Black and Asian Women's Conceptualisations of Psychosis and Compulsory Admission within an Early Intervention Service

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ABSTRACT

Aims: To explore the experiences of women from Black and Asian backgrounds, detained under the Mental Health Act (1983; 2007), on their journeys to accessing care for a First Episode Psychosis diagnosis.

Background: Black and Minority Ethnic (BME) groups are sectioned under the Mental Health Act at significantly higher rates than White ethnic groups. BME groups are also more likely to be diagnosed with psychosis – a presentation primarily understood in services within the medical model of 'mental illness', and related to stereotypes of 'dangerousness'. While quantitative research highlights the inequalities impacting Black men, BME women who show similar trends are often overlooked. Additionally, limited data exists about the lived experience of coercive pathways to psychosis care for these groups.

Methodology: A critical realist research framework was used to qualitatively explore experiences of psychosis and services with Black and Asian women. Eight semi-structured interviews were conducted with women accessing Early Intervention for psychosis Services (EIS) and previously sectioned.

Results: A thematic analysis identified three themes and six sub-themes: 'Sense of Mistrust'; 'Navigating Unsafe Systems'; and 'Impact of Adversity'. Psychosis was characterised as feeling unable to trust others, *and* yourself. Initial interactions with services, particularly the police, were experienced as unfair, re-traumatising and racially biased. Trauma-informed and spiritual models to explain psychosis, felt neglected by services in favour of the medical model. However, social and psychological aspects of care offered by services, were described as unexpectedly helpful by the participants.

Conclusion: It is proposed potentially unhelpful wider societal discourses, such as 'the Angry/Strong Black Woman', 'the Meek Asian Woman' and 'psychosis is dangerous' have an impact on experiences of accessing care for First Episode Psychosis. Recommendations discussed include: a systems-wide approach to tackling bias, acknowledging intersectionality, accommodating multiple beliefs in practice, and potential alternatives to detention under the Mental Health Act.

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our backs
tell stories
no books have
the spine to
carry

women of colour – Rupi Kaur

Firstly, I would like to express gratitude and appreciation to the women who felt it worthwhile to make this research a reality. I am honoured to have been in the presence of much dignity, honesty and hopefulness in the interview room. In a world which can often be silencing, I hope this thesis contributes in some way to elevating your voices.

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CONTENTS

LIST OF ABBREVIATIONS

APA – American Psychiatric Association

BME – Black and Minority Ethnic

BPS – British Psychological Society

CAMHS – Child and Adolescent Mental Health Services

CBT – Cognitive Behavioural Therapy

CQC – Care Quality Commission

DHSC - Department of Health and Social Care

DoH – Department of Health

EI – Early Intervention (Often used to refer to services designed for First Episode Psychosis, i.e., '<u>E</u>arly <u>I</u>ntervention Services' or '<u>E</u>arly <u>I</u>ntervention for Psychosis services')

FEP – First Episode Psychosis

HMICFRS – Her Majesty's Inspectorate of Constabulary and Fire & Rescue Services

IAPT – Improving Access to Psychological Therapies

MHA – Mental Health Act

NHS – National Health Service

NICE – National Institute for Health and Clinical Excellence

PSC – Psychologists for Social Change

TA – Thematic Analysis

1. INTRODUCTION

1.1 Relevant Terminology, Definitions and Concepts

1.1.1 Psychosis

'Psychosis' is a term used within services and existing literature to capture the stereotypical understanding and experience of 'madness'. It is characterised by an individual undergoing extreme confusion; often seeing or hearing things others do not, believing things others find strange, speaking in ways others find hard to follow, and largely appearing 'out of touch with reality' (Geekie & Read, 2009; British Psychological Society [BPS], 2017). The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2013), considers these experiences as symptoms of 'disorders' on the 'schizophrenia spectrum', such as, 'hallucinations', 'delusions' and 'disorganised thinking' (see Appendix A). The existence of differentiating understandings of 'psychosis' reflects wider theoretical and professional arguments regarding causality, approaches and management. Psychosis[1] will be used pragmatically to capture the above experiences, with the aim to achieve resonance and accessibility to this study for a wide audience, as they are terms commonly used in many systems, i.e., health services, researchers and the wider public. While the phenomena itself will be deconstructed within this study, I understand this research to be about people who have *received* a diagnosis of psychosis, not people who *have* psychosis.

A 'First Episode of Psychosis' (FEP); will be understood in this study as the first time a person presents with psychosis experiences to statutory services (Norman & Malla, 2001; Breitborde, et al., 2009).

1.1.2 Race

While 'race' may be minimised to a term used to classify one's genetic ancestry and/or features shared with other individuals, i.e., skin colour (Fernando, 2017,

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[1] After I have defined contested terms, I will no longer be present them in inverted commas

p.19), this study considers race in relation to power, domination and subjugation, rather than biological similarities and differences (Patel & Bennett, 2000; Omi & Winant, 2015). The concept of race has been used in the past to infer inferiority and legalise the oppression of certain groups in society, such as through slavery and colonisation (Gunaratnam, 2003; Durrheim, et al., 2009; Pickren, 2009). 'Racialisation' is described by Fanon (1986) as the dehumanisation of various groups of people by structuring them as 'races' according to White-European constructs of normality. While I use the term 'Black' in this study to describe individuals whose ancestry is from the African and Caribbean continents (Bhopal, 2004), 'Asian' for those with ancestry from the Asian continent (inferring 'brown-skinned', Fernando, 2017, p.96), and 'White' for groups with Anglo-European descent, I do not see these as concrete discoverable entities, but constructs that have been created and upheld by society.

Similarly, 'ethnicity' is a construct often related to a sense of belonging to a group identity – one that holds particular histories and cultural practices. Although considered to go beyond one's ascribed 'race', ethnicity and race are often used interchangeably in the wider literature (Fernando, 1991). Despite everyone possessing an ethnicity, it is often argued that this term is often only spoken to in relation to marginalised groups, potentially inferring all non-White identities and cultures as similar and problematic (Sashidharan, 1986; Fernando, et al., 1998). While the term 'Black, and Minority Ethnic (BME)' can be considered homogenising, it is a commonly used term used in public bodies such as the NHS, to traditionally highlight the inequalities individuals from non-White groups face. Due to its' wide use in research, policy and clinical contexts, I will occasionally draw on the 'BME' abbreviation in this study for ease of communication.

1.1.3 Gender

Although 'gender' is often used interchangeably with the term 'sex', the latter term has traditionally been used to describe a person's biological 'male' or 'female' status, often based on anatomical characteristics considered to be fixed, i.e., one's reproductive systems (Diamond, 2002). It is acknowledged, that a sharp distinction between these concepts is not essential (Butler, 1999; Mikkola, 2017), thus

references to gender rather sex in this study, intends to highlight socially constructed roles linked to members of the (assumedly different) sexes (Wright & Owen, 2001). This is often presented as the different cultural expectations placed on 'men' and 'women'; who hold different positions in society, highly influenced by time and context (Boyle, 1997; Newman, 2002). Gender is not considered as having essential attributes, but as an illusion maintained by prevalent power structures that impact people's material realities.

Some authors have called to avoid attempts at defining the category of 'women' at all - as it implies there is a 'correct way' to be gendered - and to instead focus on how power functions and shapes understanding of 'womanhood' (Butler, 1999). It is argued in order to respond to the oppression of women, researchers must understand women as a category in some sense, as without doing so, "it is not possible to conceptualise oppression as a systematic, structured, institutional process" (Young, 1997, p. 17). The term 'women' in this study will therefore not be simply reduced to a group's shared biological characteristics, nor assumes a "golden nugget of womanness" (Spelman 1988, p.159) which infers all share the same experience, regardless of race, class, ethnicity and nationality. I will however consider the term women to describe a particular kind of social collective, whose members share a 'thin' commonality in terms of experiences and struggles, which includes the material impact of wider structures on their lives (Jónasdóttir, 1994; Gunnarsson, 2011).

