Psychiatric Nursing Research Conference*, Oxford University.

This conference paper was an exploration of the research method and the analysis process that was employed in study 1.

2012: Conference paper: Emerging findings from an IPA study of Black men's experiences of disengagement from mental health services, *18th International Network for Psychiatric Nursing Research Conference*, Oxford University.

This conference paper reported on the emergent interpretative findings from study 1.

2013: Conference paper: NHS staff perspectives on the experiences of people with severe mental health problems who have a history of disengagement from mental health services. An IPA focus group, *19th International Network for Psychiatric Nursing Research Conference*, Warwick University.

This conference paper reported study 2. It covered the overall aim of thesis; the progress to date on the thesis; the methodological and analysis process for study 2 and the findings from study 2.

2014: Conference Paper: An interpretative study into the experience of disengagement from mental health services. *3rd European Conference on Mental Health Nursing*, Tallinn, Estonia.

This conference paper gave an overview of studies 1 and 2. The paper highlighted the aims and objectives of the overall study, examined the methodological and analysis process for the two studies and finally presented the findings; however, this was without discussion of the findings or reference to previous literature on the subject.

2015: Conference Paper: Experiences of disengagement from mental health services: an interpretative study, *RCN Research conference*, University of Nottingham.

The most recent conference paper gave an overview of both study 1 and 2, highlighted the aims and objectives of the overall study, explained the methodological and analysis process for the two studies combined and finally presented the findings and discussed them with reference to previous literature on the subject.

The inclusion of these three publications in peer reviewed journals, and the presentation of six papers at international conferences serves to highlight that the researcher is engaging in the academic process and that the work undertaken has been reviewed and endorsed by academic peers. This also points to the 'trustworthiness' of the thesis. That it has been seen and endorsed by academic peers would indicate both that the method is robust and also that the interpretative findings are recognised as credible.

CHAPTER 6: CONCLUSION

This was an IPA study designed to provide a detailed, idiographic understanding of the experiences of a small group of purposively sampled individuals with experience of the mental health care system in England. Although the methods employed did not gather data that is 'generalisable' (Parahoo, 1997), they provided useful in-depth insights on the phenomenon that are trustworthy and credible (Darbyshire et al., 2005). The implications of the work are now considered.

6.1   Implications for Practice

Disengagement from mental health services is an issue of on-going interest and concern for academics, clinicians, managers, commissioners and also service users (Chase et al., 2010). The first main finding of the study was the willingness of the study 1 participants to engage with the study. The primary diagnosis of the participants, who described their racial identity as 'black', was schizophrenia. They had all been identified as having a history of disengagement from mental health services by health professionals and the findings indicate they had limited connections to social structures (including mental health services). As a consequence of these limited connections the study 1 participants lived on the margins of society with a prevailing sense of sadness. These factors suggest that it would be hard to engage them in research. However, they willingly engaged in the research process and discussed their experiences in depth with a white researcher who they did not know. There are a number of possible explanations for why these men chose to participate in the study. A conclusion is that despite the participants in this study having the same demographic background as those people who literature highlight as being the most likely to disengage from both research and clinical work, these participants wanted to talk. Despite the efforts of the professionals, as reported in study 2, the findings of study 1 indicate that the participants did not feel listened to. Potentially, this study offered a counterpoint to that, as the researcher wanted to hear about their experiences. The participants spoke thoughtfully about different emotive issues; mostly they did not appear guarded and gave the impression of speaking honestly. It remains an unresolved point whether the study 1 participants had disengaged from mental health services or whether services had not engaged them.

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The interpretative findings from study 1, explored further in study 2, illustrate that the participants experienced disengagement from mental health services in the context of being disengaged from society more generally. This suggests that clinicians need to engage in discussions with service users to develop a broader understanding of a range of factors that contribute to their experiences of disengagement from mental health services. An interesting finding of the study was that the study 1 participants did not regard themselves as having a history of disengagement from services, and that such terminology was a professional description of the relationship between services and service users, rather than one used by the men. Both this study and previous literature serve to highlight that medication remains a difficult issue in the engagement of people with SMHP and mental health services. A finding of both this study and Davies et al. (2014) was that the participants appeared to resent the emphasis mental health services put on medication and that the main treatment being offered by mental health services was medication (see also Moncrieff, 2009). That the men felt the main treatment offered by mental health services was medication needs to be viewed in the context of current policies aimed at people from BME communities, requiring a move away from medication towards greater access to talking therapies to improve care (DoH, 2014a).

Study 1 demonstrates that the participants had an ambivalent relationship with mental health services. The interpretative findings suggest a complicated and largely negative relationship. Along with their concerns about medication, the study 1 participants also reported feeling "*hounded*" by services. A finding of study 1, recognised by the participants in study 2, was the suggestion that if mental health services really wanted to help the study 1 participants then they should just leave them alone. Because of the high levels of risk there was no possibility of this happening in the near future; however, the study 1 participants acknowledged positive experiences of mental health services, in particular addressing practical concerns. For example help with housing, finances and, in two cases, the supply of oral medication. This final point indicates that the participants made a distinction between oral and depot medication, a distinction which the study 2 participants were aware of. Perhaps the study 1 participants wanted to be "*left alone*" or alternatively they wanted to have services they chose and accessed on their own terms.

The contrast between the findings of study 1 and 2 sheds further light on an important component of the experience of disengagement. Whilst the clinicians in study 2 espoused a 'recovery' model and reported their efforts to deliver care that was holistic, individualised and, where possible, provided choice for service users, the study 1 participants' experience of mental health services was characterised by a sense of powerlessness and lack of choice. Evidence of the 'recovery' philosophy espoused by the clinicians in study 2 was that they took great care to treat the service users for whom they were responsible with as much individuality and choice as possible; for example, regarding illicit drugs, medication, spirituality or the use of language. Different views are expressed in the literature concerning the primary role of AOTs (e.g. Claassen & Priebe, 2006; Killaspy et al., 2009a) and the findings of this study reflect that divergence of opinion. On one hand the primary role of AOTs could be seen as risk management and that all other considerations were secondary to that; on the other, the focus group participants believed their primary function was to promote the well-being of patients. That these seven service users had a sense of powerlessness and lack of choice serves as a reminder that it is imperative that clinicians listen to service users' experiences in order to improve services (Van Den Tilaart et al., 2009).

It was found that the study 1 participants were aware of their diagnostic label, but not necessarily what it meant. A recommendation for future practice for clinicians working with service users who do not hold conventional beliefs about their mental distress is that they should cultivate an understanding of the service user's perspective of their mental distress (Hamilton & Roper, 2006). Additionally, such an understanding needs to take into consideration the impact the person's culture has on their perspective of their mental distress and how that perspective subsequently affects their identity.

An interpretative finding from FG1 was that the clinicians constructed a social narrative, embedded within the phenomenological context, of the black male service users they worked with. These service users are proud to be independent and are deeply affected by the social shame they feel as a result of their involvement with mental health services. The shame felt as a consequence of this perceived stigma from the involvement of mental health services is a significant factor in their continued disengagement. Two possible implications for practice from this finding are firstly that there needs to be considerable public health education

regarding mental health. Also, there needs to be further education about the nature of the work done by mental health services, both within the BME communities and society in general, in an effort to reduce the stigma of involvement from the services.

Theme B in study 1 examined the strategies that the participants had used in order to reaffirm their personal resilience and identity. The study 1 participants found solace in their spirituality and the findings of study 2 indicate that the clinicians were not immediately aware of the work they did to provide spiritual support to the service users. However, through exploring the issue further it transpired that the clinicians did work to facilitate the spiritual welfare of service users. An interpretative finding of study 1 was that the older participants were more comfortable with their relationship with mental health services. However, this finding was not completely recognised by the participants of study 2; FG1 interpreted this as the service users having been 'worn down' by the persistent nature of the mental health services and FG2 highlighted that as people get older they often receive less restrictive forms of care, for example being treated in the community as opposed to as an in-patient.

Aside from individuals developing their own strategies to develop a more positive social identity, it should also be the responsibility of services. Clinicians and commissioners working in mental health services may benefit from working collaboratively with service users to promote opportunities for social inclusion for the SMHP population, through housing, work or education for example. As highlighted by Knight et al. (2003), a potential implication for practice from this study is that it is not only the responsibility of service users to strive to establish a positive identity, it is also the responsibility of professionals and the person's immediate community.

There is a mismatch between the benefits that the participants in study 1 believed in and the literature (e.g. Kalant, 2004) as regards the use of cannabis. The findings of this study are suggestive that the participants perceived cannabis use as beneficial and a means to re-establish their identity that had been damaged as a result of diagnosis and the social consequences of diagnosis. This study does add different dimensions to the literature in providing greater depth to the reasons why people with SMHP use substances cannabis.

The current study suggests that participants had their own personal and sociological motivations for disengaging from mental health services. If a functional model of disengagement from mental health services was to be devised then it would need to be multi-dimensional, inclusive and complex. The complexity of the model would be a reflection of the service user's idiosyncratic social, cultural and psychological experience.

6.2   Implications for the Methodology

The unique features of the research design all combine to make for a robust research method, allowing for both in-depth exploration of participants' experience and also maximising the opportunities for researchers to broaden their double hermeneutic. Brocki and Weardon (2006) highlighted that an advantage of IPA as a research methodology is its flexibility in application, allowing for it to be used for a variety of data collecting methods and data types. In study 1 this flexibility allowed for the introduction of four distinctive features: the engagement phase, the clarifying interview, the involvement of two service user reviewers and the post-interview meeting.

The engagement phase of the study design proved to be an important factor in recruiting participants and enhanced the richness of data gathered. The engagement phase with each participant, before the research interview, provided the opportunity for a relationship and rapport to develop between the researcher and the participants. This observation seems to be borne out when it is considered that the one participant who declined the invitation to participate in a second clarifying interview did not have an engagement phase with the researcher.

With one exception, the study 1 participants were interviewed twice, the two interviews being conducted up to five months apart. The purpose of the clarifying interview was to obtain a more detailed, descriptive account of the participants' experience of disengagement. This stage of the study was very useful. The clarifying interviews provided the opportunity to seek clarity where the first interviews had been unclear and also the scope to explore issues in greater depth.

The transcripts were read by two service user reviewers, acting in an advisory capacity (Johnson, 2012). This stage of the analysis process proved beneficial, it fulfilled its function and informed the principal researcher's thinking on the data and broadened the principal researcher's double hermeneutic on the subject (Smith et al., 2009). Pages 22-26 of the reflective diary (Appendix 3) demonstrate the impact that the service user reviewers' perspectives had on the research interviews, the development of the researcher's double hermeneutic, and the interpretative findings.

Once all the interviews and transcriptions were complete, the study 1 participants were invited to a post-interview meeting in order for them to hear and respond to the interpretative themes. Of the four unique features of the study, this stage was the least beneficial in the research method. Whilst it may have been useful for the research participants to be told of the themes of the study, it provided little to the principal researcher in terms of progressing or expanding thinking about those emergent themes. In retrospect it may have been more beneficial to hold these meetings once the two studies had been completed so that the participants had feedback on the findings of both study 1 and study 2.

With regards to study 2 it should be acknowledged that there were quieter participants, particularly in FG1. Perhaps the quieter participants had opinions that differed from the prevailing narrative but they did not express these for social reasons and group dynamics. IPA was used to analyse data collected in study 2. Despite misgivings expressed in the literature (e.g. Green & Thorogood, 2014), IPA worked as a method of analysis, as substantive interpretative findings came from the study. However, these findings may have been different if there had been the scope to hear the perspective of all the participants in detail.

6.3   Implications for Future Research

An important piece of research that needs to be done is a qualitative study with a client group similar to the study 1 participants focusing on the length of time they have been in contact with mental health services. Through listening to the experiences of people who have seen many changes in how mental health care is delivered in the UK there would be valuable lessons to be learned, which in turn could inform future service developments.

Simultaneously, the findings of this study would also suggest that the participants in any such study would appreciate the opportunity to have someone listen to their experiences.

Similarly, further research is required into the ambivalent relationship that the participants had with mental health services. Somewhat paradoxically the interpretative findings of this study suggest that the participants believed they had schizophrenia, wanted to talk about their experiences, yet wanted mental health services to leave them alone, and felt hounded by them, whilst valuing the pragmatic support which services provided. Subsequent research is required to explore how a functional model of service delivery could be developed to incorporate these seemingly contradictory statements.

6.4   Implications for Policy

This thesis investigated the phenomenon of disengagement from mental health services; some findings are in line with current government policy and offer component solutions to strategies proposed.

Page 26 of Five Years Forward View (NHS, 2014) demonstrates that the government has an overall commitment to improve NHS mental health services and highlights that only a quarter of the population with mental illness in England are currently receiving treatment. Whilst acknowledging the complexities of providing care for people such as the participants in study 1, the findings of this thesis and Five Years Forward View (NHS, 2014, p. 16) both acknowledge that it is only through engaging with local communities and empowering people through personalised care that services, and satisfaction with services, will be improved. The 'How Will We Get There?' section of Five Years Forward View says nothing specific about mental health. However, the findings of this thesis indicate some steps that could be taken to meet the suggested strategies to change the direction of the NHS. For example, careful consideration of the language used as an important component of clinicians focusing on clients' stories, or experiences, rather than diagnosis and care planning. One of the goals of Five Years Forward View was to break down the barriers to care; the participants in study 1 were a hard to reach population. Whilst they had a history of disengagement from mental health services, the findings of this study would suggest that when the participants felt that they were being listened to and the emphasis of the encounter was shifted from risk to need

they were willing to engage with mental health professionals and the barriers to care were less evident.

The recent government mental health policy document Five Year Forward (NHS, 2015), touches on similar themes as this thesis. The first theme of the policy – 'Prevention and Stigma' – states that if the stigma associated with mental illness was more effectively tackled then people from BME groups may be more likely to engage with mental health services. The findings of this thesis additionally suggest that work needs to be done to tackle the stigma not only of mental illness but also of being involved with mental health services. The study 1 participants felt they had little choice in the treatment they received and wanted to access services on their terms. The second theme of Five Year Forward (NHS, 2015) – 'Access and Choice' – recommended that not only should it be easier to access NHS mental health services but people should be provided with a greater range of evidenced based treatments to choose from. Additionally, special consideration should be made to "targeted" groups, such as people from BME communities, to enable better access services. The study 1 participants did not understand aspects of the treatment provided by mental health services, for example being admitted to hospital; it is of note that under the same 'Access and Choice' theme there is call for people to be provided with a clear rationale about why they have been admitted to hospital. The third theme of Five Year Forward – 'Quality and Experience' – again asserts that control about decisions in treatment should be handed back to the people receiving that input, just as the perceived lack of control was a reoccurring theme for the study 1 participants.

Theme A in study 1 highlights that the participants experienced disengagement in the context of their limited connections to most social structures. SCMH (1998), Priebe et al. (2003), Keating and Robertson (2004), the Mental Health Act Commission (2006) and Rabiee and Smith (2007) all report that people of African-Caribbean descent often experience dissatisfaction with mental health services. Social inclusion was an aim of No Health without Mental Health (DoH, 2011) but the study 1 participants reported that they felt excluded from much of society. Successive governments have been aware of this dissatisfaction at a policy level (DoH, 2005, 2014a).

Whilst there may never be a straightforward mechanism developed to engage all people with SMHP with mental health services (Lister & Gardner, 2006), this thesis contributes to the body of literature on the phenomenon of disengagement from mental health services. It delivers an in-depth exploration of the experiences of people with a diagnosis of SMHP and a history of disengagement from mental health services from the perspective of both service users and clinicians. The findings indicate that the experience of disengagement for these participants needs to be understood in the context of them having limited engagement with many social structures. However, in response to on-going threats to their identity, theme B in study 1 demonstrated that the participants had developed strategies to reinforce their resilience to help them re-establish a more positive identity. Study 2 added further depth and differing perspectives on the experience of disengagement. Additionally, this thesis has a unique and robust research method and an incidental finding that people who literature suggest should not engage with mental health services and research actually did so and spoke in an apparent open and honest manner.