1.1.4 Intersectionality

Intersectionality refers to when two or more social identities overlaps, contributing to specific types of systemic oppression and discrimination (Crenshaw, 1989). I acknowledge that there are many aspects of social categorisation that can impact the life of an individual, however in this study it will be mainly used to describe, acknowledge, and bring awareness to, the crossing of racial and gender identities.

1.3 Psychosis in the Population

It is estimated 20 million people worldwide are impacted by psychosis (James et al., 2018), with 1 in every 150 individuals supposedly diagnosed at some point during

their lifetime (Moreno-Küstner et al, 2018). For every 100,000 people in England, approximately 32 new presentations of psychosis are diagnosed yearly (Kirkbride et al., 2012a).

1.4 Conceptualisations of Psychosis

1.4.1 The Medical model

The illness model is potentially the most dominant understanding of psychosis currently in the West[2]. This approach considers psychosis as a biological condition; in which individuals present with 'meaningless symptoms' (Georgaca, 2013), considered a product of chemical imbalances, brain defects or genes (see Boyle; 2002; Talbott, 2004; Harrington, 2012). The illness-paradigm approach to psychosis prevalent today in mental health services, is much informed by German psychiatrists Kraeplin and Bleuler from the late 19th century, who claimed certain signs and symptoms were an indication of 'mental illness' (Bentall, 2004). Conceptualising psychosis in this way, has led to particular interventions being prioritised, i.e., privileging of medical treatment to manage 'symptoms' of psychosis (Adame & Knudson, 2007). The medication revolution in the 1960's positioned drugs as the mainline treatment for mental health difficulties, which has been further justified by research asserting causation of psychosis is linked to chemical imbalances in the brain (Fernando, 2014, p. 83). In recent years, there has been increasing critique around the diagnostically driven medical model of psychosis, including its' lack of robust scientific findings and ignorance of the role social factors and adversity may play (Hamilton-Mason et al., 2009; Moncrieff & Middleton, 2015; Murray, 2016). Much of the published literature is dominated by the understanding of psychosis as an internal deficiency, with little relevance to external factors that may have also have an impact on a person's lived experience of distress, such as culture, relationships or the environment (Deacon, 2013).

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[2] In contemporary cultural meaning, the 'West' refers to the 'Western world'. This includes Europe, as well as many countries of European colonial origin. Often considered to be more 'economically developed'

It is argued that psychosis promoted primarily as an illness which someone has genetic susceptibility to, can be hugely stigmatising, lead to hopelessness, and also ignore several other relevant factors and/or injustices relevant to how a person may be currently presenting (Read et al., 2005). The illness model of psychosis is said to reinforce popular stereotypes of the person with psychosis, such as that they are dangerous, unpredictable, unlikely to recover and should be separated from society (Angermeyer & Matschinger, 2005; Read et al, 2003). Anti-stigma campaigns using biological explanations of mental health, although attempting to reduce negative attitudes, have been found to potentially worsen attitudes toward individuals receiving certain psychiatric diagnoses, including psychosis (Pescosolido et al., 2010). The popular statement 'mental illness is like any other illness', has been criticised for reducing a complex human problem to an ailment requiring medication (Malla, et al., 2015).

1.4.2 Biopsychosocial Model

An understanding of psychosis within a biopsychosocial model, has gradually become more mainstream in mental health services based in the UK. It is reported to be more holistic in its' approach to psychosis; taking into account the influence of individual biology as well as psychological and social dimensions of a person's life (Engel, 1997). Underpinned by this understanding, the 'stress vulnerability model' suggests interactions between genes, personality, early relationships and an individual's surrounding environment – all play a role in the probability of a person presenting with psychosis (Zubin & Spring,1977). The biopsychosocial model also considers the impact of drug use, 'unhelpful' thinking styles (Garety, 2003), and social stressors on psychosis presentations. This has informed much of the current guidance on particular interventions, such as Cognitive Behavioural Therapy for psychosis (National Institute for Health and Care Excellence [NICE], 2014).

It has been proposed that the development of a biopsychosocial approach, has led to more empathetic and compassionate culture of care from mental health services (Papadimitriou, 2017). Many Euro-American mental health systems seem to hold the view that psychiatric diagnostic labels do reflect 'illnesses', but the way people experience the 'illness' is determined by socio-cultural factors (Fernando, 2017,

p.34). It has been argued that the biopsychosocial model still continues to privilege a medical aspect of psychosis, with the role of psychological and social factors as secondary triggers, to an assumed biological predisposition (Read, et al., 2003).

1.4.3 Normalisation and Continuum Model

An emerging understanding of psychosis is that it is an understandable 'extreme' presentation of the 'normal' human experience rather than a person presenting distinctly as 'mentally ill' or healthy (Bentall, 2004). A continuum (continuous line) approach to psychosis, proposes we all move along a spectrum which ranges from 'good' to 'poor' mental wellbeing during different points in our lives. This approach moves away from diagnosis and the medicalisation of 'normal experiences' (Wiesjahn et al., 2016), understanding psychosis experiences as natural and understandable reactions to difficult life events (e.g. Bentall, 2009; Johnstone & Dallos, 2013). The Hearing Voices Network, a movement underpinned by the continuum model of psychosis; advocates that hearing voices can be a natural human reaction to overwhelming circumstances (Romme & Escher, 1989). This understanding has informed the development of 'Hearing Voices' groups, where people are supported to share their own wide-ranging explanations of the psychosis experience, without the expectation that this has to fit within an illness framework (Corstens et al., 2014).

1.4.3.1 *Adversity, Social Context and Trauma*

In line with aspects of the normalisation model, there is a growing body of research which suggests exposure to unequal power structures and material deprivation are central to peoples' experiences of psychosis (Varese et al., 2012). Quantitative studies investigating the relationship between social inequality and psychosis, have reported living in poverty (Kirkbride et al., 2012b; Richardson, et al., 2018), holding refugee status (Hollander et al., 2016), and/or belonging to an ethnically marginalised group – particularly if you are a black man, increases the likelihood of receiving a psychosis diagnosis (Boydell et al., 2001; Veling et al., 2008). As understood within an intersectional framework, several discriminatory characteristics may accumulate and have an impact on one's lived experience (Crenshaw, 1989). Research indicates high rates of psychosis diagnoses for Black and Asian groups,

correlate with levels of exposure to social adversity, i.e., living as an ethnic minority in a white-majority area, and/or enduring experiences of racism, poverty and social disadvantage (Boydell et al. 2001; Karlsen et al., 2005; Morgan et al., 2007; Morgan et al., 2008). It has been proposed that aspects of the psychosis experience, such as 'paranoia', can be understood as a human response to one's difficult social situation. Groups with less power in society, and/or have limited access to resources, may present with heightened responses, as a way of protecting and keeping oneself safe. Mirowsky and Ross (1983) reported 'paranoid' type beliefs were more strongly correlated with being female, Mexican and working class, rather than if you were a male, a White woman, and/or with higher socioeconomic status. The authors suggest 'paranoid ideas' are a response to the danger of being victimised as others, particularly as those in marginalised social positions are likely to be exposed to experiences where they lack power and control over their distressing situation.

Research also indicates severely traumatic experiences of adversity, such as being subjected to abuse, may increase the likelihood of receiving a psychosis diagnosis (Read, et al., 2005; Varese et al., 2012; Thompson et al., 2014). In addition, findings suggest, compared to men, women subjected to sexual trauma show higher rates of receiving psychosis diagnoses (Morgan & Fisher, 2007; Fisher et al, 2009; Heins et al, 2011; Elklit & Shevlin, 2011). Exposure to social inequality and trauma, i.e., impact of poverty, racism and gender-based violence, may be another lens in which to understand the psychosis experience.