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APPENDICES

Appendix 1: **Cycle of Avoidance Permission**
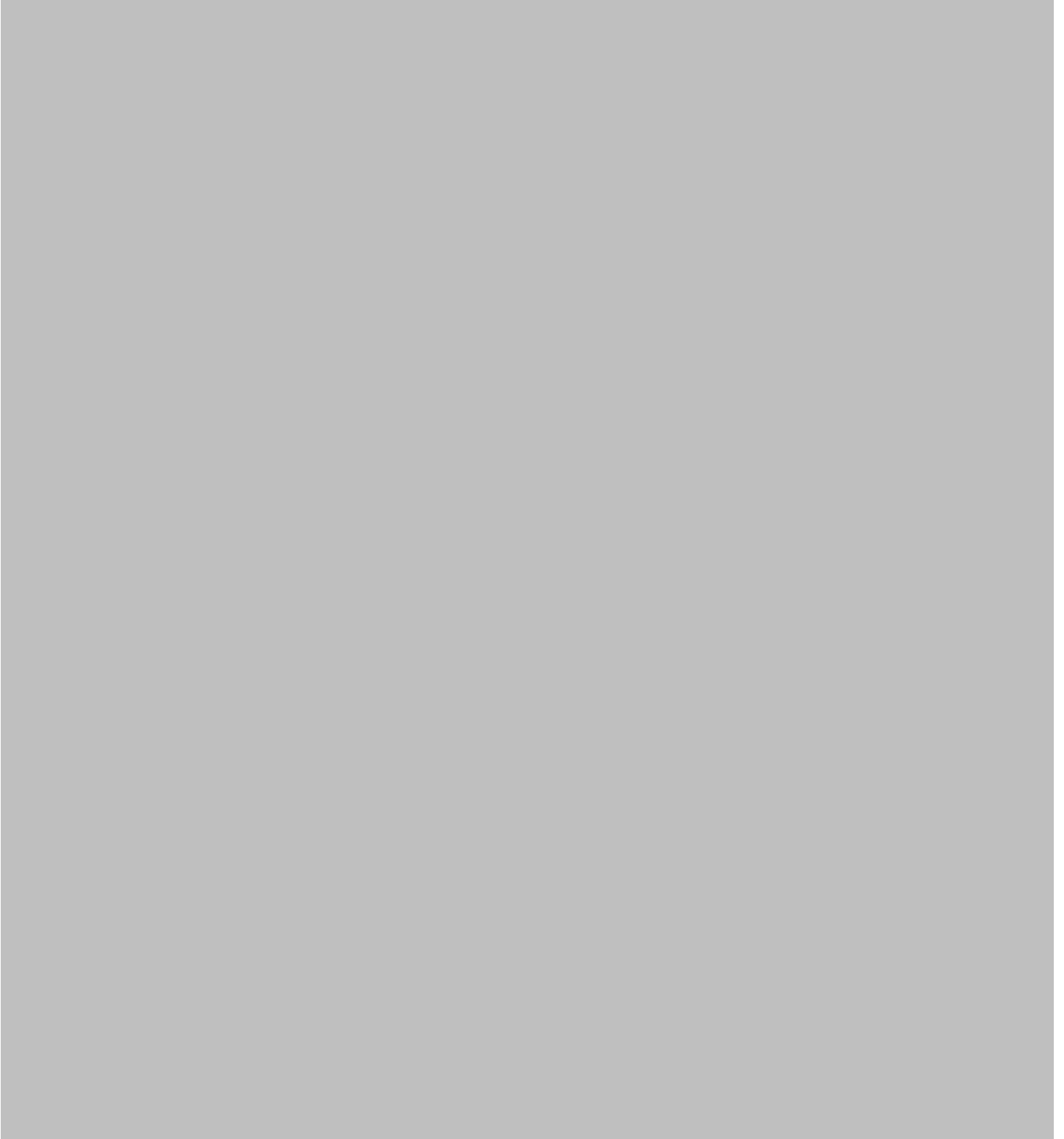
Appendix 2:   Interview Schedule

Initial questions to form Interview Schedule Guidance

The general essence of the research questions is trying to understand the multitude of reasons why the individual research participant has disengaged from statutory mental health services. Part of the I.P.A research methodology is that the research questions will grow and develop according to the responses of the participants. The broad questions here are very much starting points from which subsequent questions will develop. The questions will be based on four themes; disengagement from mental health services, personal understanding of health, well-being and illness, the role that drugs and alcohol play in the person's life and expectations of mental health services.

Below are the research questions in bold, accompanied by examples of the opening questions for each theme in italics:

Research question #1. What are the experiences of people with severe mental health problems, who have a history of disengagement from mental health services?

Example questions:

What are your experiences of contact with mental health services?
Do you think you have ever disengaged from mental health services? (Explain professional definition of disengagement if necessary)
What does disengagement mean to you?
What happened as a consequence? Is that what you wanted?

Research question #2. How do people who experience severe mental health problems and a history of disengagement from mental health services understand their own health, wellbeing and illness?

Example questions:

Would you say that you are in good health?
What does health mean to you? What does illness mean to you?
Are you mentally ill, in your opinion?

Research question #3. What are the research participants' understandings of the role of drugs and alcohol within their lived experience?

Example questions:

What role does substance use play in your life?
What bearing does substance use have on your health?

Research question #4. How do the research participants perceive their needs in relation to statutory mental health services?

Example question:

If money and time were not a consideration how could mental health services better meet your needs?

Appendix 3:   Reflective Diary

Research diary

Notes from PhD supervision 12-10-11

In discussion about the emergent theme of "Transformation" Derek tried to reframe this as "Post Traumatic Growth". It was highlighted that both my understanding of the code as Transformation and his understanding of the same code as Post Traumatic Growth was a good example of the effects of double hermeneutics – what we saw reflected our own preconceived notions about how we understand our world and by implication how the research participants are understanding their world.

Under the larger theme of "Why Disengage?" there were three subordinate themes of 'Not being listened to', 'People telling me what to do' & 'Nobody tells me nothing'. A suggestion to come out of supervision was that these three separate subordinate themes could be restructured together as a 'Communication' theme.

Across the emergent themes there is a big sense of frustration – frustration as opposed to anger. Could these be built as a theme? Similarly all the participants are isolated (disengaged from family, wider society and mental health services) and may indeed choose to live their life in this fashion. Could this be an emergent branch of the research – "The participants are isolated" and then off that different ways they are isolated from wider society/ family/ father (hood)/ services? Also trauma. To what extent have the participants been traumatised by their experiences? Do they see themselves as traumatised?

Bob spoke about how sociologists didn't think of people as individuals but rather as subjects/ objects. Within that he went on to talk about how a narrative that he was reading into the emergent themes of this research was a) the sense that the research participants were all struggling to develop a sense of agency and b) that the health services treat people as objects/ subjects and that was very much being evidenced in this research.

Related to Bob's latter point above a lot of the research participants is that they are aware of internal and external rules. Privately I had noted that there was a minor theme of people talking about the right path/ wrong path (good path/ bad path) and these two ideas are related to each other. Whereas Foucalt would talk about dominate groups developing a discourse and

a dominant ideology – and religion can be consumed into a dominant ideology. However, I feel that the participants here are quite idiosyncratic in determining their own religious beliefs – they determine their own paths and their religious beliefs are only loosely fixed onto established religions (or dominant ideologies).

Taken from T. pages 19-20.

CW   ... Does religion have an important role to play in your life?

T: Yeah.

CW   In what ways?

T: It keeps me sane.

CW   Okay. I'd love it if you'd be able to explain that for me please.

T: It just keeps me sane. I stay away from the bad and do the good.

CW   Alright. So can you give me an example of "the bad" please?

T: Stabbing someone.

CW   Okay. So you feel that without religion you'd be out stabbing people?

T: Who knows? Who knows? Probably.

CW   Really? Okay, you stay away from "the bad" and towards "the good". What's "the good"?

T: It's natural. It's in yourself. You should know. Your conscience tells you.

26-10-11

Emergent theme:

Awareness of personal transformation/
Process of post-traumatic growth

A theme that I am developing in my mind, particularly regarding Clue, is about disengaging to make life interesting and relieve boredom. He says as much but he also talks about "changes" and that disengagement is a "getaway" .

Josh, Clue, Rebel all talk about their growth/ transformation in relation to working with mental health services

Josh: "Right now I'm reacting, I'm trying to say that the injection or the medication or the Doctors make me, help me to disregard that life that I was living because I think I'm living a better life now, ... because I don't thieve no more .... I don't fight people." {p. 18}

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Clue: "Yeah, because I'm changed from stealing and them things.... and changing to just live my life, as if I'm normal, what normal do." {p. 5}

Bubbles: "Yeah that's what I <u>was</u>, schizophrenic." {p. 5}

Josh: "I got that sense of control now ... because God has done something for me .... I believe that I must reap what I sow, but I ain't sow nothing, you know. I just believe that I got to help myself again. Come back down to helping myself again ... but I don't want to do things or make a person life be miserable and inferior." {p. 20}

Rebel: This is trying to come back to my normality, to save up my health, to put me back on my feet again. {p. 5}

Rebel: I was lost before I was found as if I could have said I was blind before I could see. {p. 6}

Rebel: I struggled and struggled but I made it. I entered by the door in society, I didn't climb in through the window, like a thief you know? {p. 15}

Black Zee: I have rebuilt my life through being in that situation because that was my life, I was given that life. This life chose me, I did not choose this life. {p. 11}

<u>31/10/11</u>

Meeting with Yvette.

Please also see hand written notes from the meeting with Yvette.

There is a strong theme about wanting to be independent, but isn't this within cultural norms?

Again there is a strong them of not wanting to be controlled and the dislike of medication is probably related to this: medication is associated with control.

"**MHS try to get people to but into helping them and curing them, what are they really offering? Is there a group of people that don't benefit, or the perceived benefits of MHS means little to the individuals on the receiving end of services**" – to return to my ever growing 'ambivalent' theme MHS may well be the only consistent that people have in their life. Secondly, is this related to Mary's idea of 'carrot', what's the carrot about why people would want to be involved?

Yvette also threw a spanner in the works of the 'Transformation' theme. I say 'Transformation', Derek says, 'Post-Traumatic growth'; Yvette says, 'Given up the fight'. Now, I'm stuck with a quadruple hermeneutic!

Yvette picked up on the idea that people thought that prison was a preferable option – providing people the opportunity to escape MHS.

Throughout the transcripts one thing that struck Yvette was the lack of collaboration perceived by the research participants: they frequently expressed the view that they had no control or choice but unexpressed but implicit to that idea would be that people did not think that their relationship with MHS was a collaborative one.

Yvette agreed with my thoughts that "The Benefits of Cannabis" was a major theme. Her thoughts on the subject were that "Natural" was being used a justification. But then why - ? Self-medicating; ? Acceptance within Social Circle; ? Community activity.

These thoughts link to a theme that Yvette saw, but I hadn't noticed as separate: "Social". A theme that links Cannabis to Accommodation to Family to Identity & to criminal activity. {*Perhaps draw a diagram that could demonstrate this*}

Persecution. Mental State

Yvette highlighted that Clue and others about persecution. Community staff were against the participants; Hostel staff were against the participants; MHS staff were against the participants.

There is no collaboration between the participants and staff they are supposed to be working with plus people aren't taking any medication (and they have very little understanding of the medication prescribed) plus they feel persecuted plus people are experiencing symptoms of mental illness. This is hardly a ringing endorsement of mental health services.

Yvette linked theory/ model of mental illness to the person's label of themselves. Some believed that Schizophrenia is caused by torment or for a reason and also there was a belief that there is a theory behind the voices. For example, Bubbles felt that his schizophrenia had been caused by his drug use and being racially abused and Clue describes himself as a 'sick man'. Rebel felt that Schizophrenia was about confusion, being lost, not really being there, being caught up in a nightmare and being a tragedy.

Yvette agreed that medication was a strong theme. And again in critique of services the description being offered was that medication came across as the only service being offered. A pertinent negative that Yvette pointed out to me, you would expect people to say that they were not willing to take medication because of side effects but people weren't saying this. I don't think anyone mentioned side effects – other than a few people saying medication messes with their head (fast forward to 24/11). Individually from different people it was said that:

An effect of the medication was that whilst it made him feel calmer if stopped him from going out & about;
Reasons for medication:- to think better & to live better; to relax the mind; to help with stresses and strains.
Many have tried different medications but none have really worked – they still hear voices;

Positively Rebel relies on medication to get rid of those thoughts and to see things correctly and both Rebel & Arthur both said that they were under the impression that once they were discharged from hospital they were no longer required to take medication;

T if he had a choice he wouldn't take it and twice said he only takes it because he has to. Whilst acknowledging that he is calmer on it;

Josh feels that he can cope without it, that he is better off without it and the fact that he is on medication makes him feel as if he can't cope (with life). Also that he is more care-free without medication

Arthur has previously used medication as a bargaining tool

Strong dislike of depots (partly to do with dropping your trousers – but this reinforces that people are offered a choice). Rebel didn't question his depot he just took it but felt in a dumb maze whilst on it.

It felt as if 'health' was a game they wanted to play but they didn't know what the game was. I had framed this differently, that people saw health as an ideal but weren't motivated to be healthy. Indeed, some participants did say that services made them unwell.

In line with my own thinking Yvette felt there were themes to be developed around:

Wouldn't see services if they had a choice (later strongly reinforced by Arthur in the Clarifying interview)

Services were never there when you need them. (Though I have never clarified what needing help amounts to)

Services don't always listen.

That services do **want** help/ care. That involvement with services does eventually lead to reduced admissions (CTOs? Transformation? Acceptance/ Giving up the fight?; help with accommodation; picked him (Bubbles?) when he was 'Down & Out'; Help keep people out of trouble/ criminal activity (Josh & Clue); "Give guidance" (Clue); Be more calm (T).

Linking "How MH services help" to the "Transformation" theme Yvette noted that someone (Rebel) had said he has had to learn how to be patient and understanding in order to learn how to communicate with MHS.

The benefits have a potential down side. There is a concern that services delivering bus passes/ hand cream and housing with foster dependence. With good intentions services take away responsibility and autonomy from adults. That's even before we open up the Pandora's box of welfare benefits. To what extent has a situation where both parties have complicity allowed the participants become dependent on cannabis/ MHS/ welfare benefits.

Many of the negative experiences that I have noted were also seen by Yvette:

Choice (not being given a choice) which implies that there is a perceived lack of collaboration. This sense of a lack of collaboration leads to apparent contradictions such as people feeling as if they are being forced to cooperate and being engaged against their will.

A point that both Yvette and Lloyd & Mary noted was that there is a sense that there is no reward for being involved with MHS. What's the carrot? Ultimately what are both parties aiming to achieve?

People talked about 'Bad Luck' (Rebel, but I put this under the superordinate them of pessimism); people feel hounded (Bubbles); services don't help; services don't listen; feel services are against them; feel that services are brutalising/ policing them (Clue); always being watched/ monitored; Yvette hermeneutic was that the course of people's lives was being interfered with.

There are no rewards from being involved with services, there is always a catch. (?/ ?Yvette's hermeneutic). Clue alleges that services are partial in who they help.

From Rebel he has previously felt that services have ruined his life, contributed to him losing his flat, has felt put down and that he was not assessed properly;

T felt the initial assessment wasn't necessary but that it was his family who felt it necessary and he was dragged into services from that point

Arthur has been in & out of hospital and feels it was unnecessary. He blames the nurses and feels that he has had no choice in being engaged with services.

Identity – Participants were aware of the label "Schizophrenia" without always knowing what it meant. For some schizophrenia represents the past but not the present (Bubbles). Others don't believe that they have schizophrenia whilst simultaneously saying the agree they have the symptoms and accept that it is the label that they have been given (Agree or disagree/ Understand or not understand people knew the broad medical diagnosis that they had). Voices did not tend to cause undue distress.

A critique of the research is that the "What would you do if you were in charge MHS didn't really work." The question was too big and it would appear that the participants thought of themselves as too small. However, there were interconnected subordinate themes which in turn fed into superordinate themes:

People wouldn't be medicated so much;
Let people do for themselves {Claim autonomy/ take control as opposed to services doing it?}
Observe people to see if they needed help, which could give help/ support (but as I have noted it is unclear what constitutes needing services)
Give medication to those who need it – not forced;
Leave people alone to sort their own minds out;
Seeing the individual;
Not attacking people for not thinking the same way;
Organise as a charity, (Who said this?)
Keep the communication going
Choice about living arrangements;
Choice

Yvette noted the same pertinent negative – she was surprised that race was not there.

Arthur talks about Racism when trying to get a job;

Josh/ Clue talk about potential for racism within the community;

If it has effective the care delivered then this wasn't well articulated.

Religion/ Spirituality

A strong belief in God;

An awareness that Good/ Bad had played roles in their life

? someone believed that God controlled mental illness

People evidently read the New Testament and take inspiration from it. Supported & feel protected.

Rebel talks both about himself as being a spiritual teacher and being involved in the spiritual warfare going on around him.

Does age play a part in spiritual development? Could this spirituality superordinate theme be shoehorned into a "A way of life" superordinate theme? Part of 'Citizenship & Individuality'?

Self-Management

Trying their best to look after themselves but do not feel that they are getting anywhere. Down as a consequence of this. People are trying to do what their conscience tells them.

Want to help others (Josh), got to get out of this world away from crime and to try and live a good life. Trying to be a nice person (?)

Not using drugs anymore (Bubbles) left that social circle;

Trying not to mix with the wrong crowd;

Less criminal activity.

Self-management of life but not the micromanagement of symptoms.

Now I hadn't thought about Self-Management in the slightest and in many respect this covers the same material as the Transformation theme

Who is responsible for their mental health? Has it been put to them that they

have some responsibility for their (mental) health? But, the opposite side of this argument is that what decisions are you reasonably able to make for yourself when there is no choice in engaging, no perceived collaboration and a feeling that they have to cooperate?

At the end of the discussion I put the question to Yvette about if she was to write a paper based on this material, what would she write. She said the paper for her was about "Credibility". As MH professionals what do we perceive as helping people? When do our perceived notions of help become intrusive/ start ruining people's lives? Further on the issue of credibility all the participants involved had been in services at least ten years but they all have medically diagnosable symptoms – how effective is the service and treatment? Essentially Yvette was asking they have been involved with services all this time for what?