1.4.4 Spiritual and Supernatural Models

Other models used to conceptualise psychosis, includes considering spiritual or supernatural explanations for the experience. Although not mainstream in current UK service provision, dominant views and knowledge on psychosis and 'madness', were initially largely informed by European religious institutions (Fernando, 2014). Many people presenting with 'abnormal behaviour', were considered to be possessed, and confession and exorcism utilised as widely-accepted 'treatments' (Suzuki, 1992). The European 'enlightenment period' of the 17th-19th century, resulted in the zeitgeist significantly changing; scientific knowledge began to take over religious doctrine (Carron & Saad, 2012). During this era psychosis moved away from being

considered a result of sin or demonic possession, but instead towards the view that there was a biological base for 'unusual' behaviour. The 'psy' health professions, i.e., psychiatry and psychology, were subsequently positioned as the 'experts of the mind'), with interventions developed for mental health needs reportedly based on research considered rigorous and scientific (Foucault, 2006, pg. 529). As such, the mental health system today, does not generally advocate for spiritual understandings of psychosis, likely underpinned by the view that supernatural beliefs hold little value in a system where scientific empiricism and objectivity is regarded highly (Tseng & McDermott, 1981).

1.4.4.1   Continuum of Spirituality

Rather than dismissing spiritual explanations for psychosis, it has been advocated that they could be appropriately understood within a continuum of 'normal beliefs' about the supernatural. Studies have attempted to compare experiences of 'unusual beliefs', for example, groups who had heard 'the voice of God' and received a psychosis diagnosis, to those who had never accessed services (Heriot-Maitland, et al., 2012). The authors reported that both groups shared experiences of extreme stress prior the 'unusual experience', however individuals who had received a diagnosis were reportedly more preoccupied and distressed by their beliefs. These findings have been replicated in similar studies exploring spiritual explanations for psychosis in clinical and non-clinical samples (Peters et al., 1999; Verdoux & van Os, 2002; Peters et al., 2004). The view that expressions of supernatural beliefs may present on a spectrum of 'normality', seems to challenge the idea of a biological marker of psychosis being present - or not - within an individual.

Despite its lack of prevalence in the UK mental health system, typical features of the psychosis experience, such as hearing voices, seeing visions and communicating with the unseen, continue to be understood within spiritual frameworks by various communities around the world (Redko, 2003; Igreja, et al., 2008; Earl at al., 2015; Luhrmann, et al., 2015). In some Black and Asian communities outside the Anglo-West, religious healing for psychosis is sometimes held in equal regard to medical treatment for one's recovery (Raguram et al., 2002; Tobert, 2014). Acknowledging the importance of possible religio-cultural differences, may be relevant for understanding the experience of BME communities accessing services for psychosis

in the UK, who reportedly draw on more supernatural explanations for psychosis than biological ones (McCabe & Priebe, 2004; Codjoe et al. 2019). Compared to white British groups, South Asian groups in Britain seemingly utilise more spiritual explanations for psychosis, which the authors suggest has implications for help-seeking and service-engagement (Mirza et al., 2019). While medication and psychology may be considered first line 'treatments' in services (NICE, 2014), 'evil eye', black magic, communicating with spirits, possession, prayer and religious rituals, may be drawn upon as relevant concepts to understand and manage psychosis experiences for many individuals (Igreja, et al., 2008; Irmak, 2014; Lim, et al., 2015; Rassool, 2019). It is of note, that women are also reportedly more likely to describe their psychosis experience in spiritual terms compared to men, which has an impact on their satisfaction with care (Goldstein & Lewine, 2000).

1.5 Service Frameworks for Psychosis

The traditional management of psychosis presentations in the UK has been to exclude and separate people physically from society, often to large asylums utilising intrusive approaches, i.e., shackles and lobotomies[3] (see Suzuki, 1992, for an extensive historical account). Eradicating 'symptoms' via neuroleptic medication, currently dominates modern mental health practice and research for psychosis in the West (Rogers & Pilgrim, 2003; Adame & Knudson, 2007; Beresford, 2010), although the offer of psychological interventions appears to be building prominence in service guidelines (NICE, 2014). Whilst medication may help to reduce unwanted and distressing experiences for many, it seems medical approaches are often prioritised in practice over other interventions and understandings in the West (Spandler & Calton, 2009).

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[3] A surgical operation in which a lobes of the brain, are cut into or across

1.5.1 Responses to Acute Psychosis

Current policies informed by the presumed efficacy of medication, allow mental health services to enforce compliance of 'treatment' for acute presentations of psychosis (Spandler & Calton, 2009). The Mental Health Act [MHA] (1983, 2007) operates in the UK as the lawful justification of non-consensual admission to psychiatric hospital (Szmukler, 2004). The most recent review of the Act, further reiterated longstanding concerns about the disproportionate number of people from BME groups detained under such law (see Department of Health and Social Care [DHSC], 2017; 2018. The Mental Health Act covers both the powers of trained mental health staff, as well as the police, to detain and 'section' someone, needing 'care or control' in public places and deemed to be a significant risk to themselves or others (DHSC, 2015, s.7.16). Those who have been sectioned and diagnosed with FEP are entitled to aftercare and support from an Early Intervention Team.

1.5.3 Early Intervention Services

EI (Early Intervention) in psychosis teams are now a key feature of modern mental health provision in England and the global West (Warner, 2008). EI teams have been designed to improve access to community mental health services for people presenting with FEP (Tait, et al., 2003). The development of such services were considered to revolutionise the care approach to psychosis, with traditional mainstream services considered neglectful and pessimistic towards those who received the diagnosis (Shiers & Smith, 2014). The service is underpinned by concepts such as; intensive intervention during the first three year 'critical period of psychosis', in order to reduce the 'duration of untreated psychosis', considered to prevent future acute presentations and long periods of accessing services (Breitborde, et al., 2009; Norman & Malla, 2001; Marshall & Rathbone, 2011). This includes a 'comprehensive range of interventions', that includes pharmacological and psychological input, and also offers educational, employment and occupational support (NICE, 2014). Reported positive outcomes of EI service input compared to standard care includes: decreased likelihood of hospital admission, decreased severity of distressing experiences, lower rates of disengagement, lower suicide

rates, increased employment rates, higher likelihood of independent-living and overall improved quality of life outcomes, such as preservation of social skills (Marshall et al., 2005; Neale & Kinnair, 2017; Chan et al., 2018; Sullivan et al., 2019).

1.5.2 Responses to Acute Psychosis – A Focus on Race and Gender

Despite the positive development of EI services, individuals from BME communities diagnosed with FEP, continue to be overrepresented in pathways which involve the police and being sectioned (Bhui et al., 2015; Ajnakina et al., 2017; Halvorsrud at al., 2018; Oduola et al, 2019). It has been consistently conveyed that people from BME communities are more likely to be sectioned under the MHA and receive pharmacological interventions, compared to their White counterparts (Fernando, 2003). Much of the quantitative research has suggested that belonging to a racialised group, and receiving a psychosis label – particularly as a Black male – significantly increases the likelihood of being subjected to sectioning under the Mental Health Act, often involving the police (Webber & Huxley, 2004; Morgan et al., 2005a; Morgan et al., 2005b; Morgan et al., 2006; Ghali et al., 2013). Findings on Asian groups admitted under the Mental Health Act, have also reportedly shown higher rates of psychosis diagnoses compared to other ethnic groups (Law-Min, et al., 2003).

A group which has received less attention regarding their journeys to mental health services for psychosis, are women from BME groups. Research investigating pathways to mental healthcare for 287 women across four London boroughs, reported 48% of Black women in their sample were admitted compulsorily, compared to just 13% of White British women (Lawlor, et al., 2010). The authors commented Black women were more likely to be diagnosed with psychosis and detained involuntarily to inpatient wards, where White women were more likely to be diagnosed with a 'personality disorder' and access voluntary interventions. A more recent meta-analysis examining ethnic differences in psychosis and pathways to care in White-majority countries, have reported the higher sectioning rates shown for BME groups in general, were significantly influenced by the number of Black and Asian women sectioned on their pathway to care (Barnett et al., 2019). As for

research focussed specifically on FEP, sectioning rates and gender, an audit by Mind (2003) reported Black men were 4.3 times more likely to be sectioned compared to white groups, and Black women were 3.9 times more likely; only scarcely behind their male counterparts. Additionally, Mann and colleagues (2014) reported Black African women were eight times more likely to experience compulsory admission when diagnosed with FEP, compared to White women - a finding only marginally less than previous research which indicated Black women were 13 times more likely (Knowles, 1991). Additionally, research that has just focussed on gender, suggests women seem to experience FEP for longer periods of time before accessing EI services, compared to men (Køster, et al., 2008; Nawka et al., 2013). The disparities in sectioning rates for women from BME diagnosed with FEP, warrants further exploration and understandings.

1.6 Race, Gender and Psychosis Services

1.6.1 Institutional racism and psychosis

The high rates of psychosis diagnoses in Black populations has been said by some sources to be due to genetic predisposition (Selten et al., 2001), however others report there is limited evidence to support this (Fernando, 1998; Jenkins, 1998; Rose, 2001). Other explanations for the over-diagnosis of psychosis in BME groups, include cultural differences in presentations of distress (see: Sharpley, et al., 2001), and that negative cultural stigma towards mental 'illness' impacts timely help-seeking (Mantovani et al., 2016). However, it is argued, explanations which emphasise cultural differences in communication of distress, reinforces the othering of minority and migrant cultures as 'alien', which ignores the role of potential systemic injustice (Kalathil & Faulkner, 2015).

This complex relationship between racialised communities, mental health and criminal justice systems, coined the 'Circles of Fear' have been emphasised as having a role in the perpetuation of coercive routes into services for Black men (Keating, et al., 2002). The authors write that individuals from Black communities may distrust and fear mainstream mental health services, often considered unhelpful, and at worst inhumane and racist. This is likely informed by the knowledge

of and/or lived-experiences of traumatic institutional injustices towards the African and Caribbean community by authorities in power, i.e., slavery, scientific racism, racial eugenics and police brutality, to name a few (see Mercer, 1984; Sivanandan, 1991). This may lead to an avoidance of/resistance to, using services for as long as possible, which results in individuals from Black groups coming into contact with mental health services at crisis points; when services are more likely to be restrictive and punitive. Alongside this, professionals in these systems may fear aggressive behaviour from Black men, due to the perpetuation of negative stereotypes, prejudices and racist misconceptions, such as, Black people are 'dangerous' (Lewis, et al., 1990; Barnes & Bowl, 2001; Spector, 2001). Therefore, services may be less likely to take risks with this group, underpinning the use of coercive approaches to section Black men; whose behaviour is potentially racialised and perceived as an extreme threat to others. The authors suggest these complex cycles prevent Black people from using services when they are needed, whilst also stopping services from engaging with Black communities in ways that are responsive to their needs, and sensitive to the wider context of injustice.

The stereotyped discourses of 'mad person' as dangerous and unpredictable (Read, et al., 2003), alongside 'black person' as 'Big, Black and Dangerous' positions black people diagnosed with psychosis as a particular risk to others (Prins, et al..1993; Barnes & Bowl, 2001). These racialised ideas may perpetuate systems in power giving rise to *institutional racism*; a form of racism embedded deeply in a society's culture, structures and political institutions (Fernando, 2017). Some examples of how structural racism has been considered to operate in mental health services, include: the now-defunct diagnosis of 'drapetomania' for Black slaves who attempted to run away (see Beard, 2000), a significant increase of schizophrenia diagnoses given to Black people involved in civil rights protests (Metzl, 2011), and the death of David Bennett - a Black man diagnosed with schizophrenia, who stopped breathing whilst under restraint in a psychiatric hospital (Blofeld, et al., 2003). For Black men, it is understood that there may be a justified fear of mainstream services, which may be linked to a resistance in engaging with such systems (Sivanandan, 1991; Keating et al., 2002). While on one hand the attention on understanding the experiences of Black men diagnosed with psychosis is due to their overrepresentation in services, this focus could also be understood as society's efforts to control this group, primarily

perceived as dangerous to the wider public. Societal discourses which position Black males as 'violence-prone', may in turn position females presenting with psychosis as not as disruptive, as threatening, or as deserving of attention as males (Seeman, 1982; 2018).

1.6.2 Gender Discrimination and Psychosis

The historical over-diagnosis of women considered to be experiencing 'hysteria', resulted in many receiving 'treatment' for behaviour considered unusual and bizarre, i.e., having a sex drive (Tasca, 2012). It has been advocated that such practices could be considered products of misogynistic and patriarchal systems, used to control and pathologise women through mental health labels (Ussher, 1992; Bondi & Burman, 2001). The label of 'crazy woman' has been said to silence differences in emotional expression, and in particular behaviours considered 'aggressive', put women at risk of being judged as unfeminine and labelled 'mentally ill' (Nicki, 2001). In this same vain, a group of women diagnosed with psychosis, presented with higher levels of 'gender-role-strain', compared to controls, i.e., they felt more of a gap between themselves and the gender roles expected of them (Haarmans, et al., 2018). The authors claimed BME women diagnosed with psychosis compared to White women, held more strongly on to traditional feminine ideals around preserving sexual purity. They advocate for future research exploring the psychosis experience, to attend to gender and its' interactions with cultural identification.

1.7 Racialised Women & Mental Health Services

It has been argued that Western feminist psychology seems to claim and impose 'universal' understandings of gender oppression, while largely neglecting the voices of racialised women (Spelman, 1988; Grabe, 2016; Kurtiş & Adams, 2017). Although likely unintentional, placing a colour-blind, middle-class lens on gendered structural oppression, can be harmful and dismissive of the ways BME women may experience mental health services differently to White women in society. Concerns about racial disparities and mental health services, seldom include an additional lens on women from BME groups and vice versa. This section explores some of the discourses

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afforded to racialised women in the UK and the implications seems to have had for interactions with mental health services. The decision to speak to Black and Asian women separately, is an attempt to avoid the homogenisation of their lived experiences and respect their unique histories. I have also chosen to focus on the visible minorities most represented in the UK statistics, who are most likely to experience prejudice on the basis of skin colour.

1.7.1 Conceptualisations of Black Women in the West

Wider societal stereotypes about Black women thought to be perpetuated in Western society and systems, include the 'angry black woman' and 'strong black woman'. The former positions Black women as, aggressive, unfeminine and overbearing, (Malveaux, 1989; Morgan & Bennett, 2006; Walley-Jean, 2009), while the latter positions women as naturally robust, resilient and self-contained – thought to be developed to counter and resist the 'angry' dominant negative discourses (Reynolds-Dobbs et al., 2008; Woods-Giscombé, 2010). Different to the discourses afforded to women from other racial groups, such as they are, docile, vulnerable and weak (Ahmad, 2003; Malveaux, 1989), discourses impacting Black women seem to strip them of their right to feel emotions such as anger, and additionally position this group as not requiring or deserving of additional support (Ashley, 2013; Beauboeuf-Lafontant, 2007). It has been suggested that such discourses have developed from groups in power, which constructed Black women as a group who could bear more pain than others; used to justify the historical enslavement of Black women and their communities (Dudley, 2012; Hoffman et al., 2016; Plous & Williams, 1995).

A King's Fund paper focussed on the interactions between ethnicity and the mental health system, reported professionals often viewed African-Caribbean women in stereotyped images such as 'loud and difficult to manage' (Keating, et al., 2003). The authors suggest this can result in their needs being ignored and overlooked by services and policies. While there is no dearth of further research into how the 'angry' stereotype may impact mental health service use, there have been some studies into how expectations to be 'strong' can prevent help-seeking for diagnoses such as 'anxiety' and 'depression' (Donovan & West, 2014; Thomas, et al., 2004). A resistance to depend on others and be responsible for any difficulties one may

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encounter, may be perpetuated as a construction of Black female identity, rather than accepted as one's coping strategy for surviving in a racist and sexist society (Hamilton-Mason, et al., 2009; Woods-Giscombé, 2010). Powerlessness may be both an internal experience as well as an external reality, potentially creating an unreasonable cultural expectation of strength for Black women (Thomas & González-Prendes, 2008). There seems to be an absence of focus on how the identity of Black women may be relevant to interactions with the mental health system, particularly for psychosis. Metzl (2011), writes society's neglect of Black women's experiences of psychosis, likely makes it harder for these women to have their suffering validated and attended to.