Related to credibility is also responsibility. The research participants desperately need to forge positive links with their community which would really help them move forward. However, they are forced down the MH route – but where has it got them?

I replied that, other than a methodology paper, the first paper I was minded to write was one about cannabis. Yvette agreed adding that there is a lot to write about why they were smoking it. In Yvette's opinion as health professionals we are reluctant acknowledge the secondary benefits that people get from smoking (acceptance, company, adhering to social norms). Another question that needs to be asked is, "What else have they got?" Cannabis brings love, wisdom, creativity etc., what else in their life brings that? Potentially one of the most positive impacts that cannabis has is that it stops some of the isolation that this population feels.

1/11/11

Still dithering about two different strands of theme. There's the "Nature" theme – related to God? Related to anti-medication? Related to cannabis? Are all four inter-related? Can I create a theme of 'Natural' of which the subordinate themes are God/ Cannabis/ anti-medication?

The other theme that I'm mindful of is the 'Transformation"/ "Post-Traumatic Growth"/ "Given up the fight". I would be tempted to say that it's just the maturing process except for that quote from Black Zee talking about how religion got him out of this situation. Definitely need to check with Black Zee what he meant by "this situation."

2/11/11

Saw Clue.

He was reluctant to see me and needed persuading to do interviewing. Wanted paying again. Not pleased to see me. But had to be woken from a sleep at 1 to do the interview. Lack of warmth. Continued sense of over-riding sadness. As so as the interview finished he walked

out of the room, indeed he was walking before the tape had already been switched off. As I was driving away I too felt depressed/ sad/ miserable.

3/11/11

Saw Arthur.

He was ok to see me. Although he was initially reluctant to see me, saying that we had never agreed to a second interview he was easily persuaded. He was much friendlier than previously. More talkative. No anger, no questioning about money. No bad atmosphere. Unlike Clue, he did not deny anything that had been said previously

On reflection regarding the Arthur interview earlier today. For the most part for the two interviews Arthur was quiet, uncommunicative talking in one word answers and half sentences. But then in the clarifying interview for entered into an eight minute monologue. What was this monologue about? Well, in his terms he was explaining the highlights of his involvement with MHS and how he saw the events knotted together. In my interpretation of what he was saying he was talking about transience; he was talking about not understanding why events were happening; he was relating his physical health to his mental health; within the same monologue he was expressing his ambivalence about MHS – it was *Dr* ___ who got the colostomy bag sorted out, it was *Dr* ___ & associates who kept him tied into MHS even though his original sentence from the Home Office had been served; and he was also talking about the beguiling issue of housing – MHS would find him houses and they also move him.

So, what am I saying?
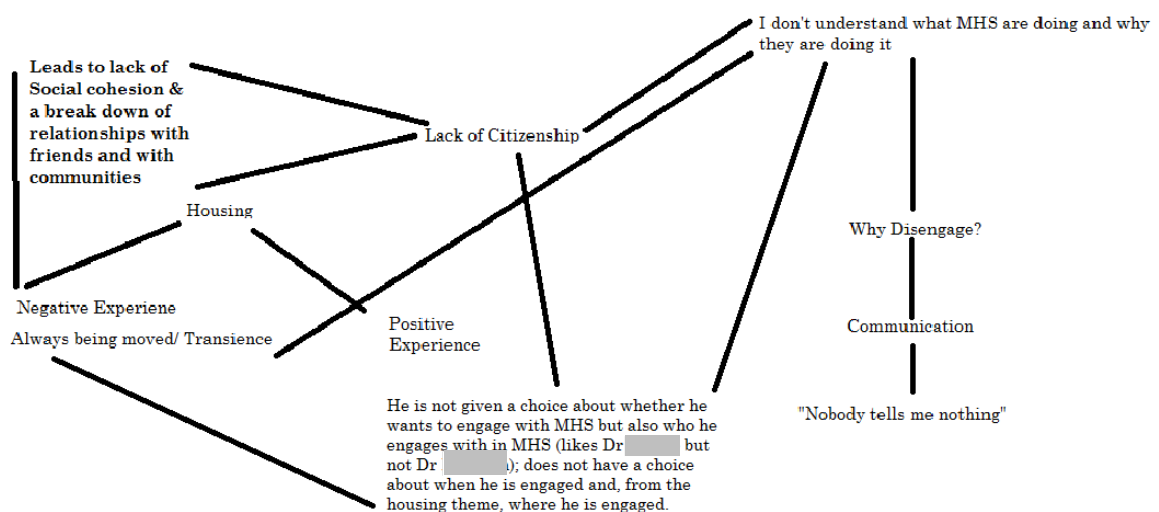
Also what should be noted was that in the first interview Arthur was angry, to the extent he threw the gift card at me. However, in the clarifying interview he wasn't letting off angry vibes. Nor when you read the text was he angry about his situation in the world.

11-11-11

Saw Bubbles.

He wasn't expecting me but was pleased to see me.

He wasn't as sad as he had been in the summer, he was bright, smiling, happy and engaging. Happy to answer questions, no quibbling about money. Thanked me half a dozen times at the end of the interview for taking an interest in him. Also at the end of the interview we had a chat about 'the good old days', people we used to know, hospitals we used to know. He asked about ▬▬▬, an ex-girlfriend of his. He had beaten ▬▬▬ almost to death ten years ago when I was his key worker. In the mayhem in the fall out after that Bubbles & I never spoke properly about why he did it. Today he seemed to have two justifications, A) She had stabbed him previously (about two years previously as I recall) and B) She walked into a pub with another man – it was jealousy. Again, as an abdication of moral responsibility he said he had done his jail time so therefore he was no longer (morally) responsible.

Post-Yvette there is a theme (or is it question?) developing in my mind – why do MHS take so much responsibility for their clients. To whit Bubbles and his bus pass. Bubbles needs a new bus pass and it would appear that his team completed the paperwork and sent it off on his behalf. On the one level this is pragmatic and sensible – it ensures a necessary job is done and Bubbles gets the bus pass. But it takes adult responsibility away from him, and multiple that across 30 odd years you end up in a situation where people aren't expected to take on anything that might challenge them. It's like Clue & the hand cream, he expected this to be done there was no recognition that this was a situation he could directly influence if he decided to do things for himself.

With regards to the "Nobody tells me nothing" theme Bubbles doesn't know the name of the medication he has been prescribed, nor the name of the nurse who delivered it. Perhaps I have been approaching this lack of memory/ not knowing them wrongly. I have been thinking in terms of "Services explain themselves once, but that it is not enough people need repeated explanation before they grasp the details of their treatment" but maybe I

When Bubbles wanted to say, "I'm ok/ I'm alright" he said, "I'm natural". I still haven't come to a full interpretative understanding of what this natural theme is. 'Natural' is evidently equated with good/ ok/ alright. Medication = Synthetic = Bad, Cannabis = Natural = Good. That I understand, but it is more complex than that.

One thing that I have to say about the Bubbles transcript is that we laughed a lot.

Clue

After rereading Clue's clarifying interview I am quite taken about how little he gives me. A significant proportion of the interview is taken by me trying to explain my questions and persuading him that he did say the things that he was quoted as saying. In the first interview he was talkative, warm & forthcoming so why in the clarifying interview is he so reluctant to talk?

21-11-11

It occurred to me the housing/ continually being moved theme links to "Telling me what to do" sub-theme.

Added in the two pertinent negatives of the lack of racism and the "not side effects".

Need to ask what is the "Themes"; "Superordinate themes" & "Subordinate themes". How does one distinguish?
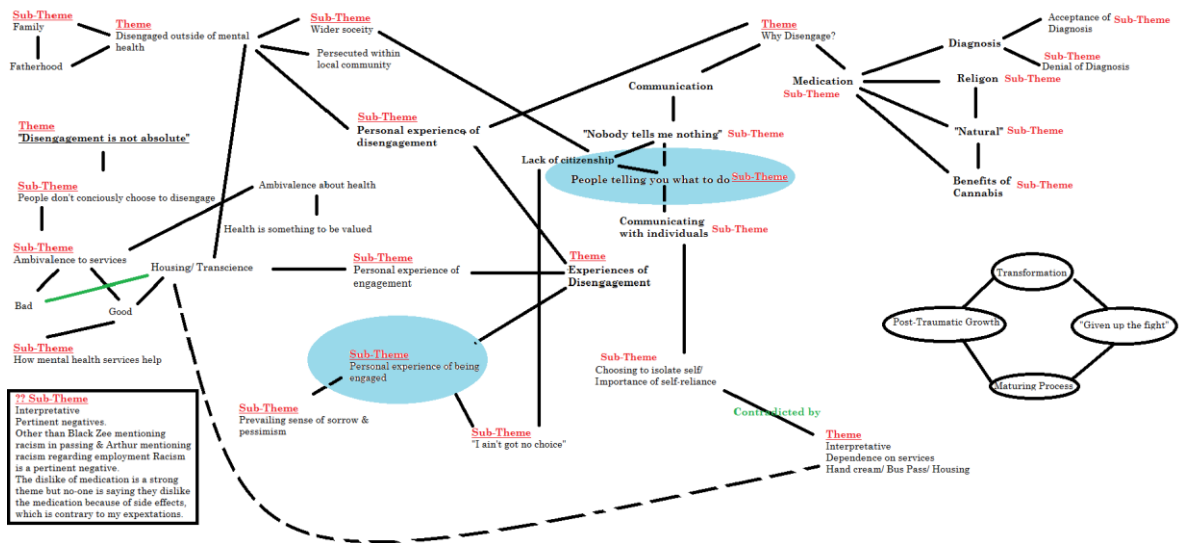
23-11-11

Supervision.

To answer the question from Monday:

"Themes": A collection of superordinate themes

"Superordinate themes": Ideas that more than one person expressed

"Subordinate themes": A means to understand an individual participant which I have surpassed now.

Presented most recent 'Paint' diagram:

Sub-Theme
Family

Theme
Disengaged outside of mental health

Sub-Theme
Wider society

Persecuted within local community

Theme
Why Disengage?

Acceptance of Sub-Theme
Diagnosis

Diagnosis

Communication

Medication
Sub-Theme

Religon Sub-Theme

Sub-Theme
Denial of Diagnosis

Fatherhood

Sub-Theme
Personal experience of disengagement

"Nobody tells me nothing" Sub-Theme

"Natural" Sub-Theme

Theme
"Disengagement is not absolute"

Lack of citizenship

People telling you what to do Sub-Theme

Benefits of Sub-Theme
Cannabis

Sub-Theme
People don't conciously choose to disengage

Ambivalence about health

Communicating with individuals Sub-Theme

Health is something to be valued

Sub-Theme
Ambivalence to services

Housing/ Transcience

Sub-Theme
Personal experience of engagement

Theme
Experiences of Disengagement

Transformation

Bad   Good

Post-Traumatic Growth

"Given up the fight"

Sub-Theme
How mental health services help

Sub-Theme
Personal experience of being engaged

Sub-Theme
Choosing to isolate self/ Importance of self-reliance

Maturing Process

?? Sub-Theme
Interpretative
Pertinent negatives.
Other than Black Zee mentioning racism in passing & Arthur mentioning racism regarding employment Racism is a pertinent negative.
The dislike of medication is a strong theme but no-one is saying they dislike the medication because of side effects, which is contrary to my expectations.

Sub-Theme
Prevailing sense of sorrow & pessimism

Sub-Theme
"I ain't got no choice"

Contradicted by

Theme
Interpretative
Dependence on services
Hand cream/ Bus Pass/ Housing

And the main conversation was around this.

AS regards the quadruple hermeneutic on the Transformation theme the 4th component should be labelled as "Maturing" but more as "Growth and Development" – but all four ideas are about people reinventing themselves. Not only did Bob relate this to Foucault and the uses/ abuses of Power & Knowledge but also to P. Bourdieu and the symbolic violence that people experience. From here the conversation moved onto the newly installed pertinent negatives. With racism not being present in the text there needs to be caution as to whether it is implicit in the totality of people's experiences. If I was black would have made a difference to how the participants responded? If the interviews were groups as opposed to individuals, would this have made a difference? Also, were people explicitly asked? I had forgotten that some of the participants had said that their dislike of medication was about the medication make them feel bad and clouding their thinking. But regardless the essence of my point continues – classically one of the reasons why people are reluctant to take medication is due to the side effects and none of the participants are saying that psychotropic medication gives them tangible physical side effects.

Maybe I should drop the pertinent negatives, are they really taking me anywhere?

With the new Personal responsibility theme two points came out: 1) We should talk about individual autonomy (responsibility is a bit too Daily Mail) and 2) And the process of de-institutionalism was supposed to be handing responsibility/ autonomy back to individuals yet we find ourselves in 2011 with MHS taking over arching responsibility for people with severe and enduring mental illness. Who is not letting go, services or the individual? Are the two that enmeshed with each other?

Derek then said that I should rebrand each of my themes – essentially abandon the diagram above and then divide the same superordinate themes into:

Experiences of disengagement

Citizenship & Individuality
Disengagement as a partial narrative
Disengagement & Society
Think of these as discrete chapters in a thesis or discrete lectures. There are over laps and they are interlinked but for now present them as separate entities.

24-11-11

Why am I proposing to do a Delphi study? If a Delphi study is about bringing conscientious, why am I using it? I'm not looking for conscientious, I am looking for informed discussion.

To be raised with Bob & Derek.

25-11-11

Whilst continuing to work through Yvette's notes it occurred to me that there are potential links between "How do services help" & "Transformation". But note to self they are both now under the new theme of "Disengagement is only a partial narrative".

30-11-11

CW: Ok, and what do you think the injections were for? **Rebel:** I don't know, I didn't really get it resolved. I wasn't asking questions like, "What is this about? What was that about? Or, "What does it do for me?" or anything. At the end of the day I just received it and take it. {p. 2}

This quote is part of the new theme "*Citizenship*" but also does fit with the "People do not consciously disengage" superordinate theme which is part of the "Disengage is only part of the narrative" theme. Similarly the same can be said for:

Rebel: I was receiving letters in the post from this assertive place and I had no idea who they were. I never knew who these letters were from. {p. 3}

Rebel: I didn't know I was on medication because I thought I was I had nothing to do with medication at the moment. I was discharged from hospital and discharged from medication and everything like that. I wasn't taking any drugs at all. {p. 3}

These quotes fit with both Themes. Of course this raises a questions are these themes closely related enough to be one? And then also with the ambivalence towards diagnosis – is that the same that there is more to the narrative of the person than disengagement and part of this wider narrative is not understanding (ambivalent to) their diagnosis. So is "*Experiences of disengagement*" a super ordinate theme of *"Disengagement is only part of the Narrative"*?

As mentioned above the Ambivalence about mental health may fit into the "....Narrative" theme. Do I link them to the two physical health slides? People are ambivalent about their

physical and their mental health? That people are ambivalent about services/ their health &
their mental health. Is this about active citizenship? People actively choosing what is
important to them – whether that be health/ services or their personal definition of what MH
is?

Maybe the Cannabis super ordinate theme fits in the *disengagement & Society* theme. I
haven't put the, "***CW:*** *... we were talking about cannabis and smoking marijuana and you
said everyone does it...* ***Black Zee:*** *It is everywhere isn't it, it was everyone*" quote in the
data but this would place cannabis both in the *Individual/ Citizenship* theme and the
Disengagement & Society theme.

1/12/11

Saw Josh. Warm, friendly, welcome. Eager to talk. Parts weren't fully comprehensible – as
in they didn't make sense. Still that idea of "Them out there" being against the person but
unable to identify who "Them out there" are. Safe in ██████████ but brutalised by society
wider than that?

Lots of anger about medication but concluded by saying that maybe it's helped him. After the
recorder was switch off he said, "All my life is wasted." And spoke about how if he went for
a job, even a simple cleaning job he wouldn't get it because potential employers would see
him as someone who, "couldn't stop himself from flipping".

2/12/11

9-12-11

On page 9 of Josh's clarifying interview there are two points that make me pause for thought.
1) I would like to go back for a third time, what does he mean, "Take people's swagger"
How is crack smoking being different? How is it taking people's swagger? Do I have an
unnecessarily negative perception of crack smokers? 2) Josh has not worked, in the
employment sense of the word, but, "*I contribute my willingness and my effort to work. So I
contribute to the country.*" Suggests that he perceives this differently. I am struggling to
understand his meaning. I am struggling to grasp how someone who has been on benefits for
so long understands themselves to be contributing to the country. Is this about him grasping
at an identity that would be consistent with the values of society? Am I becoming a Tory
boy? Am I judging people for living on benefits for their adult lives? No, I am confused to
understand his meaning and it does clash with my meaning.

16-12-11

Lloyd's feedback on T.

How do I deal with this other than to become terribly defensive?

When I next see Lloyd for a PhD discussion we need to talk about it point-by-point.

Let's deal with the positives first:

<u>6-1-12</u>

I previously raised a question about the importance of individual subordinate themes relative to larger super-ordinate themes and which should take priority.

Being a good PhD and tried to answer my own question and done some reading around the subject. One possible way to answer this question is that there seems to be an inherent tension within IPA in that it is based on idiography and the particulars of individual cases, but also about looking for similarity and convergence between those cases. Within that convergence isn't just about counting numbers of people for whom a theme is apparent - the subjective importance of the issue is also important.