1.7.2 Conceptualisations of Asian Women in the West

Wider societal stereotypes about Asian women, include the 'meek asian' which infers this particular group are wholly compliant, quiet, weak and nonaggressive (Ahmad, 2003; Garg et al., 2018). Asian women seem to be often positioned as if they are 'in need of saving from their patriarchal communities, and thus understood as lacking independence, voice and agency (Haw, 2011; Meetoo, 2019). This is in contrast with the freedom that the 'West' offers for White females, who are considered to be more liberated from parental restrictions and cultural expectations (Shain, 2000; Puwar, 2003). It has been proposed groups in power constructed the identities of Asian women as 'inferior and backward' (Jiwani, 2005), as a way of validating colonisation (Said, 1987) and contributing to the subjugation of ethnic minorities migrating to the UK, i.e., virginity testing for Indian women by immigration officers at Heathrow (Smith & Marmo, 2011).

Research into Asian women's mental health needs, has been overwhelmingly focussed on 'common' mental health problems (i.e., 'depression'), suicide and self-harm (Anand & Cochrane, 2005; Bhui et al., 2007; Hussain & Cochrane, 2016). Keating et al.'s (2003) paper mentioned above, which focussed on mental health provision for BME communities, reported discourses surrounding Asian women's mental health were often viewed as exclusively rooted in 'cultural conflict or practice' within the family. Again, the authors suggest this can result in their needs being ignored and instead one's culture or family are pathologised, for example, Raleigh &

Balarajan's (1992) claim increased suicide rates of Asian women in the UK is related to aspects of South Asian culture, i.e., rigidly defined roles, submission to males and elders and arranged marriages. Additionally, it has been reported, professionals may construct violence against Asian women as a part of their culture (Hague, et al., 2006). It has been argued the attention on Asian women's experiences of depression and suicide - while possibly responsibly raising awareness about such issues, may perpetuate discourses that Asian women are victims of the cultures they belong to, with no emotional agency beyond sadness (Bhardwaj, 2001). Similar to Black women, Asian women's experiences of psychosis and services, has not received adequate attention.

1.8 Summary of Background Literature

It has been shown that the medical model of understanding psychosis, has been long associated with pathology, dangerousness and intrusive interventions. While there have been some shifts in UK mental health services, such as the adoption of the biopsychosocial approach, it appears psychosis is still primarily understood as an illness, with psychological and social factors as secondary triggers. The dominance of the biological model tends to dismiss other explanations i.e., psychosis as an understandable reaction to adversity, or a spiritual event - which may be particularly important to individuals from BME backgrounds and/or women. This is particularly concerning given the critiques that cast doubt on the validity of the biological construct.

Furthermore, despite the development and reported success of EI services in the community, certain groups such as those from BME communities, and women, report less favourable experiences. It appears Black and Asian women, are more likely to access such services through forced routes, compared to women from White backgrounds. There have been arguments to suggest institutional racism and gender discrimination are prevalent in the mental health system and has an impact on individuals' experiences. Furthermore, there may be certain wider racialised stereotypes about Black and Asian women, which may have an impact on one's experience in engaging in mental health support for a psychosis presentation.

The literature pertaining to Black and Asian women's experiences of psychosis and services, will therefore be reviewed.

1.9 Literature Scoping Reviews

<u>1.9.1 Rationale for Scoping Reviews</u>

Scoping reviews are used to seek the literature across broad topic areas, and provide an overview of the existing evidence base (Peters et al., 2015), i.e., race, gender, psychosis and service provision. They are utilised to map key studies, discern what is already available, and identify gaps in the scientific literature to establish future research (Arksey & Malley, 2005).

As discussed in the introductory sections of this chapter, research on psychosis, race, gender and mental health services are predominantly dominated by quantitative epidemiological studies. These studies consistently evidence disparities in the experience of certain racial groups accessing the mental health system. While they may highlight inequalities, they offer limited understanding of one's lived experience beyond objective numerical data. Thus, a decision was made to focus the scoping reviews on qualitative literature, i.e., use of interviews as the main methodology, to explore potential reasons for outcomes and processes, by focussing on studies which prioritised subjective service user accounts and perspectives.

As reported in the introductory chapters, certain groups, i.e., BME communities and women, may understand psychosis in ways that differ from the dominant illness-based approach. Hence, for the first scoping review, it was decided appropriate to explore the evidence base on Black and Asian women's conceptualisations of psychosis. Additionally, in an attempt to balance some of the existing discussions focussed on Black men's experiences of acute mental health services (Sivanandan, 1991; Keating et al., 2002; Mind, 2003) a second scoping review was carried out, focussed on gauging literature specifically on Black and Asian women's experiences of services *for psychosis*. Whilst there have been commendable efforts exploring BME women's interactions with the system – see Kalathil (2011) for a key piece of research – these have not been solely focussed on racialised women's experiences of psychosis in relation to mental health service use.

1.9.2 Scoping Review I: Black and Asian Women's Conceptualisations of Psychosis

To identify relevant literature, "psychosis", was entered into Academic Search Complete, CINALH Plus, psycinfo, Science Direct, and Psycharticles, together with terms related to "race", "gender" and "conceptualisations". Full range of search terms, limiters, inclusion/exclusion criteria used, and number of articles identified can be found in Appendix B. Grey literature was then also examined through the use of Google Scholar and other open source platforms, i.e., university repositories. Literature included was based on relevance to the topic, with qualitative research and peer-reviewed papers were prioritised. A total of five studies were retrieved.

Cheng (1985), reported an ethnographical case study on the experience of "Mrs K" a 36 year old Singaporean Chinese lady who accessed Australian mental health services, presenting with distressing experiences of spirits entering her body and hearing the voices of dead relatives. Mrs K described spiritual and supernatural explanations common in Chinese culture for her experience; bad luck, black magic and revenge from both evil and ancestral spirits. It was reported she also believed this had been the cause for her marital difficulties and recent miscarriage and thus was reluctant to take medication. Instead Mrs K was facilitated to see a medium from her culture and her husband was encouraged to take more time off from work – socio-cultural explanations and interventions the author reported was important to Mrs K's recovery as a Chinese women accessing Western services. While this paper did seek to include service user descriptions of psychosis, the accuracy of the account from Mrs K's understanding could be questioned, as it did not feature any direct quotes, nor seemed to request her consent to take part.

A larger study involving 200 participants accessing mental health outpatient services in India, utilised semi-structured interviews to explore gender differences in the experience, meaning and impact of a psychosis diagnosis from a socio-cultural perspective (Loganathan & Murthy, 2011). Using a thematic analysis methodology, a main theme reported for the 82 women who took part, was the stigma around their reduced capacity to be mothers, whereas male participants were reportedly more impacted by the stigmatisation of their capacity to work. The use of a thematic analysis seemed to allow for the identification and effective communication of an

important topic, i.e., gendered stigma related to psychosis, across a large data set. However, as this study was carried out with women native to India, who had not presented with psychosis in the last 6 months, it is uncertain whether these stigmas would be shared by women from ethnic minority backgrounds, accessing mainstream services for psychosis in the West for the first time.

Another study also conducted in India, completed thirteen pairs of open-ended interviews with women diagnosed with psychosis and their families (Corin, et al., 2005). The research aimed to explore similarities between participants' and family members' descriptions and explanations for psychosis. The women described a lived reality where they felt threatened, suspicious and experienced an invasion of voices. This was described as having an impact on their ability to engage socially with others. Family members on the other hand, were reportedly more likely to mention women's presentations of aggressive behaviour and the impact this had on their daily roles. Supernatural and psycho-biological explanations for psychosis were shared by both groups, although additionally the study reported many of the women did not feel any explanation for psychosis was adequate, due to the complex nature of the experience. This study offers insight into the impact and understanding of psychosis for women and their families. A study dedicated solely to the lived experience of psychosis of BME women may allow time for a richer analysis of this complex phenomena to be explored.