{Unfortunately as I wrote that I thought of another question – research participants will generally talk around the issues that are put to them, how then can a researcher gauge subjective importance given that the self-same researcher has a great deal of control of the semi-structured interview? Double hermeneutic be dammed!}

One way to manage this may be to
  a - first deal with the convergent AND uniformly important themes; ,
  b - then the convergent themes where there is less consensus about importance, and
  c - finish off with idiographic themes which are, however, very important for the one or more people who mention them.

So using my research as an example we find that;
  a - The importance of their dislike of depot medication or the benefits of smoking cannabis
  b – The majority, but not all, feel persecuted by the wider society to a greater or lesser extent;

  c - Rebel feeling that 'Bad Luck' as impacted on every as aspect of his life, for example

In this way the convergences are prioritised while still leaving room for divergence and uniqueness.

Now, I jokingly referred to the double (or triple) hermeneutic above. But there is a serious side to that which I am struggling with. Take the example of Housing. One way of reading the transcripts is that one thing the MH services do well is organize housing for people, however the Housing issue can also be read as a narrative of transience – people are always being moved and they don't know why thus compounding the feeling of not understanding

what's going on, the feeling they have no control and feeling 'disengaged' from wider society. Therefore with every idea being open to different hermeneutics/ layers of interpretation how do I (or any IPA researcher) come to a point where you decide that this a theme where there is convergences or divergence?

Lloyd's comments on Josh's original transcript

As a convergent theme in common with the other six transcripts MH Professionals seem only to be concerned in giving medication and see this as the only option for patients. No choice is discussed and a feeling of powerlessness felt by the recipients of medication;
A convergent theme, where there is less consensus about importance, that MH Professionals have little insight into patient lives and feelings of indignity at being given depot medication;
A strongly convergent theme that there is often poor contact with children and other family members;
Knowledge of the Bible and importance of religion in life beliefs;
Difficulties in keeping relationships and contact with family due to stigma associated with mental illness;
Feeding the strongly convergent theme of the commonality to drug use (see page 8)/ part of life (see page 9);
Not knowing what 'Schizophrenia' is;
The misinterpretation about what the role of depot medication is;
Feelings of isolation from community & society (see page 7);
Feelings of being controlled (see page 8)

Idiographic themes
Common view that medication does not clear thoughts or the 'head' and make people able to participate in ordinary society;
View that a person's life cannot be judged by how much medication they are given without an understanding of the whole person;
Common desire to have a life which is not identified by mental illness ignoring other aspects of personality.
Response to comments:

P. 4 – "Relationships – not specifically relevant to mental health" I agree but I wasn't suggesting they were;

P. 5 – "Bizarre questions" if we look at the two previous statements by Josh {**"*So I, really, what was, what they said about my kind of people or me, or persons, my people, is like, is that I was like hating people when people love me and I didn't know that they loved me in that way or people cared for me, or should I say care, you know what I mean? Like the Schools and the Police cared for me and all that, I know that.*"** .... "*Yeah, I didn't realise at the time, just like when the girl had the baby, I didn't realise neither, that would be a part of my life. I would be like a man, you know what I mean, you know, a man.*"} I do not think my question is bizarre. Part of Josh understanding his own identity (and to understand what it meant to be a

man) was to understand who cares for him and also to understand his relationship with the police. This is not connected to questions to other research participants but that reflects the idiographic nature of the research.

As regards the two issues on P. 6 – "Not related to research aims" and "Not questions asked in other transcripts" this is unfolding research and so because an issue has been raised (or hermeneutically interpreted) by a previous participant then it is correct within the research design to introduce a new area of experience that wasn't in the research aims.

On P. 13 Josh appears to be saying that because he has contact with MH services and taking medication he cannot fully engage with his local community, however Lloyd's comment seem to suggest the opposite – this needs to be questioned. And in terms of divergent themes – integrated into community/ persecuted by society/ disengaged from society – this is part of that divergence.

On P. 14 Lloyd highlights a theme that hasn't been expressed before – that there is seemingly no "reward" for people to engage with MH services.

Lloyd feels that the comments on P. 22 are not relevant. I think they are. They are relevant because if Josh had been offered some bereavement work/ grieve counselling as opposed to medication then maybe the outcome of his treatment and his attitude to services would be very different. In terms of trying to view someone holistically, and Josh saying he had spent the past 30 years striving to become a better person to make his mother proud is relevant. He wants to feel that he belongs to a family that cares for him and the fractured nature of the family lives of the research participants has been a convergent theme of the research.

27-1-12

Black Zee was very thought disordered when I interviewed him today – and not all the material gathered will be useable. After the interview he kept saying that for him the most distressing part of his relationship with MHS is how long it goes on. That he can never escape services and there is no apparent end to services. Whilst he was very clear about this after the recorder was switched off, it isn't that clear during the interview.

16-3-12

In terms of my foreknowing as I have said previously at the stage when it was decided that the study was going to look at the experiences of Black men only I presumed that racism would be a component part of their experience of disengagement. Arthur mentioned racism in relation to trying to find work and Black Zee talks about racism more, and probably the most of the participants. However, it is not a major theme. I acknowledge that there is the dynamic of a Black man talking to a White man and that may inhibit what Black Zee wanted to talk about but the lack of focus on racism is for me a surprise outcome of the study.
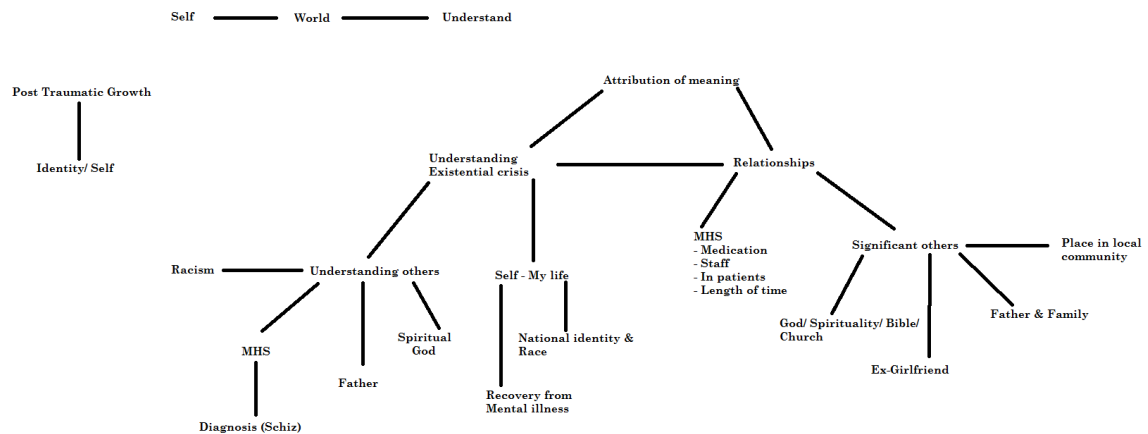
Very productive supervision meeting.

There was stuff about the Methodology paper which will be dealt with outside of this diary.

The other part was an in-depth discussion of Black Zee.

Point 1: I didn't know that Black Zee was a type of cannabis.

Point 2: His model now look like this

Derek wants to position the Post-Traumatic Growth issue as central. To my mid the awareness of personal change is an issue but it is only a minor issue. The argument is that that there are two strands – "**Understanding his existential crisis**" and his "**Relationships**" and with both of these Black Zee is searching for some form of '**Attribution of meaning**'.

If we take this two strands idea and then apply it to Arthur then we can reinterpret Arthur as:
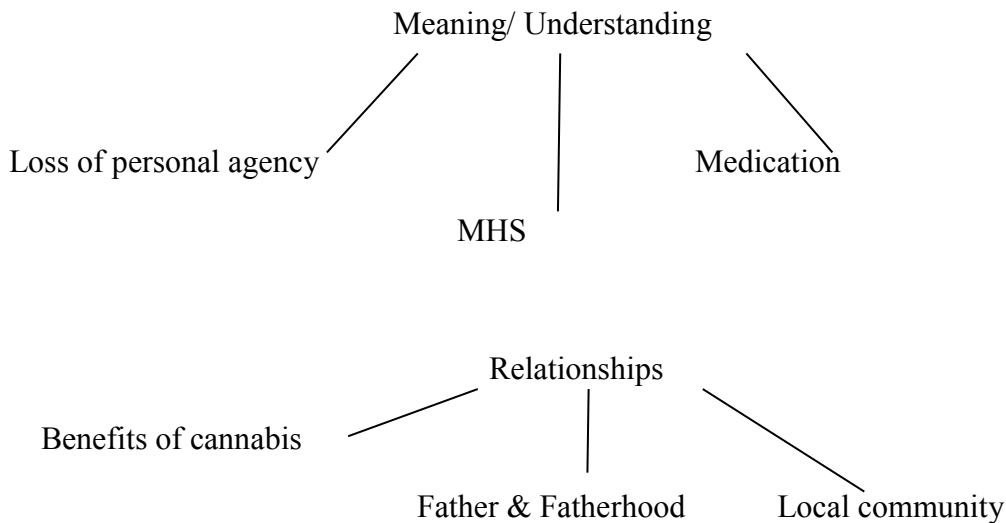
Thinking about Bubbles. There is that one line about moving around muddles him up. As a consequence of that I can attach his ideas about travel and geography into the superordinate them. That's an awful lot to put onto half a sentence but I think it's justified.

Is there an emergent theme about being persecuted – Black Zee, Bubbles, Clue - ?

Bubbles idiographic statement

Bubbles has to be slightly different from the other research participants in that I had worked with him clinically previously and knew things about him that he didn't bring to the research interview. Bubbles tried to take the position that he had never disengaged from MHS and it was my input into the research interview process saying that he most definitely had disengaged, wilfully or otherwise, from MHS.

In my interpretation of Bubbles' experience of disengagement from MHS the sentiment of "I'm just an everyday person" is central to that experience. This sentiment can be linked to other themes & sub-themes – "I was schizophrenic", Disengagement {"Leave me alone"}, Relationship with & experiences of MHS, Identity and Life is alright/ Life is miserable.

As a consequence of being an "everyday person" Bubbles is able to assert that he is able he is no longer schizophrenic; Bubbles repeatedly says that MHS should leave him (and others) alone because he is an everyday person; Because Bubbles sees himself as an "everyday person" it is not necessary for MHS to be involved with him, he speaks at length at his difficult sense of identity (ex-con, ex-patient, mixed race) but used the identity of being an "everyday person" as a way reasserting a sense that he is ok really and finally he was able to assert that life isn't all misery and that in fact life is alright by identifying himself as an everyday person.

In relation to the other developing superordinate themes Bubbles does speak to those themes:-

Bubbles has been moved to parts of town that he doesn't know and as a consequence he gets muddled up (line 521 "You know, they move me on and muddle me up."). This idea reinforces what other participants have said that simultaneously one of the most important services MHS perform is finding people somewhere to live but as a consequence of frequent moves, or being moved to an area where the person doesn't want to live, the sense of **transience** has a destabilizing effect.
Medication is uniformly disliked by the Bubbles and the other research participants (line 556, "They (tablets) freak me out") and in Bubbles' case the dislike of medication is a key component in why he has disengaged from MHS (please lines 420-425).
The theme of **Family & Fatherhood** is present for Bubbles: he barely knew his father, he has infrequent contact with his family which he is dissatisfied about and he has had only limited contact with his own children whilst they were growing up.
Whilst Bubbles says that he has stopped doing drugs what he means is that he has stopped smoking crack. He is very clear that he still uses cannabis and alcohol and speaks of the

benefits that these provide for him (Line 445, "Well they (drink and cannabis) just put a little happiness back in my life"). Other participants spoke in terms of **cannabis being beneficial** because it brought love, creativity and health benefits Bubbles sees the benefits of cannabis as being happiness and being calm.

One of the potential emergent themes has been **personal transformation or post-traumatic growth**. Whilst the reader can certainly see evidence for this kind of transform (indeed one of the themes is labelled "Things are different now") Bubbles isn't embracing of the idea and flat out denies being traumatised by his mental health or experiences of MHS.

As commented upon in the reflective journal there is a potential theme of **persecution** that is evident in Bubbles, Clue and Black Zee transcripts. For Bubbles the theme of being picked on or persecuted links with other themes and sub-themes – "Voices and paranoia", "Keeping your guard down", "Identity", "Geographic location", "Crack" and "Things are different now"

As commented on above the central theme to understanding Bubbles experience of disengagement from MHS is "I'm just an everyday person" and whilst other participants had spoken of their desire to be left alone Bubbles was the only one to use the idea of being an everyday to assert many things about himself.

24-4-12

Meeting with Mary and Lloyd.

The meeting was really about the confirmation of themes. However, a couple of methodological notes both Lloyd and Mary questioned the value of the clarifying interview, wondering whether it was an unnecessary step. In Rebel's and Clue's case I can see where they are coming from – did my clarifying interview clarify the first interview or did it in fact make their idiographic pictures more complicated? Mary commented I was trying to get the participants stories into chunks of time (and she is right, I was trying to do that to make the participants more understandable) but I failed. Arthur's transcript does not run chronologically. Mary also asked for a geographic map of Birmingham, many of the suburbs of Birmingham are mentioned but for someone who is not that familiar with the city will not know where places are and a map would add understanding. For Mary one of the main themes of the research was not only do people dislike medication but also people have no idea what medication they are taking. One of the possible interpretations of why this happens is that people over the years have been prescribed many different medicines and therefore cannot keep up with what and why they have been prescribed. To illustrate this point Mary asked if a list of medication could be provided for each participant. I highlighted the logistics of doing this and whether that level of time investment was really justified.

Discussion of emergent themes

For both Lloyd and Mary one of the main themes was that the participants **did not know what schizophrenia was**. I hadn't been inclined to have this as one of the themes but for

them it was of importance. I entered into this research project wanting to explore the hypothesis that people disengage from MHS because they do not think of themselves as mentally ill, at best a couple of people confirmed this hypothesis whilst the majority did not disagree that they had schizophrenia but simultaneously did not know what schizophrenia was. Indeed in the interview Josh even asks me for an explanation.

I had intended to have the dislike of **medication** as one of the key themes, Lloyd and Mary agreed but wanted a sub-theme of the participants not knowing what the medication was for (also see above).

Lloyd and Mary agreed with my reading of the transcripts that the participants felt part of their immediate **community** but felt disconnected and disengaged from wider society. It is unclear why people experience this but there are probably a multitude of reasons. Lloyd and Mary postulate that stigma is a big reason behind this disenfranchisement - stigma from mental illness, stigma from being mixed-race, stigma from living in a group home, stigma from being chronically unemployed or the dynamics of self-stigma.

For me one of the most surprising themes is the **ambivalent relationship** the participants have with MHS. Simultaneously participants could say that MHS have brought them nothing but misery and also the MHS have saved their life – and this duality is one the important themes from my perspective. Mary agreed that this one of the important themes but added that perhaps one thing that is settled in the participants life is contact with MHS whether they like it or not.

Related to this duality theme is also the **Transience/ Housing** theme. The theme was born out of discussions last time we met. My perspective had been that one thing that MHS did well was find people somewhere to live, however Lloyd had highlighted that as a consequence of this that people get moved around frequently and they get moved to environments that they don't know or like. So the clarifying interviews confirm this complex relationship: yes, MHS found people somewhere to live but as a consequence people lived in areas they didn't know or like (Bubbles for example); felt very persecuted by the person who ran the group home (Clue); had fights with the other residents whom they had not chosen as house mates (Arthur).

All the participants have fractured relationships with their families and their children. Lloyd's take on this was that Afro Caribbean families exert the same levels of discrimination and stigma as other parts of society. Families reject the individual because they are mentally unwell (and within that, Fathers in particular shut out their mentally ill sons) and then the Mothers of the participant's children exclude the participants because they do not want the 'madness' near their children. This is a controversial point of view and if it is a theme to be used in the research study then it will have to thoroughly backed up by research evidence. But just to clear, both Lloyd & Mary agreed that one of the themes to feature prominently in the transcripts was the fractured nature of their **family relationships**.

The **benefits of cannabis** was one of the prominent themes, from my perspective and from Lloyd's and Mary's. Whether the participants got love, pain reduction, anxiety management, happiness or a closer relationship with God all the participants talked about the benefits of their cannabis use. It may be that people use cannabis as their own personal medication but if

it is the case this is not reflected in the transcripts. Anecdotally, Lloyd highlighted that crack is now cheaper that cannabis but only Josh and Clue admitted to be currently using crack. Equally most of the participants used alcohol but only Bubbles cited alcohol having the same beneficial properties as cannabis.

Previously I had been minded to have **God and religion** as one of the themes of the research however of late I don't feel that it is as such a strong theme. Regardless, Lloyd and Mary believe that it is a strong theme noting that is God and the Bible which are important not organized religion. To contextualize Lloyd felt that most of the participants will have read the Old Testament repeatedly and in particular the Book of Revelations. Lloyd also felt that Rebel was probably versed in the Maccabe Bible, the Bible usually used by Rastafarians. There was a discussion whether the reason for the participants not being involved in organized religion was whether the same process of stigmatization had occurred as in other areas of society and that people felt shun by the church.

One of the potential themes of the research study is about **transformation/ post-traumatic growth**. All the participants are able to reflect on their growth and development however how unique is this experience, most people can look over the past 20 years and reflect upon how they have grown and developed as a person. Mary highlighted that it may be precisely the contrary – people are stuck and the world around them has moved on. They are stuck because they are disempowered by the society & MHS. MHS enables people to be stuck by keeping them in a sick role. There is potentially a sub-theme developing of **waiting for professionals to do something (being passive in treatment as opposed to assertive).** This is evidenced by Bubbles and the bus pass and Clue and the hand cream. Two men who are capable of taking care of their own needs (to some extent) are reliant on MHS to provide basic amenities of life, and they are realistic to expect that out of a sense of kindness and paternalism MHS will try to meet these needs. Lloyd agreed within the mental health sub-culture, and with the research participants, this was evident: an idea that people see themselves as service users and victims and therefore are not able to do things for themselves. Such a theme would incorporate looking at the notion that the closure of the large psychiatric hospital in the 80s & 90s was supposed to end institutionalisation but jointly service users and MHS have combined to create institutionalisation in the community. However, such thoughts have to be tempered against the idea that people are "stuck" by their illness, in medical terms five of these men are 20/30 years into a schizophrenic illness and therefore are experiencing a lot of negative symptoms of schizophrenia – notably apathy, lethargy and confusion – and therefore need help getting hand cream and bus passes etc.

Related to the transformation theme there may be another sub-theme that the majority of the participants were have been labelled as **violent men** by society and there is a narrative to be explored about how and why these men have been labelled/ stigmatised/ marginalised/ described as violent. How do white researchers in the 2010s understand the cultural context of violence of Black men that occurred from the 1970s onwards. Realistic response to oppressive culture? Chronic unemployment? Drugs? Stigma? The stigma that all Black men/ all schizophrenics are violent? Reacting to social/ economic environment? This was not a theme that I had thought about previously.

Of late I can see an emergent theme about persecution – see Black Zee, Clue, Josh, Bubbles and, perhaps, Arthur – and Lloyd agreed that it was very much there. From the discussion there at least six levels on which people felt persecution were 1) from the local community where they are stigmatised for their mental illness and they are shunned (see the religious theme as well); 2) that there was a large degree in which people persecuted themselves/ exercised self-stigma; 3) the participants felt that that they were/ are persecuted by the police and the prison system; 4) That within the Black community that there was persecution towards mixed race people (Clue and Bubbles both allude to this); 5) As mentioned above that the participants have fractured family lives and this maybe because of stigma and persecution by their own family; 6) Perceived persecution by MHS, both currently and previously, and this is felt by all the participants.

I thanked Lloyd & Mary for the impact that they have had on my thinking and therefore the study. Our discussions have broadened my thinking about the "Housing/ Transience" theme; "Citizenship" not so much about race but being a citizen whilst being under a CTO & MHA; the nature of "Stigma" whether that is stigma from mental illness, stigma from being mixed-race, stigma from living in a group home or the dynamics of self-stigma. Lloyd also helped my understanding of language and provided some greater context for understanding the drug issues in the study.

Prior to supervision on 14-5-12 Derek took the themes that are listed above and rebranded them as:

Problem. Uncertainty
Medication. Dissonance
Community connectedness
Relationship ambivalence
Hierarchy of needs
Interfamily relationships
Pro cannabis
Religion, belief and belonging
Transformation/ Post-traumatic growth {sub-theme: subjugation}
Violence
Persecution
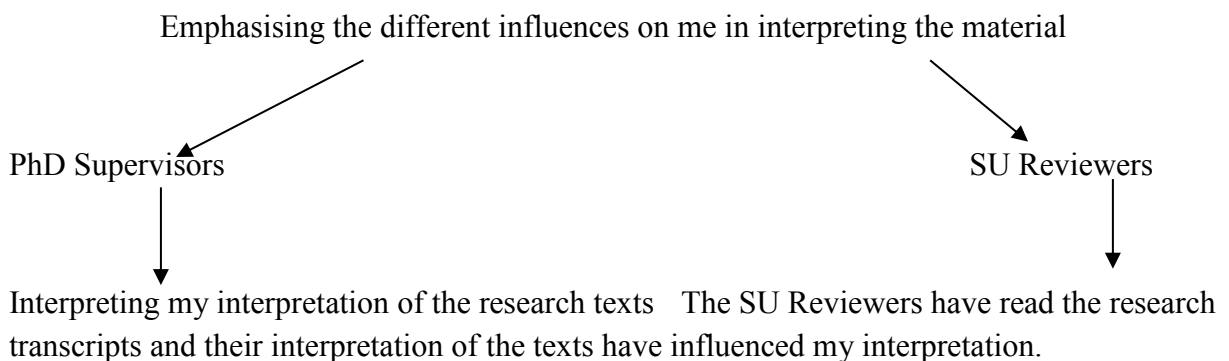
14-5-12

Supervision

Clue has two relationships – a relationship with drugs (and their consequences) and a relationship with MHS. He sees them as two alternatives, and one is a trade off against another. His relationship with drugs and his relationship with MHS is a duality between ideas and lifestyles. His identity is bound up in understanding his duality of position between these

two ideals and lifestyle choices. Clue is engaged with two entities that most people don't have anything to do with – MHS & crack.

One of the functions of the crack is to have friends and to have a social network. In terms of his comments about the positive value of cannabis Hermine phrased these as 'positive substance related beliefs'.

The methodology chapter. For Derek the important thing was to emphasis the important role that the SU reviewers played in the research methodology. Derek sees their role as providing a meta perspective on the themes. For Bob the central theme of the paper should be about accessing people who are hard to reach, distinctly vulnerable and their engagement needs a high degree of sensitivity. As a co-author Derek wants the paper to show that the use of the SU reviewers was a creative adaptation of IPA not an atypical research design. That the participants were interviewed twice is not inconsistent IPA so therefore not such a big deal should be made of it in the text. The use of the SU reviewers provided a meta-analysis of my analysis and added to my phenomenological understanding and helped me to make sense of the double hermeneutic. There was a discussion about the study having a double/ triple/ quadruple/ hermeneutic. My thinking is unchanged – it's a double hermeneutic.

Emphasising the different influences on me in interpreting the material

PhD Supervisors   SU Reviewers

Interpreting my interpretation of the research texts   The SU Reviewers have read the research transcripts and their interpretation of the texts have influenced my interpretation.

Supervision. 11/6/12

Only Derek present.

We talked about Bubbles. Derek gave his interpretations of the Bubbles transcript and how he interpreted the emergent themes, in some cases it was seeing themes that I hadn't seen, in some cases it was rebranding themes that I had highlighted and in other cases it was agreeing with the themes that I had set out. There is a division to be made between the emergent themes across the participants and those which are unique to the individual – Clue and the "Changes", Rebel and "Bad luck", Bubbles and "I'm just an everyday person".

The superordinate themes that Bubbles links in with are: **Identity; Ambivalent relationship with services; Dislike of medication; the role of substances; family & fatherhood; Transience & Meaning & Attribution {Diagnosis/ Medication/ Role of services}.**

Oppression & persecution {"I used to be a violent man"}

Identity is a tough one, it's an IPA study where people are asked questions about themselves, therefore there will be an emergent theme about their various identities. Yet the responses are idiosyncratic and different so it would be hard to nurture this into a theme. **Ambivalent relationship with services** is strong with most of the participants and here Bubbles says both that services have been, "Not very good, not very good" and that services have been, "Well, they're alright". All of the other participants **dislike medication**, but most of the other participants save their anger for injections but Bubbles is different in that he is more expressive in his dislike of tablets, which is portrayed in the quote, "But they freak me out {Laughs} They freak me out, yeah." (556) and, "you can't give medication to people ... It messes them up." (541). Bubbles makes a very clear distinction between using alcohol & 'spliff' as he does now and using crack as he used to. Early on in the interview he says has stopped using drugs but what he really means is that he has stopped taking crack. However, as with the others **cannabis**, and alcohol, play an important part in his life:- "That's why I smoke to get me out of my misery" (80). The **family & fatherhood** theme is very strong in Bubbles' case; he had very little contact his Father whilst he was growing up and again as a parent he has had minimal contact with his own children. Lloyd's model of family's alienating their mentally ill children doesn't fit, Bubbles' mother did everything she could to support Bubbles and she remains in regular contact with him. His mother moved herself & her children from London to Birmingham when he was four and he had very little contact with his father after that.   Whether Bubbles elected to have not to have contact with his children or their mother refused him access is unknown, but in keeping with the other participants he does described the lack of parental contact as a "sore subject" (180). Despite this theme being present in the literature I will not be running with Lloyd's idea ......

His son was approached about being a research participant (he met the inclusion criteria for the study) but he was unwilling to fully cooperate with the structure of the research process. **Transience** is very much an issue for Bubbles and for the first time I'm starting to see this theme being a component part of the over-arching **meaning and attribution** theme. Bubbles lives in the North West of the city, not through choice but because that is where accommodation was found for him. He feels he does not belong, he wants to be in the South of the city. There is that section where he feels attached through his memories and because he doesn't have memories (or "memorandus") in the North of the city he does not feel any connection. He therefore travels to the South of the city on a daily basis, he claims, and certainly he is frequently seen travelling on the buses around the city. Also, it explains the urgency of why it is so important to get his bus pass. Whilst the story of being thrown of the bus and breaking his teeth is shocking, it does lack context and we are not aware of the antecedents.   Regardless, the **Transcience** theme is there – he has been moved to an environment that he does not know, like or feel connected with and he does not appear to have consented to the move or understand why the move was organized on his behalf and he regularly travels beck to a neighbourhood where he feels connected to by his "memorandus".

One of the strong emergent themes across the participant's texts is about how the participants don't know or don't understand what is happening to them. At present this large over-arching theme is labelled as **Meaning & Attribution.** In Black Zee's case the whole idiographic understanding was built around all that he did not understand; as commented above half of the threads from Arthur were captured under the **Meaning & Attribution** banner – loss of personal agency, MHS, medication; and now with Bubbles he acknowledges that he doesn't understand his **Diagnosis/ Medication/ Role of services.** Let's be clear this isn't me reading the transcripts and saying that the participants have misunderstood what is happening, this is either the participant saying "I do not understand" or the participant saying two contradictory ideas about the same subject in close succession.

There was an interesting discussion about diagnosis, which in many respects has become part of the **Meaning & Attribution** theme. All the participants are able to say, "I am schizophrenic" but none of them are able to explain what that means. Indeed two (Clue & Josh?) even asked me to explain to them in the research interview what schizophrenia was. Bubbles take is different, he says he was schizophrenic but stopped being so when he stopped smoking crack. Yet he admits that he still hears voices and some of his ideas could easily be described as pathological paranoia, from a medical perspective it would be possible to describe Bubbles as continuing to experience symptoms of schizophrenia. So this is the sub theme within the **Meaning & Attribution** theme, not understanding the medical diagnosis that has been attributed to them.

Don't forget to include the discussion about the meaning of "I was schizophrenic"

Similar to the above discussion about **identity** and **meaning and attribution** there is a large catch all major theme of **Relationships**. In Bubbles case there is a relationship with services, with his family, with drugs and, arguably, with his former self.

9-8-12

Reflections on whether there should be a separate "I ain't got no choice" theme

Josh: "..well it's not my choice you know.   I ain't got a choice because ... if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it." {p. 1}

Bubbles: "Well I've got no choice have I?" {p. 3}

T: "I've got no choice." {p. 2}

T: "If I had a choice I wouldn't take it." {p. 4}

Arthur: "I have to. I don't want to end up back in hospital." {p. 16}

Rebel: "But they insist, "*Give it him.*"" {p. 15}

Black Zee: "... this has been going on for a long, long time and my freedom is not being appreciated." {p. 20}

Rebel: "but they want to give me medication but I don't really want to take medication." {p. 5}

Previous comments from Lloyd & Mary prior to clarifying interviews

Defacto detention in the community

Seemingly unaware of the Human Rights Act

There is no acknowledgement that they understand their rights. The participants do not acknowledge their rights and do not create a narrative about the abuse of their rights. (Learned helplessness??)

Very passive acceptance of situation regarding the 'acceptance' of medication.

Do they know they are citizens and have rights? Consumer citizen rights? {Does this then link this theme in with the 'disengaged from wider community' theme}

Do they know how to complain?

A sense of fear runs through this – fear of the consequences of not taking the medication

Taught not to complain/ Taught the consequences of complaining (see Rebel)

Also on p. 22 when Bubbles is asked about how he would run mental health services, he replies regarding medication that, "*No I wouldn't if they're no good, I'd just help them get back to, you know help them sleep then. Help them rest. That's all I could say. That's all I could say really. Take a tablet and just not say nothing.*" Confirming the point of learned helplessness/ not complaining/ not questioning the treatment regime.

It is worth noting that both T. & Arthur are on CTOs and that Clue is on a 37/41. Black Zee has only recently been on a 3 and for what it is worth was on a 117. However, Bubbles & Josh aren't on a CTO or a 37/ 41 so legally they have a choice.

Separately, is there an "I am my own man" theme? Could this be lumped in with "I am a solitude", is one a sub-theme of the other? It is interesting that in early notes that I made the potential "I am my own man" theme a sub-theme of the transformation theme, now I see it as more related to the solitude theme.

As much as I have probably resisted I probably do need to write a reflection on Dad's death and the impact that this has had on the research. Indeed I know that part of the reason that I am doing a PhD at all is to emulate my father. To what extent am I seeking out the loss of Father theme to reflect themes that run in my life?

<u>**13-8-12**</u>

In Josh's case the '*Part of the local community*' theme is rebranded as '*Part of the local community (Relationship with statutory institutions)*' because he does indeed feel part of the community but he predominately expresses this through his relationship with the statutory services. But this in turns also reflects his own development as a person – his '*Transformation*' theme, and also his '*Identity*' theme, are bound up with how he views his evolving relationship with the statutory services. Codes 50-58 provide further evidence of links between 'Transformation' & 'Part of the local community'. When talking about God and evil reflects on the fact that he believes in God impacts on his relationship with the community he lives in (codes 69-72). However, at 111 this develops further. The 'Injection' theme also enters the fray. Josh said, "*until they treated me like that and started giving me injections or trying to say I'm what I'm not*". Josh in effect joins four of the prominent themes of the research together – 'Injections', 'Identity', 'Relationship with the local community' & 'Transformation'. I believe that the above quote demonstrates that Josh previously saw being given an injection as symbolic of being oppressed by the community in which he lives.

I need to draw my attention to code 92. (92. I would like to give up certain things because the community is heading for a collision of racism and I want to take myself away from that.) Firstly, I presume he is talking about crack and secondly I have included this in the 'Part of the local community' theme working on the logic that if one is part of the local community then one is in the position to withdraw one's from that community.

95. "So if I put myself in that situation where I can't see things like other people, then what I'm seeing eye to eye with people and somebody come and confuse, destroy that fate what me have with people, you know what I mean, I think it's wrong."

This was summarised as "If I were to take myself out of the local community and didn't view things the same as other people, then if someone was to come and confuses the issue and destroys the fate that I had with people, in those instances when I did see eye to-eye with people, I think that's wrong."

Code 110 is an anomaly – in code 109 he clear says he wants to take revenge, then he denies that he said it and then proceeds to discuss who & why he wants to take revenge on. Therefore I didn't cluster 110.

14-8-12

Still on Josh. Codes 124/125 are quite confusing. In 124 I presumed by "they" he was talking about MHS, but in 125 he clarifies this and says by "they" he means the leaders in the community. There is an alternative way of looking at this, Josh views all people in power as a homogenous mass and MHS are part of that homogenous mass and to Josh MHS compose part of the vague, anonymous group , "leaders of the community".

21-8-12

The first theme on my chart of themes is causing me stress – is it Relationship with MHS? Experiences of MHS? But this so bland as to be worthless, of course the research participants have a relationship with MHS. It is not an honest theme to say that they have problematic relationship with MHS because not all of them do – many of them can point to positives that involvement with MHS has brought.

Is "Reflections on the complex relationship with MHS" an appropriate title for the theme?

Would the "Medication" themes become a subordinate theme of this?

Reflections on the complex relationship between the individual and Mental Health services
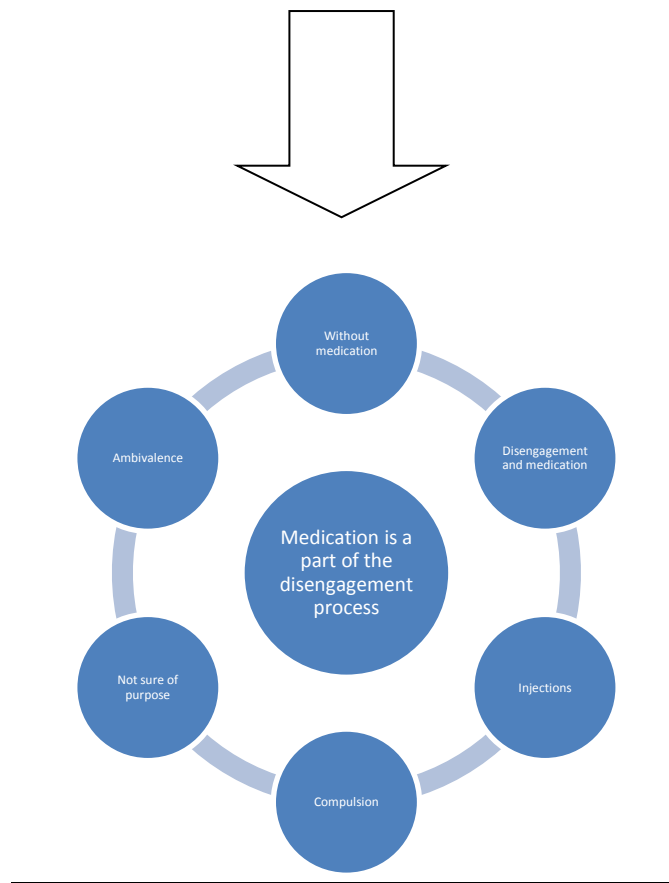
This note is to clarify how the themes of the research were condensed yesterday.