A study conducted in America by Sosulski et al. (2010), utilised narrative analysis methodology via interview data, to present the experience of "Maria", a Black woman diagnosed with "bipolar". The aim of their research was to explore how Black women with 'chronic mental illness' conceptualise their life experiences and 'mental health challenges'. "Maria" is reported to have experienced visions as well as hallucinations, which the authors describe she understands as partly a spiritual gift from god and partly a symptom of mental illness. Maria describes additional difficulties as a Black woman accessing mental health services, i.e., coping with the lack of contact with women who look like her and share her struggles, alongside juggling important positions of responsibility she holds over several domains, i.e., work, family, church and community relationships, and the author's use interview extracts to illustrate this. This paper highlights the richness that can be offered by

exploring and contextualising Black women's experiences of psychosis as they define it for themselves, offering first-hand insight which may help to inform suggestions for service improvement more dedicated to this group's needs. While this was a participant recruited through a community mental health project in America, it is uncertain whether Black women accessing statutory services in the UK - where the racial and service context is different – would make sense of their psychosis experience in the same way.

Finally, a study with 15 women from the African country of Swaziland, sought to explore their meanings of the psychosis experience using semi-structured interviews, (Nxumalo-Ngubane, et al., 2019). An Interpretative Phenomenological Analysis (IPA) of the data reported participants felt their experiences were a result of injustices committed upon them, i.e., dismissed by others, marital difficulties and spiritual attacks. Similar to the studies above, the women seemed to report multiple explanations for the psychosis experience and the author helpfully uses direct quotes to illustrate this. Also similar to other literature in this scoping review, as the participants were native to the country they were being interviewed, these findings may only offer us limited insight into the experiences of BME women accessing services in the UK.

1.9.3 Scoping Review II: Black and Asian Women's Experiences of Psychosis Services

The following search terms; "Black" or "Asian" or "Race", and "Female" or "Women" or "Gender", were entered into Academic Search Complete, CINALH Plus, psycinfo, Science Direct, and Psycharticles, alongside "Psychosis" and "mental health services". As only one study retrieved explored the service use experience of women from racialised backgrounds (Kwok, 2014), searches were further expanded. This entailed a further two separate searches, one that omitted 'race' as a search term (Appendix C) and one that omitted 'women' (Appendix D). This yielded slightly more results. Including grey literature, a total of six articles of relevant literature were retrieved.

1.9.3.1 Women's Experiences of Psychosis Services

A study by Hagen and Nixon (2011) conducted interviews with 18 women, aged 27-57, exploring their experiences with psychosis service in Canada. Utilising an IPA methodology, the findings reported participants' interactions with the mental health professionals were often negative and made them feel "invalidated and unheard" and subjected to "violence and violations". This included being sectioned against one's will and how this experience reminded them of past traumas, i.e., abuse and being watched. The participants also reported feeling diagnoses were based on symptoms rather than life experiences, i.e., exposure to trauma or abusive relationships. This study highlights practices which are potentially oppressive, particularly when experienced by women. As this sample was recruited via magazine adverts and word of mouth, and reported on average to not have experienced any psychotic experiences in the last eight years – this was not technically a clinical sample, and service provision likely may have changed in that time compared to current day.

Another Canadian study, this time focussed on a clinical group, investigated gender differences (12 women and 13 men) in pathways to EI services, using focus groups and interviews (Ferrari et al., 2016). Using a thematic analysis methodology, the main subthemes related to women's experiences, included, 'feeling ignored and mistrusted' when help-seeking, 'being labelled as overdramatic or a drama queen' and 'being too functional'. Such encounters reportedly put women off asking for help again, leading them to accessing services for psychosis much later than preferred. This was different to males who reportedly avoided help-seeking altogether due to masculine stereotypes to be strong. This study identifies gender stereotypes may function as a barrier to accessing EI services for women in Canada, and it would be insightful to explore whether this experience would be similar for EI services in the UK.

The final study in this scoping review is a systematic review which synthesised the findings of nine qualitative studies based on the experiences of young adult women (18-35) diagnosed with psychosis (Chernomas et al., 2017). The studies conducted in USA, Australia, Canada, Sweden, used a range of designs, such as grounded theory and IPA, and some of the findings are as follows. Women described experiencing feelings of trauma and loss of control, when forced into police vans and

sectioned to hospital, reportedly mirroring experiences of violence and trauma encountered earlier in their lives. Diagnoses were experienced as having negative consequences for the future, particularly within society, and used as a way to deny the value of their voices. However, they also described having multiple needs met within one service, including developing meaningful and consistent relationships, as particularly important for their care. While this was a valuable piece of research that summarised important subjective data, the sample was focussed on women generally without an additional lens on race.

1.9.3.2 Black and Asian Communities' Experiences of Psychosis Services
A study based in the UK explored Black and Asian service user experiences of EI services using focus groups (Islam, et al., 2015). This included 11 females and 11 males of Pakistani, Bengali, Black Caribbean and Black African backgrounds. A thematic analysis identified themes such as 'help-seeking' and 'social stigma and shame' and 'meeting cultural, spiritual, religious needs'. Participants reportedly reached mental health services through crisis, with authors citing stigma as reasons for delayed access. Positives of EI services included the provision of interpreters, however negatives were reportedly feeling uncomfortable sharing spiritual understandings of psychosis with staff and finding talking therapies irrelevant to their needs. This study helpfully emphasised the need for EI services to improve cultural acceptability, however a study based solely on Black and Asian women's experiences of EI services may offer us a more nuanced and detailed insight into this specific group's needs.

Another study with a racially-diverse sample of young adults diagnosed with FEP, utilised interviews and hospital observations to explore their experiences (Myers et al. 2019). Following their hospital admission, data was collected from 19 individuals from Latino (8), Black (7), White (2) and Asian (1) backgrounds, over a 12-week period. Utilising a grounded theory methodology, researchers reported participants expressed traumatic experiences with police in their pathways to care. The experience of being sectioned was experienced as particularly disempowering and seemingly had a direct impact on interest in engaging with services in the future. This study conveys coercive pathways to care are likely to have an impact on help-seeking for BME groups experiencing FEP. However, as this research was

conducted in America where healthcare is not paid for by the state, and the racial make-up is different, these findings may not easily translate for services users in the UK.

Finally, a case study presented by Kwok (2014), details the author's own experience as a second-generation Chinese woman, accessing mental health services for psychosis in Canada. Her history includes repeated experiences of being sectioned and she writes of how she felt how racialised and gendered discourses impacted her care; *'those who did notice that I was Chinese seemed to think I should comply with the stereotypes of Chinese women: be quiet, submissive, dependent. When I did not fit the stereotype, they gave me more medications."* While this is only one woman's experience, it provides insight into how some service users may feel stereotypes and discourses impact the care they receive, particularly as racialised women on the receiving end of coercive interventions. It appears this author had a long history with services, and it would be insightful to hear about the experiences of ethnically-marginalised women diagnosed with psychosis accessing mental health services for the first time and see if they too feel their identity has a role in how services manage their care.

1.10 Research Rationale

The limited research exploring Black and Asian women's experiences of psychosis, suggest participants often hold models about psychosis that differ from the medical model dominant in the West. In studies focussed on women's encounters with psychosis services, individuals have reported they often felt dismissed and subjected to coercive experiences by the mental health system. While insightful, much of this research has been dominated by a participant sample of women from predominantly White backgrounds, and additionally all conducted in services outside the UK. There has been some effort to understand the experiences of psychosis services for Black, Asian and Minority groups, often as a response to the reportedly high diagnostic rates of psychosis compared to other groups. Findings suggest individuals from BME groups also felt they were subjected to coercive treatment, from services which often did not understand their experiences or needs.

Currently, there is a gap in the research which considers the identity characteristics of both female gender *and* marginalised racial background, in understanding one's experience of psychosis. While much of the focus has been on Black men, there is relatively little research with women from ethnic minority backgrounds, given a psychosis label, despite them showing similar trends in poor experiences of services, such as, an increased risk of detention under the Mental Health Act compared to women from White groups. EI for psychosis teams which have evidenced above to Also presented above, EI teams part of the psychosis pathway here in the UK, have evidenced good outcomes for psychosis. They are the first community service individuals will access for FEP, and thus present an ideal setting to explore Black and Asian women's experiences, as much of the existing research into women's experiences of receiving a psychosis diagnosis, has often been a label they have lived with for some years. Exploring the accounts of women first encountering the system, may offer us insight into meaning-making of psychosis for Black and Asian women, prior to their exposure to the dominant models held in services.

In order to further develop supportive services for Black and Asian women, we need to seek their first-hand subjective accounts. This will help us understand needs particularly important to this group, develop more supportive mechanisms if indicated, and suggest service improvements. This research also aims to hold an intersectional lens which considers the overlapping impact of receiving a psychosis diagnosis, being Black and/or Asian and identifying as a woman, while living in the UK. Psychologists have an important role in considering how external structures of power intersect and contribute to distress (Baah & Yeboah, 2020). It is hoped this research will allow for suggestions of contextual and multi- level interventions, which improve the experiences of Black and Asian women diagnosed with FEP accessing services in the UK.

1.10.1 Research Questions

1) How do Black and Asian women describe experiences of a First Episode Psychosis?

2) How do Black and Asian women describe experiences of Mental Health Services for First Episode Psychosis?

2. METHODOLOGY

This chapter outlines the philosophical assumptions underpinning the study, as well as a reflective overview of what informed these choices. Details of the study's design, implementation and ethical considerations follows, concluding with the procedures used to analyse the data collected.

2.1 Ontological and Epistemological Considerations

2.1.1. Dominant Philosophical Positions in Clinical Psychology and Psychosis

It is important to establish the philosophical positions taken in relation to a piece of research, as this has implications for what new knowledge a study claims to provide from its' findings. Clinical Psychology's philosophical roots are similar to that of the general sciences; that knowledge is gained through discovering 'truths'; an epistemological position often known as 'positivism' (Witmer, 1996). This idea claims knowledge produced from scientific research, i.e., controlled psychological experiments, generates and reflects reliable and valid truths about reality (Leahey, 1992). Such methods of knowledge which claim an objective understanding of the world are currently privileged in research; quantitative approaches, such as Randomised Controlled Trials and epidemiological studies, dominate research into psychosis. This 'positivist' approach promotes the existence of objective facts that can be known about reality, independent of the role of the 'discoverer'. In affiliation with the positivist claims of scientific research, psychology has generally presented an objective standpoint on the knowledge claims it makes. This has often minimised the impact of social context, as well as the relationship between the researcher and that being researched (Crotty, 2003). Harari (2001) writes that a significant drawback of relying on empiricism for research in psychology, is that 'psychiatric phenomena' is considered a scientific objective fact, although such concepts are based on

judgements, made by people trained within a particular cultural framework. For example, psychosis is often legitimised as a medical diagnosis by professionals operating within a Westernised biological approach.

2.1.2. Selected Philosophical Position

A critical realist (Maxwell, 2012; Pilgrim, 2013) approach has been adopted for this research, as it was felt to meet the study's overarching aims, was consistent with the research questions and additionally reflected my worldview. This position gives attention both to participants' material realities, as well as the contexts that shape how these realities are made sense of.

Epistemology is the philosophical concern focused on 'methods of obtaining' knowledge (Burr, 2003, p. 202). It is related to queries, such as, 'How can I go about gathering knowledge about the world?' and 'How do I know what I know?' (Harper, 2011). The following questions were useful in considering the possibilities for exploring Black and Asian Women's experiences of psychosis and services; 'What and how can we know about these groups' experiences?', and, 'What kind of knowledge am I aiming to create from this research?' (Willig, 2008, pp. 12-14). A critical realist standpoint allowed for a *relativist epistemological* position – experiences are understood as influenced by personal, social and historical contexts, reflecting an interpretation rather than a direct reflection of 'reality' (Harper, 2011). Therefore, psychosis is not seen as an entity that can be objectively found within a person, but as one of many possible ways of understanding, which has been influenced by cultural current and historical beliefs about socially-acceptable behaviour and nature of 'mental illness'.

Ontology is a branch of philosophy concerned about the nature of the world and its phenomena (Willig, 2013), relating to questions such as, 'What is there in the world to know?' A Critical Realist approach involves a *realist ontological* position (Price & Martin, 2018), which posits that there is a reality that exists, independent of our knowledge of it (Pilgrim, 2013). This means, for example, that distress experienced by people who receive a diagnosis of psychosis is acknowledged as a 'real' and embodied experience, as are the social and material consequences of receiving this

diagnosis within current society and the psychiatric system (Pilgrim, 2016). This occurs independently of the ways these experiences are understood.

Regardless of the contestable nature of race and gender (see section 1.2), these groupings are frequently applied at individual and societal levels; Black and Asian women in the UK do have lived realities which differ from other groups. There are disparities in environments, opportunities and resources available to racialised women, and the existence of this reality operates outside of my own or others' perceptions or constructions upon these circumstances.

2.2 Methodological Considerations

2.2.1. Qualitative approach

A qualitative methodology was selected as best suited for exploring deeper understandings of Black and Asian women's accounts of psychosis and mental health services. Qualitative methods enable understanding of experiences and processes (Finlay & Gough, 2003), and move towards the 'illumination and understanding of complex psychosocial issues' (Marshall, 1996). Qualitative approaches are suited to research that aims to generate new understandings, rather than to test existing ones (Strauss & Corbin, 1998). Although research into the topic of FEP has been dominated by objective approaches, subjective explorations of lived experiences can help inform the development of more person-centred models of psychosis care (Boydell, et al., 2010).

2.3 Method

2.3.1 Recruitment

2.3.1.1 Participant Inclusion Criteria
Participants recruited into the study had to meet the following requirements: 1) Currently accessing EI Services, 2) Female, 3) Black, Asian and/or Mixed Heritage, and, 4) Experienced detention under the Mental Health Act in the last 12 months.

2.3.1.2 Recruitment Sites

The study took place across two EI service sites, based in ethnically diverse inner-city London boroughs. The teams were typical of many EI services, providing a range of interventions for people aged 16 and over, including medication, social activities, employment support and psychological therapy; predominantly Cognitive Behavioural Therapy (CBT)-informed, individual and family work (Garety et al., 2001; Onwumere et al., 2011).

2.3.1.3 Recruitment Procedure

Background information to the study was first presented to EI teams
in the form of PowerPoint presentations (Appendix E). Following ethical approval, care coordinators and psychologists screened their caseloads and 36 potential participants were identified. With the aim of prioritising participant well-being, service users who were experiencing high levels of distress, presenting with significant risk issues, or deemed not to have capacity to consent, were not recruited to the study. Non-English speakers were excluded due to lack of funding available for interpreters. This is recognised as a significant limitation of the study and the impact of this on the research findings are discussed later (see section 4.5.1). The remaining 29 potential participants were approached with the recruitment poster (Appendix F) during a meeting with their care team. Capacity to take part was assessed at this point. EI practitioners explained there was no obligation to participate, and the decision to decline would not affect care received from the clinical team. I consequently called and emailed twenty-five individuals who expressed initial interest and provided consent to be contacted. Details about the study were provided, guided by the Participant Information Sheet (Appendix G). Reasons for not taking part included not wanting to discuss distressing experiences, university/work commitments and lack of appealing incentives. Follow-up calls were made two weeks later, confirming interest, clarifying queries and arranging a suitable time to partake in the study.

2.3.1.4 Sample Size

Six to twelve participants were aimed for recruitment, suggested as an appropriate number to conduct qualitative research using thematic analysis (Guest, et al., 2006). This allowed for the selection of information-rich cases (Patton, 2015), well suited to the research questions (Breakwell, et al., 2012). Although small sample sizes may lack the generalisability expected of quantitative research (Kvale & Brinkmann,

2009), a small number of interviews can provide meaningful findings using qualitative methodologies (Banister, et al., 1994) and help to understand 'the essence' of an experience (Morse, 1994, p.224).

2.3.2. Participants

Eight women met the study criteria and participated in interviews. Although efforts were made to recruit an equal number who identified as Black and Asian, this was a challenge and reflected in the sample make-up. Table 1 lists basic demographic details. While such information helps to contextualise the position in which participants speak from, there is discomfort in opting for broad categories which minimise ethnic and cultural differences within racial groups. However just as pseudonyms were used to preserve anonymity, due to the small sample size, omitting ethnicity was felt necessary to protect patient confidentiality.