Theme #1. Effectively there have been four categories brought into one; to start with there was *experiences of MHS*, *experiences of in-patient care*, *relationship with MHS* and *Transience*. Prior to the meeting yesterday the first three had already been combined but since the *Transience* that the participants discuss is transience related to MHS – admission & discharge from hospital, being moved between group homes – then this is now a component part of people's ***the lived experiences of MHS*** with *Transience* being a subordinate theme.

Theme #2. As previously discussed I was thinking along the lines of saying that *Medication* was a sub-theme of *experiences of MHS,* arguing that medication was an important component of people's experience of MHS. However, since *Medication* is such a large theme it was decided that it should exist as a theme in its own right – with the 6 component parts. There was discussion about where the *Religion as a replacement for medication* theme would sit – with *Medication* or with *Religion & Belief systems*. We opted for *Religion & Belief systems* if for no other reason than to bolster that theme.

Theme #3. For a long time there has been a theme of "*I'm unsure what's happening*" and this overlapped with the medication theme ('I am unsure why I am prescribed an injection', for example), the Transience theme ('I am unsure why MHS keeping moving me', for example) and the participants relationship with MHS ('I am unsure why MHS need to be involved in my life', for example). These themes have all come under a new theme of *Living with uncertainty*. Also in previous thinking there was also a strong theme of the participants saying "*I have schizophrenia, what is schizophrenia?*" and this too has become a subordinate theme of the new *Living with uncertainty theme*. Related in subject matter, but previously existing as a separate theme was the *Denial of illness* theme. Only Arthur, T & Black Zee straight out denied having a mental illness, in many ways this was a very important theme because at the start of this research I had a hypothesis that I wished to explore that people disengaged from MHS because they did not believe that they were mentally ill. Now these three previously separate themes have been combined under the new *Living with uncertainty* theme. There was a detailed conversation about whether to include the *Denial of illness* theme within this new theme. In the end the reason why this theme was included was because if the participant was saying, "I do not have schizophrenia" and MHS were repeatedly saying, "You have schizophrenia" then this constitutes living with uncertainty.

Theme #4 The only two changes to this theme were firstly to add in the *Religion as a replacement for medication* sub-theme and secondly to change the title from *Religion, belief & belonging* to *Religion & Belief systems*. Previously there had been notions of linking *Religion, belief & belonging* to the eventual 'Engagement with society' theme but there were not strong enough links to make this connection. It is an important point to bear in mind that although most of the participants talk about religion and the choosing the 'right path' none of them showed any inclination to engage with organized religion and their religious practice was personal and individual pursuit.

Theme #5. This theme is now called *Fluctuating levels of engagement* and it is the amalgamation of four previous themes – the theme regarding people being *engaged & disengaged simultaneously*, "*I want to be disengaged from the MHS*", "*I have never disengaged from MHS*" and the *Why disengage?* theme with its four sub-themes. This theme is therefore expanding connected ideas around engagement; that people can be engaged & disengaged with MHS simultaneously, that two of the participants in the interview said that if they had the (legal) choice that they would disengage from MHS at this point in time (the opposite is also a salient point five of the participants did **not** say in the interview that they wished to disengage from MHS at this point in time), the theme of participants saying that they had never disengaged from MHS, including two of the participants would by professional standards would have been considered as very disengaged at points in time and finally the *Why disengage?* theme with the sub-themes of *Medication, Communication* (inc. *people telling you what to do*), *To be an individual, Live a normal life*. These latter two sub-themes have now been merged.

Theme #6. *Health, Illness & Anxiety* remains untouched. My initial thoughts that people who disengaged from MHS would also disengaged from other forms of healthcare were not totally borne out, however it is of note that there was a prevailing attitude of people being very concerned about their physical health but not really doing anything about it.

Theme #7. Throughout the development of the themes one of the strongest themes has always been *Benefits of cannabis*. All the participants spoke about the benefits of cannabis – it brings "love,

"wisdom", "It's good for me", "keeps the voices away", "creativity", acceptance in the local community, makes people more friendly, relaxation and brought people closer to God. As a separate theme there was *Role of other substances,* wherein the couple of participants who smoked crack or drank alcohol did not speak about these activities with the same reverence. One of my fears has always been that when this study is published someone would pick up on the *Benefits of cannabis* theme and use it as a means to attack the research. Therefore these two themes have been combined to co-exist as *Illicit substance use.* Derek wanted to go for illicit substance <u>mis</u>use but I resisted this as it betrayed the idiographic and collective positivity that the participants had for cannabis – they certainly did not see their use as misuse.

Theme #8. One of the strongest themes to emerge from the research has always been the fractured relationship that the participants have with their families, in particular their own fathers and themselves as fathers to their children. The *Family & Fatherhood* theme will remain but it will now incorporate the *Separation & loss* sub-theme. Death has been taken out of this sub-theme as the participants aren't necessarily questioning their existence in an existential manner but reflecting on the various loses that they have experienced in relationship to their friends and family.

Theme #9. The new theme is emerge is "*The individual within the community and society as a whole.*" This is the combination of the previous "*I am a solitude*", "*Being your own man*", "*Oppression & Persecution*", '*Part of the local community*' and the '*Not part of the local community*' themes. Within this new theme the relatively minor theme of the loneliness people feel is discussed as is the theme about being your own man and having self-resilience. As I have commented before I have struggled to know where to place this sub-theme and it was never large enough to really be a standalone theme so perhaps a theme wherein the participants discuss their place in society is the place where they talk about the need to be your own man and be self-reliant. As I have commented before I have always been struck that more of the participants did not talk about racism as a feature of their disengagement from MHS. In terms of my foreknowledge and prejudices perhaps it is part of my own thinking about the world that black men will have experienced racism as part of their experience of MHS. It was Lloyd who said, and he is statistically correct from this research, it is the mixed race participants who will experience racism more than the non-mixed race participants. The two large themes '*Part of the local community*' and '*Not part of the local community*' are natural fits in this new larger theme.

Theme #10. For a long time one of the main themes of the research has been about *Transformation,* and for four of the participants this was an important theme. Also for four of the participants there was a strong theme of '*I was a violent man*' (three participants fitted into both themes). Since there were obvious connections between the two the two themes are now combined. I am still not clear how to portray this but since a salient feature of this theme is that it is older five participants who contribute the theme is now called *Time and change.* That people change over 30 years is not a surprise but the narrative of how and why they have changed is important.

The theme of *Identity* was dropped. Although all the participants discuss their identity it was only with Bubbles that I had it as a theme so we decided to get rid of the theme. Bubbles' personal affirmation statements of "I'm alright really" were unique to him alone.

Theme #11. The *Quality of life* theme raised important issues about people's happiness – repeated references to having their life ruined, that life was misery/ sorrow/ shit – and thus needed to be preserved and didn't readily fit in with any of the other themes.

For formatting reasons Appendix #4 has been removed

Appendix 5:   Examples of Clustered Codes

Phenomenological clusters for T.

1. "I've disengaged from MHS"

2.   Disengagement means not using the services;

3.   Yeah, I've disengaged from MHS;

4.   I disengaged because I didn't want the help.

5.   The help that MHS offered me was drugs

6.   By drugs I mean medication

7.   Medication was the only thing that MHS offered me.

8.   I didn't take the medication because I didn't think I needed it.

33. One positive thing about actively disengaging from MHS is that I didn't get the help and support **they said** I needed.

34. I was better off without their help & support.

144. People disengage from MHS because they are medicated up.

145. There is no other reason why people disengage.

146. There is nothing else about engagement/ disengagement that I haven't already told you.

192. The people who took ecstasy at the same time as me haven't disengaged from the MHS – so they haven't been caught.

199. To understand how taking ecstasy, seeing dead people, disengaging from MHS and taking myself out of mainstream society ties to together you would have to take ecstasy yourself.

25. If I had a choice I wouldn't meet with MH professionals.

26. Would I see MH professionals as people?

27. Even if MH professionals came round to me just to talk & offer social support I wouldn't see them if it wasn't for the CTO.

28. If it wasn't for the CTO I would stop contact with the professionals as well.

2. Medication

4.   The help that MHS offered me was drugs

5.   By drugs I mean medication

6.   Medication was the only thing that MHS offered me.

7.   I didn't take the medication because I didn't think I needed it.

12. Yeah, I have a depot medication

13. I have no choice about having the depot.

14. I take the depot because I've got to take the depot.

15. I take the depot because of the legal compulsion.

16. If I wasn't on my CTO I wouldn't take a depot.

17. If it wasn't for the depot I wouldn't take any medication.

18. I wouldn't take any medication because I don't think I need it.

63. I described medication as keeping me calm.

66. I feel drowsy for the first couple of days after taking the injection, but after that I feel normal.

77. If I was in charge of MHS I wouldn't drug people as much.

78. Instead of drugging people I'd just let them get on with their lives.

87. I think that MHS drug people too much.

88. I've seen people in hospital been drugged too much.

89. I can just tell when people have been drugged too much.

90. You can tell when people have too many drugs in their system.

91. When I was in hospital and saw people who I believed to be too drugged I thought "Oh my God".

92. People should be treated with less drugs.

93. Just treat people with less drugs.

94. I used to be over medicated, but not anymore.

95. MHS only need to offer medication, hospitals & support.

134. I've been calmed down on medication now.

143. Religious instruction may help more than medication, but it depends on the type of religious instruction.

2.1 "No choice"

13. I have no choice about having the depot.

14. I take the depot because I've got to take the depot.

15. I take the depot because of the legal compulsion.

16. If I wasn't on my CTO I wouldn't take a depot.

2.2 Medication/ Not being on medication

19. The difference between on or off medication is that I'm a lot calmer

20. I am a lot calmer when I am on medication

21. Sometimes I like being calmer.

22. As a consequence of not taking medication I got more angry quicker.

23. I was also louder when I didn't take medication.

24. I'm louder when I'm not taking medication because I'm not calm

2.3 People drugged too much

77. If I was in charge of MHS I wouldn't drug people as much.

78. Instead of drugging people I'd just let them get on with their lives.

87. I think that MHS drug people too much.

88. I've seen people in hospital been drugged too much.

89. I can just tell when people have been drugged too much.

90. You can tell when people have too many drugs in their system.

91. When I was in hospital and saw people who I believed to be too drugged I thought "Oh my God".

92. People should be treated with less drugs.

93. Just treat people with less drugs.

94. I used to be over medicated, but not anymore.

144. People disengage from MHS because they are medicated up.

145. There is no other reason why people disengage.

3. "I don't want to be part of this community."

148. I don't feel part of this community.

149. "I don't want to be part of this community.";

150. I don't want to be part of this community because they don't do the same things as me.

151. I don't want to be part of this community because they don't do the same things as me – I smoke weed.

152. "They" go out for a drink, I smoke weed.

153. "They" work, I don't.

154. I don't really miss working.

155. I don't need to go to the pub to meet up with my friends.

178. I have actively chosen to separate myself from society.

179. I made the decision to actively separate myself from society nine years ago.

180. I made the decision to actively separate myself from society nine years ago because that is when I took the drug.

181. I made the decision to actively separate myself from society nine years ago because that is when I took ecstasy.

191. I made the decision to actively separate myself from society nine years ago because that is when I took ecstasy and other people took ecstasy at the same time as me.

193. The people who took ecstasy at the same time as me opted to stay in main stream society after taking the drug.

195. They took ecstasy and had the same terrible visions as me and they have stayed in mainstream society.

196. I can't say whether staying in mainstream society has been good or bad for them – I can only speak for myself.

197. I am distancing myself from mainstream society because of what I saw when I was on ecstasy.

199. To understand how taking ecstasy, seeing dead people, disengaging from MHS and taking myself out of mainstream society ties to together you would have to take ecstasy yourself.

3.1 Support

95. MHS only need to offer medication, hospitals & support.

96. MHS need to offer verbal help & support.

97. I don't think that I benefit from verbal help & support.

98. No, I really don't benefit from verbal help & support.

99. I support myself.

100. My friends & family support me.

103. There are a lot people out there who support me.

135. There is no one else who supports me other than my family.

156. I meet my friends at my house.

157. Friends come over to the house to see me.

158. My friends don't provide support, it's just friendship.

159. I don't think friends and family provide support

160. You just support yourself and your friends and family are just there.

161. My friends and family don't actually support me.

3.1.1 Family

101. I'm close to my family.

102. My immediate family includes my Mother & my siblings.

103. There are a lot people out there who support me.

104. I see my family when I'm ready, when I want to see them.

105. I see them on my terms.

106. My family all live locally.

107. It's easy for my family to pop round.

130. That my family called MHS in the build up to my first admission did subsequently effect our relationship.

131. After my first admission I wasn't around my family much, I distanced myself from them and I just wanted to be on my own.

132. This hasn't changed – I still distance myself from my family & I still want to be by myself.

133. Chilling in my flat is different from me distancing myself from my family.

135. There is no one else who supports me other than my family.

3.1.2 Experience of hospital

29. A positive consequence of being involved with MHS has been that I have been out of hospital for a year now.

30. It is a good thing that I have been out of hospital for a year now.

31. My experience of hospital was alright.

32. My experience of hospital was alright because of the way it is.

128. My first admission to hospital was unnecessary

129. However, my family felt that my first admission was justifiable because they were the ones who called MHS

3.1.3 Support/ Religion

136. Religion plays an important part of my life

137. Religion keeps me sane.

138. Religion keeps me sane – I stay away from the bad and do the good.

139. An example of the bad would be stabbing someone.

140. Without religion I would probably be out stabbing people.

141. The good is natural; the good is in yourself; you should know what the good is; your conscience tells you what the good is.

142. During the time I was "crazy" in those years subsequent to my Dad dying
religion did help me a little bit but it can't bring back my Dad so......

143. Religious instruction may help more than medication, but it depends on the type of religious instruction.

3.1.4 Trust

158. I don't trust people because of people's mentalities.

159. By people's mentalities I mean back stabbing.

160. I feel that people have frequently back stabbed me.

161. With people in general I would say that you can't trust people.

162. You can't trust people because I don't trust people easily.

163. People can earn my trust but it is hard.

3.2 Fatherhood

108. My father committed suicide

109. My father's suicide had a big impact on me.

110. My father's suicide had a big impact on me in a crazy way.

111. My father's suicide made me go crazy.

112. My father's suicide really made me go crazy.

113. There was about a year between my Father's death and me coming into contact with MHS.

114. A lot of things were going on in my head; I was grieving.

115. Yeah, other people would grieve too after the death of their father;

142. During the time I was "crazy" in those years subsequent to my Dad dying
religion did help me a little bit but it can't bring back my Dad so......

147. It's a cycle that I am in of fathers not connecting with their kids.

148. My Dad didn't connect with me, my Mum's Dad didn't connect with her, my Dad's father didn't connect with him.

150. My parents split up as well.

151. So my father never had a father.

152. My relationship with my father was rubbish really.

153. I was just starting to know him when he committed suicide.

154. And because I was just starting to know him when he committed suicide made grieving even harder for me.

155. It's a cycle of Fathers not knowing their children.

156. I don't know if I'd like to become a father.

157. If I met a woman and she wanted a child with me I'd be opposed.

158. If I met a woman and she wanted a child with me I'd be opposed because I don't trust people.

4. Smoking cannabis is beneficial

51. I regularly smoke cannabis

52. Cannabis gives me relaxation.

53. Smoking cannabis is just something to do.

54. The reason why I smoke cannabis as opposed to going out for a run is running just isn't me, it just isn't my style.

55. I feel more relaxed when I smoke cannabis.

56. I don't use any other drugs.

57. I have smoked cannabis since I was 14.

58. I have been smoking cannabis for a long time.

59. Smoking cannabis has helped me in a lot of ways.

60. I don't want to say how cannabis has helped me.

61. I won't say how cannabis has helped me because it's personal.

62. Cannabis relaxes me & keeps me calm.

63. I described medication as keeping me calm.

64. The calmness from medication is different from the calmness of cannabis.

65. Cannabis makes you sleep.

67. I enjoy sleeping after smoking cannabis and the feeling of relaxation.

68. If I was suddenly unable to get hold of cannabis I'd want some and have urges for it.

69. I'd miss cannabis if it wasn't there.

70. Smoking cannabis is bad for me. Smoking is bad, full-stop.

71. At the same time I enjoy smoking cannabis.

72. I choose to ignore the bad parts about smoking cannabis

73. I choose to smoke cannabis & enjoy it and not think about cannabis damaging my health.

74. I am comfortable with the arrangement of on the one hand knowing that cannabis is bad for you but on the other hand enjoying it.

75. Smoking cigarettes is also bad for you.

76. I smoke both cannabis & cigarettes.

167. I don't want to be part of this community because they don't do the same things as me – I smoke weed.

168. "They" go out for a drink, I smoke weed.

4.1 Drugs/ grieving/ "Crazy"

116. Drugs turned grieving into being crazy.

117. I was grieving & I took drugs.

118. You could say that it was taking drugs whilst I was grieving that took me the next step down the line into being crazy.

119. I would say that taking drugs whilst I was grieving that took me the next step down the line into being crazy.

123. I went crazy a year after my Dad died.

124. I may have gone crazy a year after my Dad died but I didn't have MH problems.

125. I saw my craziness as a reaction to the grief.

126. My grief resolved itself 3-4 years after my Father's death.

142. During the time I was "crazy" in those years subsequent to my Dad dying religion did help me a little bit but it can't bring back my Dad so......

4.2 Ecstasy/ Nine Years ago

180. I made the decision to actively separate myself from society nine years ago because that is when I took the drug.

181. I made the decision to actively separate myself from society nine years ago because that is when I took ecstasy.

182/ 183. I took ecstasy nine years ago - It was also nine years ago that I first came into contact with MHS.

184. I made the decision to actively separate myself from society nine years ago because of what I saw when I took ecstasy.

185. I saw things when I took ecstasy nine years ago.

186. I don't want to talk about the things I saw when I took ecstasy nine years ago.

187. I don't want to talk about the things I saw when I took ecstasy nine years ago because it's personal.

188. I don't want to talk about the things I saw when I took ecstasy nine years ago because it's personal and it ties in with religion.

189. I saw lots of things when I took ecstasy nine years ago, including dead people.

190. I saw dead people when I took ecstasy nine years ago.

191. I made the decision to actively separate myself from society nine years ago because that is when I took ecstasy and other people took ecstasy at the same time as me.

192. The people who took ecstasy at the same time as me haven't disengaged from the MHS – so they haven't been caught.

193. The people who took ecstasy at the same time as me opted to stay in main stream society after taking the drug.

194. They took ecstasy and had the same terrible visions as me.

195. They took ecstasy and had the same terrible visions as me and they have stayed in mainstream society.

198. There is religious content to this ecstasy experience;

199. To understand how taking ecstasy, seeing dead people, disengaging from MHS and taking myself out of mainstream society ties to together you would have to take ecstasy yourself.

201. Your experiences when on E wouldn't be radically different from mine.

202. Everyone sees the same thing when they are taking E

5. Diagnosis

8.   I don't think I have schizophrenia

9.   I still don't think that I have schizophrenia now.

10.   I don't think that I have schizophrenia.

11.   I don't think I have any MH problems.

39. It's not up to me to judge whether other people have schizophrenia.

40. It's not up to me to judge whether other people have schizophrenia.

41. I have no comment as to whether other people have mental illness

42. I cannot comment as to whether other people have mental illness or not because I haven't been through what they have been through.

43. It's up to other people to determine for themselves whether they have a mental illness.

120. Earlier in the interview I said I didn't have schizophrenia.

121. And also earlier in the interview I also said that I didn't have any MH problems

122. No. I've never had any MH problems;

123. I went crazy a year after my Dad died.

124. I may have gone crazy a year after my Dad died but I didn't have MH problems.

125. I saw my craziness as a reaction to the grief.

126. My grief resolved itself 3-4 years after my Father's death.

127. It took me 3-4 years to get over my Father's death

5.1 Judging/ Behaving/ Diagnosing

78. Instead of drugging people I'd just let them get on with their lives.

79. It's a thin line between who to leave in peace and who to get professionally involved with.

80. If I was in charge of MHS I would get professional involved with someone if they weren't acting right.

81. I don't know how you can tell if someone isn't acting right.

82. You could tell someone wasn't acting right by their behaviour

83. We judge whether someone as 'not acting right' by judging their behaviour against stereo types of human behaviour.

84. Normal human behaviour is just normal human behaviour.

85. You can tell that someone is not engaged in normal human behaviour by them doing things that are out of place.

86. I don't know what behaviour I would consider to be out of place.

6. I am healthy

44. I'm in good physical health

45. I don't have any problems with my physical health.

46. Health is just health

47. We are all going to die one day.

48. Your health is going to go one day, isn't it?

49. I tell myself that my body is healthy at the moment

50. I think I am healthy because that is how I think.

70. Smoking cannabis is bad for me. Smoking is bad, full-stop.

72. I choose to ignore the bad parts about smoking cannabis

73. I choose to smoke cannabis & enjoy it and not think about cannabis damaging my health.

74. I am comfortable with the arrangement of on the one hand knowing that cannabis is bad for you but on the other hand enjoying it.

75. Smoking cigarettes is also bad for you.

76. I smoke both cannabis & cigarettes.

7. How I spend my time

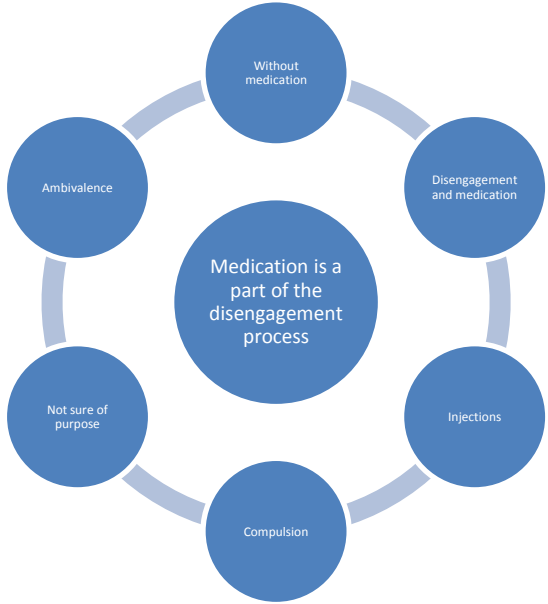35. I spend my time the same now as I did when I was choosing to be disengaged

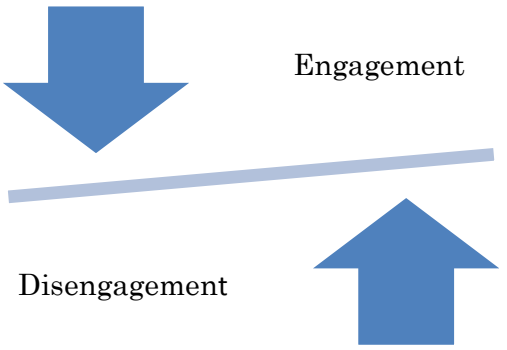36. What I do with my time is chill.

37. I chill by listening to music, going on the internet, speaking to friends

38. I could listen to music, go on the internet, speak to friends with or without MHS.

133. Chilling in my flat is different from me distancing myself from my family.

Appendix 6:   Summary Table of all Themes

	Rebel	Arthur	Black Zee	Clue	Josh	Bubbles	T.
Experiences of (& relationships with) MHS Inc. experiences of in-patient care	X	X	X	X	X	X	X
Transience	X	X	X	X		X	
Unsure what is happening {Schizophrenia, medication, housing, admissions, MHS}	X	X	X		X		
Unsure what is happening {Schizophrenia} Subjective experience of illness	X	X	X		X	X	X ("crazy" when his Father died)
Denial of illness		X	X				X
	X	X	X	X	X	X (related to experiences)	X
"I ain't got no choice"		X	X		X	X	X
Disengagement and medication	X	X	X	X		X	X
Life without medication	X				X		X

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Dislike of injections	X	X		X	X	X	
Ambivalence about medication		X	X		X		X
Unsure of purpose of medication	X	X	X		X		
Religion as a replacement for medication	X				X		
	X		X	X	X	Minor	X
	X	X		X		X	
I want to be disengaged from MHS			X				X

|							
I have never disengaged from MHS	X					X	
Health, Illness & Anxiety	X	X		X	X	X	X
Benefits of cannabis	X	X	X	X	X	X	X
Role of other substances				X	X	X	
Family & Fatherhood	X	X	X	X		X	X
Separation, death and loss	X	X	X	X	X	X	X
"I am a solitude"	X		X		X	X	X
"I have changed"/ Things are different now	X				X	X	
"I was a violent man"		X		X	X	X	
Being your own man {Is this a sub-theme of Transformation, a sub-theme of "I am a solitude" or a sub-theme of identity}	X			X	X		X
Oppression & Persecution (incl. Racism)				X		X	
Identity						X	
Quality of life	X	X	X	X	X	X	
Part of the local community			X		X	X	
Not part of this community and society	X			X	X	X	X
Why disengage? Medication	X	X	X	X	X	X	X
Why disengage? Communication (inc. people telling you what to do)	X		X	X	X	X	
Why disengage? To be an individual	X		X	X	X		

Appendix 7:   Permission from RCN Publishing
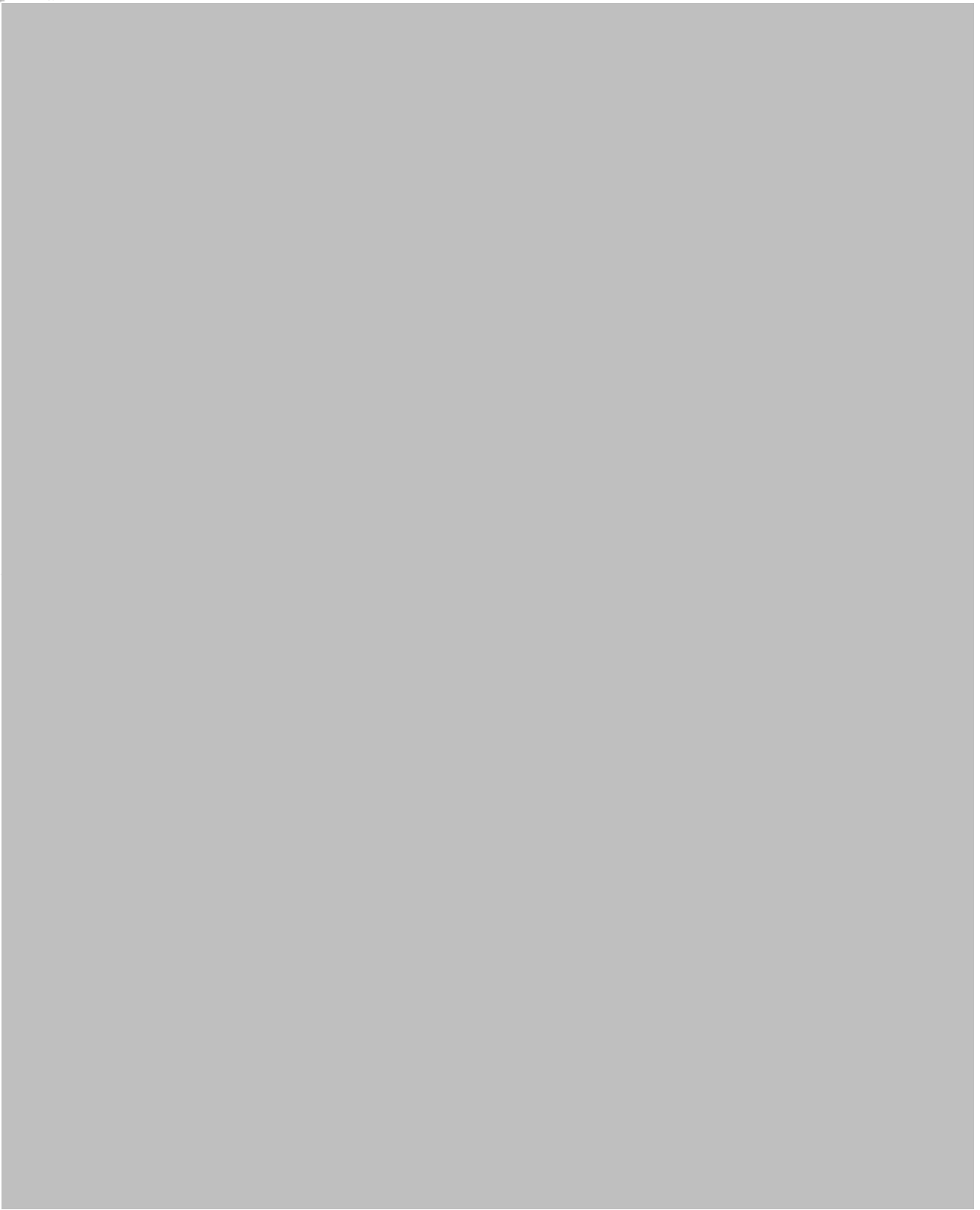
Appendix 8:   Ethical Approval from BEN NRES
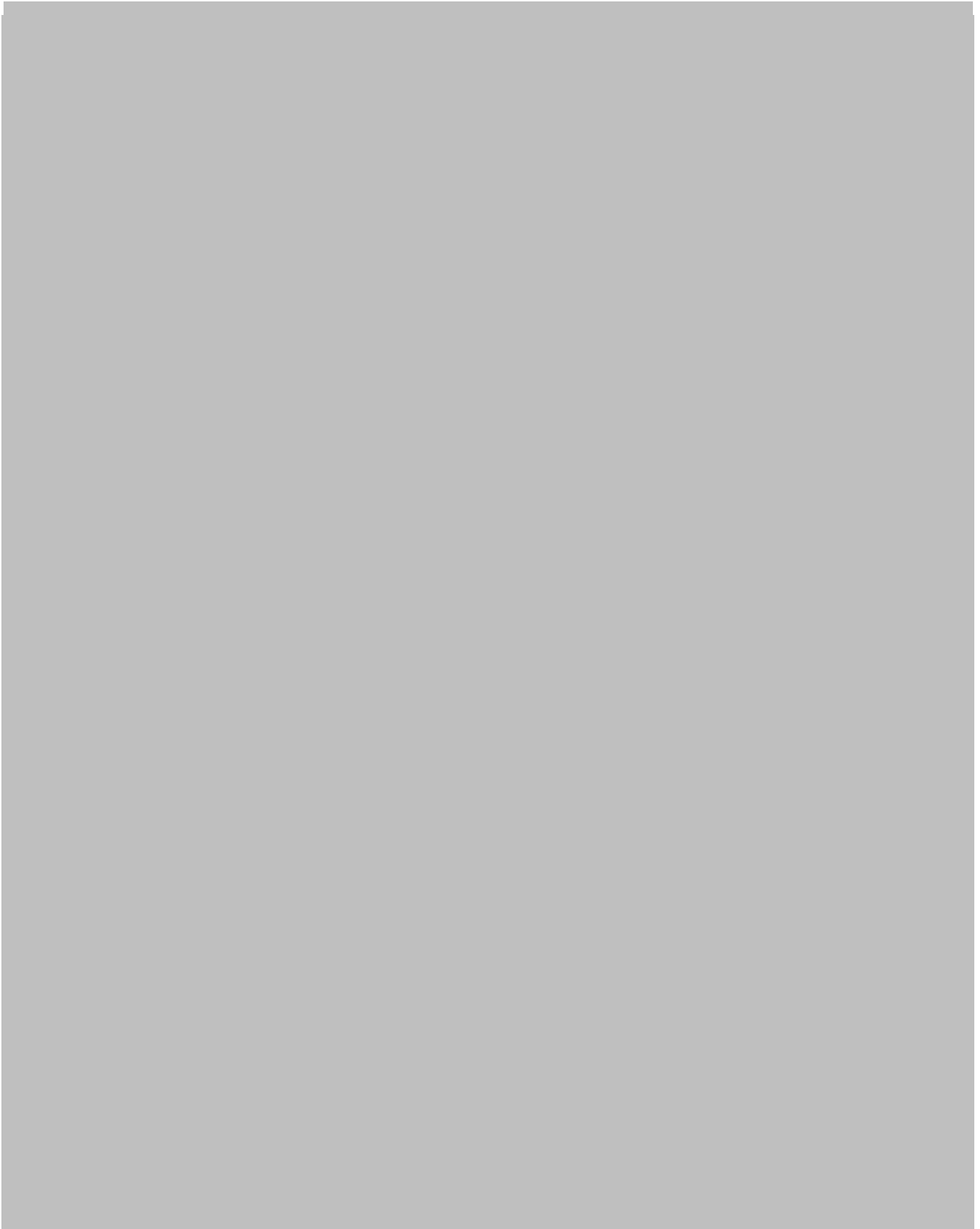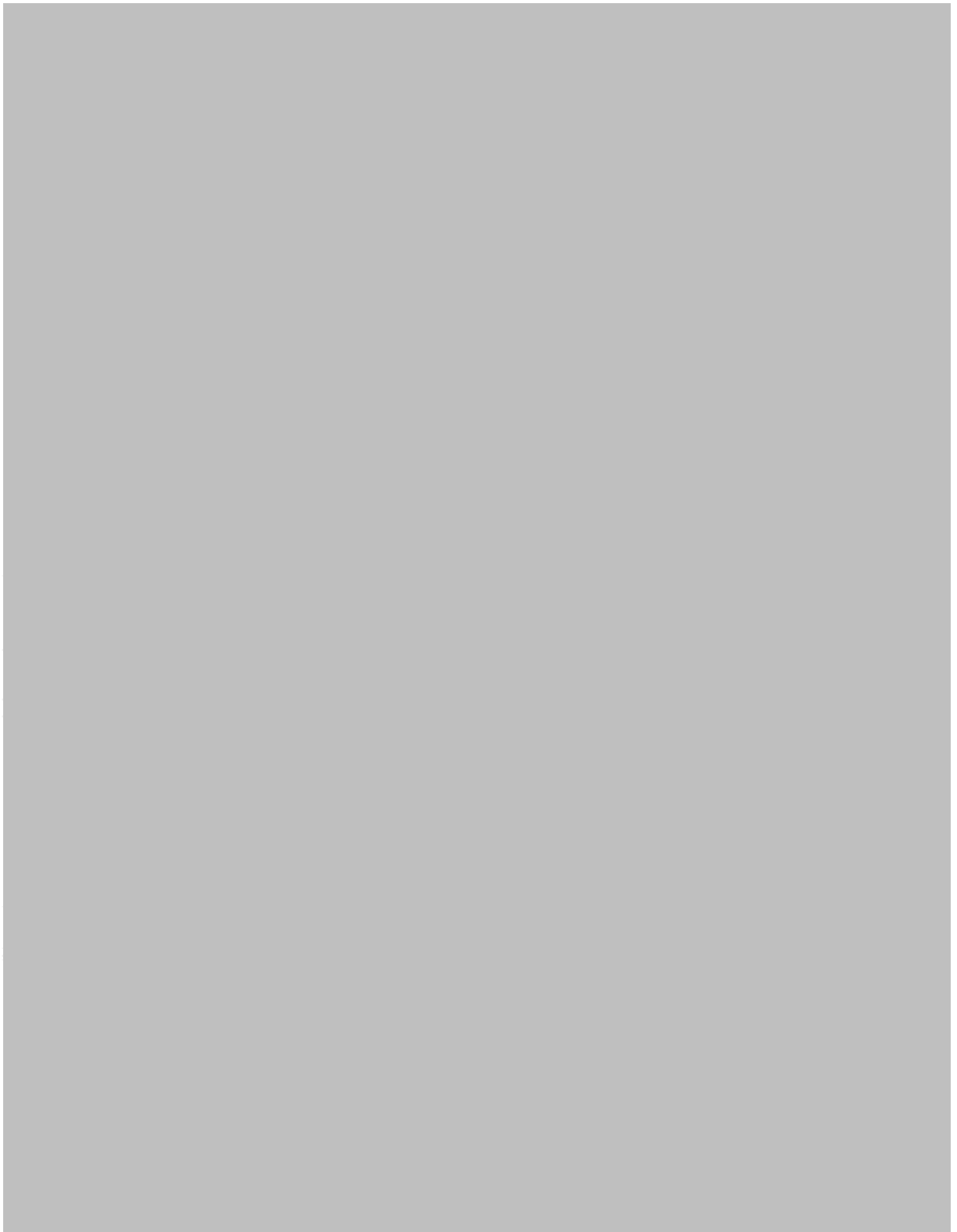
Appendix 9:   Consent Form

Patient 'research name' for this research:

CONSENT FORM

Title of Project: An exploration of service user's experiences of disengagement from mental health services

Name of Researcher: Chris Wagstaff

Please initial each point and sign at the bottom.

Please tick

I confirm that I have read and understand the information sheet dated 18-2-2011 (version V) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
I understand that information relevant to the research will be discussed by the clinical team responsible for my care and the researcher from University of Birmingham where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree that the research interview will be recorded and that the research interview will be transcribed.	
I understand that the researcher may use anonymised direct quotes taken from me in the writing up of the research report.	
I agree to take part in the above study.	

Name of research participant Date   Signature

Appendix 10: Patient Information Sheet (PIS1)

Patient Information Sheet 1

Study title: An exploration of service user's experiences of disengagement from mental health services

I would like to invite you to take part in this research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. I suggest this should take about 15 minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?
The aim of this research is to understand how you feel about your mental health and working with the mental health services.

Why have I been invited?
You have been chosen for this research project because you have a medical diagnosis of a severe mental illness. Also, for a number of reasons, you have chosen to not always engage with mental health services. For the purposes of this research disengagement is defined as non-adherence to treatment. Non-adherence includes several factors: for example not remaining in contact with services, not collaborating in treatment plans and not being open about difficulties, (Hall et al. 2001).

Do I have to take part?
It is up to you to decide whether or not to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

The research will be one interview, which should take about an hour. The questions in the interview will be about you, your medical diagnosis & mental health and, potentially, drug/alcohol use. The research interview will be recorded and that recording will be transcribed.

The possibility remains for us to meet more than once in order to complete the research interview. Potentially, we could meet more than once if I need to clarify things that you have said in the initial interview.

There will also be a post-meeting that all the participants will be invited to. However, it is not a required component of the research that you attend this latter session. It is anticipated that the post- meeting will take about an hour.

The research methodology being used in this study is Interpretative Phenomenological Analysis, meaning that the researcher will be looking at your own individual lived experience and also interpreting your experience in relation to the experience of other research participants.

Expenses and payments

You will be provided with a gift voucher as compensation for the expenses you may incur; such as, travelling to the interview and organising childcare and the time to contribute to this research project. The gift voucher will be for £20.

What are the possible disadvantages and risks of taking part?

The risks of your participation are that you will be discussing sensitive areas of your beliefs; however I can assure you that this information will be treated with utter confidentiality and sincerity. It is between you and me to negotiate where the research interview is going to take place, and the interview will take place in a venue where you feel comfortable. A member of your clinical team will attend the interview but won't necessarily be in the same room. The decision about whether they should be in the same room is entirely up to you.

What are the possible benefits of taking part?

I cannot promise the study will help you but the information gained from this study will help improve the treatment of people with a Severe & Enduring Mental Illness and a history of disengagement from mental health services.

Help & Support available

I am a Registered Mental Health Nurse, with a Diploma in Mental Health Nursing and an MSc in Health Sciences. I am also a NMC Registered Clinical Nurse Specialist in mental health, with 14 years clinical experience. If you, for any reason, find the research interview too distressing then we are in the position to call upon the services of the member of your clinical team who will be nearby.

What if there is a problem?

Any complaint about the way you have been dealt with during the research will be addressed. In the first instance you should speak to the researcher, and I will do my best to answer your questions. Contact details are on page 4. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Jayne Parry, (University of Birmingham, College of Medical & Dental Sciences, School of Health & Population Sciences, 52 Pritchatts Rd, Birmingham, B15 2TT).

What will happen if I don't want to carry on with the study?

If at this stage you feel that you do not wish to participate in the research then the clinical team responsible for your care will continue to work with you as previously. If you withdraw from the research project any data held about you by the researcher will be destroyed.

Harm

The University of Birmingham has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities in this research study are included within that coverage.

Confidentiality

The research interviews will be recorded, so I have a clearer record of precisely what was said. During the research interview I will refer to you by whatever name you choose, to preserve anonymity. The research interviews will be transcribed. Again, when I am writing up the research I will refer to you by this 'research name'. Once the recorded session has been transcribed I shall store the recording in a locked cupboard in a locked room for five years before being destroyed (in line with university protocols).

The transcripts of the research interviews, using your 'research name', will be seen by me as the primary researcher, my three research supervisors and two service users. Any information that could reveal your identity will be removed from the transcripts.

At the post-meeting individual transcripts will be available for the respective individual research participant to read. In the post meeting group discussion quotes from research participants will be used, but these will be made using the 'research names.' Copies of the final research report will be available to research participants upon request.

Disclosure

If issues of immediate concern, such as the expression of suicidal ideas or an intention to harm other people, are raised during the interview these will be fed back to the clinical team. I have a duty of disclosure, if you confess to committing a crime during the research interview. If this is the case then your clinical team will be informed and decisions will be made about how to proceed. The only other record of the meeting will be a note in your clinical records to say that you met with me for this particular research study.

Funding

The research is funded jointly by the University of Birmingham and privately by me.

Who has reviewed this study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Birmingham East North & Solihull REC.

If you have any further questions, or want further clarification, you can contact me on the above number where I can answer your questions over the phone or I can visit in person.

Chris Wagstaff

Post-Graduate Student. University of Birmingham

PALS can be contacted on 0121 678 4455 as a source of independent advice

Appendix 11:   Study 2 Consent Form

<div align="right">**Version III. 8-2-13**</div>

CONSENT FORM

Title of Project: NHS staff perspectives on the experiences of people with severe mental health problems (in particular black men) who have a history of disengagement from mental health services. An IPA focus group.

Name of Researcher: Chris Wagstaff

Please initial each point and sign at the bottom.

<div align="right">**Please tick**</div>

I confirm that I have read and understand the information sheet dated 8-2-13 (version III) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up until the point when the recording of the Focus Group starts.	
I agree that the research interview will be recorded and that the research interview will be transcribed.	
The researcher has a duty of disclosure; if during the research interview you confess to committing a crime then this may be taken to the appropriate authorities.	
I understand that the researcher may use anonymised direct quotes taken from me in the writing up of the research report.	
I agree to take part in the above study.	

Name of research participant Date   Signature

Appendix 12:   Study 2 Participant Information Sheet (PIS2)

<u>**Version III. 8-2-13**</u>

Participant Information Sheet

Study title: NHS staff perspectives on the experiences of people with severe mental health problems (in particular black men) who have a history of disengagement from mental health services. An IPA focus group.

I would like to invite you to take part in this research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. Please read through this participant information sheet and I will answer any questions you have. Talk to others about the study if you wish.

What is the purpose of the study?
The aim of this research is to understand the perspectives of NHS staff that have experience of working with people with severe mental health problems (in particular black men) who have a history of disengagement from mental health services.

Why have I been invited?
You have been invited to participate in this research project because you have experience of working with people with severe mental health problems (in particular black men) who have a history of disengagement from mental health services.

Do I have to take part?
It is up to you to decide whether or not to participate in the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason, up until the stage that the recording begins as I will not be able to remove your data from the transcript.

What will happen to me if I take part?
If you agree to participate in this study you will be expected to join other staff from ▨▨▨▨▨ in a one hour focus group. The points for discussion within the focus group interview will come from an interpretative phenomenological analysis study into the experiences of disengagement from mental health services for people (in particular black men) with severe mental health problems. The research interview will be recorded and that recording will be transcribed.

The research methodology being used in this study is interpretative phenomenological analysis, meaning that the researcher will be looking at your individual lived experience and also interpreting your experience in relation to the experience of other research participants.

What are the possible disadvantages and risks of taking part?
The risks of your participation are that you will be discussing sensitive areas of your beliefs; however I can assure you that this information will be treated with utter confidentiality and sincerity.
What are the possible benefits of taking part?

By participating in this study the account of your experience will help to provide a broader perspective and as such assist in future service development for people with severe mental health problems (in particular black men) who have a history of disengagement from mental health services.

Help & Support available
I am a Registered Mental Health Nurse, with a Diploma in Mental Health Nursing and an MSc in Health Sciences. I am also a NMC Registered Clinical Nurse Specialist in mental health, with 14 years clinical experience. If you, for any reason, find the research interview too distressing *then I will be available to offer support to you once the group interview has finished*

What if there is a problem?
Any complaint about the way you have been dealt with during the research will be addressed. In the first instance you should speak to the researcher, and I will do my best to answer your questions. Contact details are on page 3. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Alistair Hewison, Head of School (University of Birmingham, College of Medical & Dental Sciences, School of Health & Population Sciences, 52 Pritchatts Rd, Birmingham, B15 2TT).

What will happen if I don't want to carry on with the study?
If at this stage you feel that you do not wish to participate in the research then you can withdraw from the study. If you withdraw from the research project any data held about you by the researcher will be deleted.

Harm
The University of Birmingham has in force a Public Liability Policy which provides cover for claims for "negligent harm" and the activities in this research study are included within that coverage.

Confidentiality
The research interview will be recorded, so I have a clearer record of precisely what was said. During the research interview I will refer to you by whatever name you choose, to preserve anonymity. The research interview will be transcribed. When I am writing up the research I will refer to you by this 'research name'. Once the recorded session has been transcribed I shall store the recording in a locked cupboard in a locked room for five years before being destroyed (in line with university protocols).

The transcripts of the research interviews, using your 'research name', will be seen by me as the primary researcher and the research supervisors. Any information that could reveal your identity will be removed from the transcripts.

Disclosure
I have a duty of disclosure; if during the research interview you confess to committing a crime then this will be taken to the appropriate authorities.
Funding
The research is funded jointly by the University of Birmingham and privately by me.
**Who has reviewed this study?**

This study is part of the student's PhD and is being conducted on behalf of University of Birmingham. The supervisor for the study is Dr Herman Wheeler (contact details: *Dr. Herman Wheeler, Lecturer in Health Sciences, College of Medical and Dental Sciences, University of Birmingham, 52, Pritchatts Road, Birmingham, B15 2TT, England.*   . *Tel*   ) This study has been reviewed and given favourable opinion by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee and abides by University Code of Practice for Research.

If you have any further questions, or want further clarification, you can contact me on the above number where I can answer your questions over the phone or I can visit in person.

Chris Wagstaff

Post-Graduate Student. University of Birmingham

Appendix 13:   Study 2 Ethical Approval
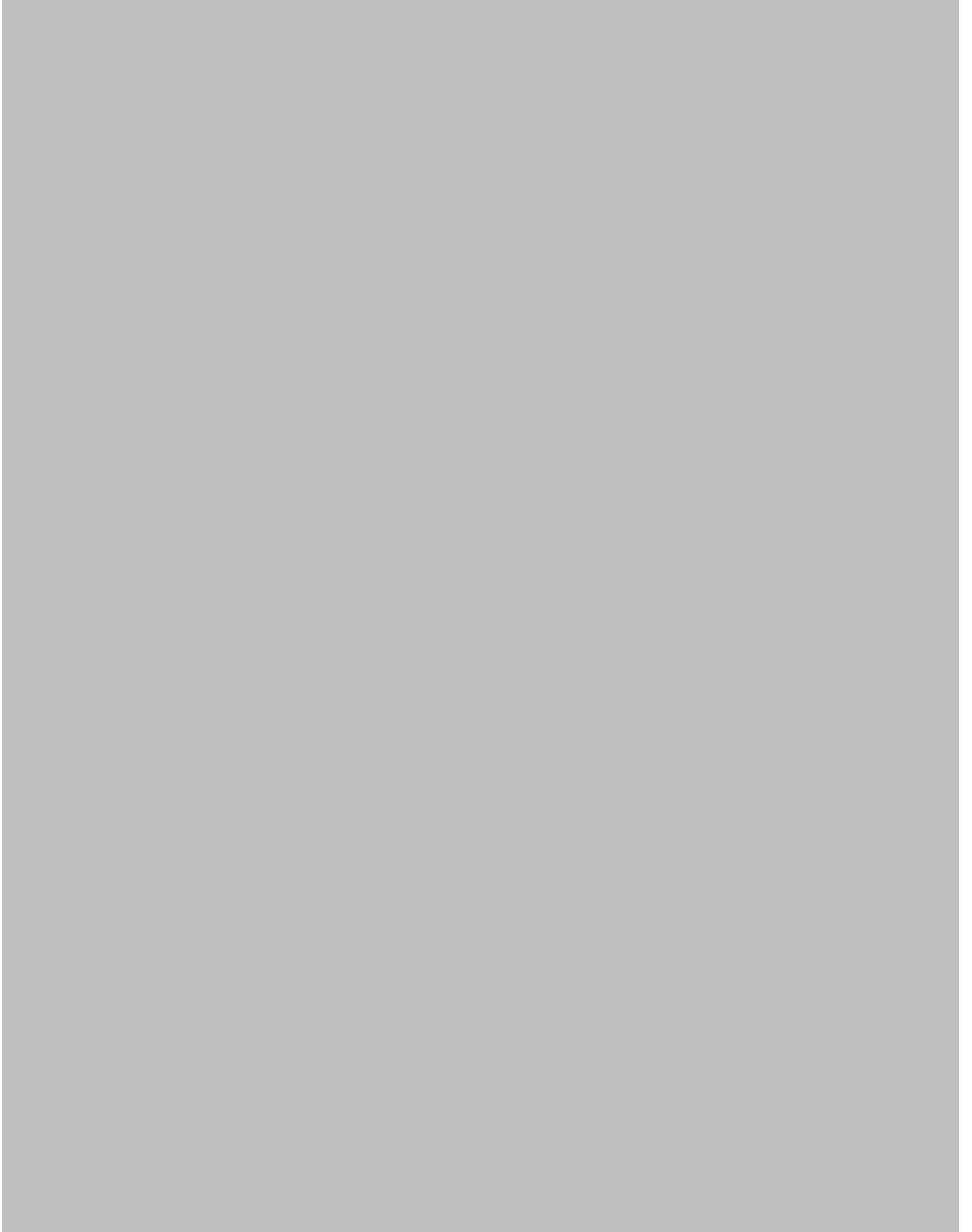
Appendix 14: **Oxford University Press Permission**