Table 1: Pseudonyms and 'racial background'

Dami	Black
Dianne	Black
Sylvia	Black
Christina	Black
Amanthi	Asian
Ayaan	Black
Sabina	Asian
Fahima	Asian

2.4 Data Collection

2.4.1. Use of Semi-Structured Interviews

The use of semi-structured interviews, allowed for me to present participants with a prepared guide to help answer the research questions, but also allowed for flexibility to follow new leads if appearing relevant to the study's aims (Bernard, 1988; Kvale & Brinkmann, 2009). I briefly considered the use of focus groups, which may have

mobilised participants to discuss, dispute and negotiate (Bryman, 2008) their experiences. However, it was felt that personal accounts of FEP and services were sensitive topic areas, that may have had an impact on what participants may decide to share with a group of strangers (Willig, 2013, p. 35). Focus groups may have reduced the richness of accounts likely more accessible from individual accounts. Furthermore, the adaptability and intimacy offered by semi-structured interviews felt particularly important and respectful to this participant group's needs, whose individual voices within research have often been restricted, neglected and ignored (see section 1.7).

The interview format is however considered an artificial form of interaction (Potter & Hepburn, 2005) and what I understood from participants' responses and the directions I decided to take, were inevitably shaped by my own critical realist position (Mason, 2003) as well as, social identities/experiences in regard to gender, age, ethnicity and professional background. Thus, it was felt vital to engage in critical reflections post-interviews, to make sense of and contextualise interview data (see Appendix V).

2.4.2. Interview Guide

I constructed a first draft of the interview guide following an initial literature review and discussion with my supervisor. I avoided using terms such as 'psychosis' in the questions, in order to allow space for participants' own words. To explore participants' accounts, a mix of 'descriptive' questions such as, *'What kind of experiences led up to your hospital admission?*' and 'evaluative' questions, such as, '*Following your admission, how did you feel about being referred to an Early Intervention Service?*', were used (Spradley, 2016). As part of a consultation process, while the study was still in its' design phase, a presentation of the project was presented to the host Trust's service user and carer research panel, to gain feedback (see Appendices H and I). The consultants advised the addition of the question - '*Where do you think it would be useful to share some of the experiences you have spoken about today?*' Finally, the question, *'What made you decide to take part in this research?*' was included, as I was interested in what motivated these particular women to be interviewed, following the high refusal rates experienced

during recruitment. Justification for this question is further reinforced by Willig (2013, p. 29), who writes, 'the researcher needs to know what the interview means to the interviewee to fully understand the interviewee's contribution'. These additions were incorporated into the final interview guide (Appendix J).

2.4.3. Interview Procedure

Interviews were conducted face-to-face, in a private meeting room based at the participant's local EI service. The aims of the study were reiterated, followed by a short discussion checking comprehension of the information sheet (Appendix G), and offering the opportunity to ask further questions. They were then asked to sign a consent form (Appendix K). Interviews varied in length from 35 to 70 minutes in total.

2.4.4 Transcription

A digital voice recorder was used to audio record all interviews. I completed a word-to-word written documentation of all interviews, based on Banister et al.'s (2011) transcription framework (Appendix L). I added basic punctuation to ease readability, whilst also considering how best to represent intended meanings of participants' talk as I heard it (Parker, 2005). As transcription is seen as an interpretative act (Lapadat & Lindsay, 1999), every interview was transcribed within a week of being conducted, to allow effective and meaningful engagement with each data set.

2.5 Ethical Issues

2.5.1. Ethical approval

Ethical approval for the study was gained from the NHS Health Research Authority (Appendix M). Research and Development approval from the local host Trusts were also obtained and Letters of Access issued (Appendix N).

2.5.2 Informed Consent

Informed consent was supported through the information given during the recruitment and interview stages using information and consent sheets (Appendix G and K, respectively). During the interview, participants were provided with the

opportunity to ask any further questions and reminded of their right to withdraw up to a specified date following completion of the interview.

2.5.3. Confidentiality

All interview data was stored securely on an encrypted USB device. Any further identifiable information from consent forms or email correspondence was kept separately and securely away from the research data. Participants were made aware that despite being referred to the study by their EI service, only the research team would have access to their interviews. Pseudonyms were used during transcription and any identifying information changed to ensure anonymity. All audio-recordings were subsequently deleted following transcription. Participants were informed that interview data may be kept securely for up to five years, in line with UEL's data retention policy and General Data Protection Regulations (GDPR, 2018).

2.5.4. Minimising Harm

Particular attention was paid to minimising potential harm caused by the discussion of sensitive issues in the interview. I recognised a possibility that the planned interview questions exploring participants' lived experiences of psychosis and interactions with mental health services, could cause distress. This ethical issue was consulted extensively with the service user and carer research panel connected to the host Trust, and informs much of the following. All participants were informed about the nature of topics discussed in the study, the right to refuse any questions, request breaks, reschedule and/or discontinue interviews, without any consequence to their care from EI teams. I also utilised 'check-ins', throughout the interviews, to ascertain any levels of discomfort. The limits of confidentiality were discussed and that, in the case of disclosure of information that related to current risk to themselves or others, the interview was to be terminated and the participant referred to a clinician for appropriate action; a process agreed with EI staff teams. Following completion of the interview, participants were invited to discuss any additional questions or concerns during a debrief. Details of supporting agencies were provided to all participants, including information about avenues to raise complaints about the treatment they received from mental health services, or distress caused by the research itself (Appendix O).

2.5.5. Gesture of Appreciation

Participants were offered a £10 high street voucher as a token of gratitude for taking part in the research. I engaged in much thought about the ethical implications of offering this, including what may or may not be considered an appropriate amount. Following discussions with EI staff teams, the service user and carer research panel, the NHS ethics panel, and references to relevant literature (Grant & Sugarman, 2004; BPS, 2014), this gesture was deemed appropriate for consenting adults willing to take part, and not of substantial enough value to risk experiences of coercion.

2.6 Data Analysis

2.6.1 Thematic Analysis

A thematic analysis was chosen in this study as a method to explore the interview data. The objective of thematic analysis is to elicit rich and meaningful patterns, 'themes', across data sets, relevant to answering the chosen research questions (Braun & Clark, 2013; Boyatzis, 1998). It goes beyond a more constrained and singular analysis of the text towards a rich, detailed and complex account of the data (Willig, 2013). Thematic analysis is considered to be theoretically flexible, described as applicable from a range of theoretical, ontological and epistemological positions (Braun & Clarke, 2006). These aspects of thematic analysis resonated with my critical realist stance, and my hope to consider Black and Asian women's meaning-making of their experiences of psychosis and services, and how their context inevitably impacted upon the process of this (Nightingale & Cromby, 2002). The analysis employed an inductive analysis to generate themes. An inductive approach builds research from the 'bottom up', driven by what is *in* the 'raw' data (Braun, et al., 2015).

2.6.2 Considering other analyses

I have chosen Thematic Analysis instead of a Foucauldian Discourse Analysis (FDA), as the latter requires extensive mapping and theorising of the subject's multiple broader influences of historical, social and material realities (Arribas-Ayllon & Walkerdine, 2008). The genealogical backgrounds of Black and/or Asian women

living in the UK are multiple, vast and complex (i.e., conditions of slavery, colonisation, forced/reluctant/voluntary migration, gender discrimination, to name a few). Although highly valued, exploring these conditions in-depth using a FDA approach, was felt to be beyond the scope of this study; extensive resources would be required to honour such topics respectfully. Furthermore, such an analysis would complicate the 'realism' in my epistemology that considers issues of racism and sexism as 'truths', and the greater relativism of FDA may, undermine the historic, social and material realities that I see to be incontestable (Paulraj, 2016). An Interpretative Phenomenological Approach (IPA) which focuses on the quality and texture of participant's subjective experiences was also considered. This approach was felt to be incompatible with my ontological and epistemological view of participants' accounts as 'serving a range of interpersonal and societal functions', rather than a 'window into a person's thoughts and feelings' as assumed within IPA (Harper, 2011). Employing a critical realist stance within a thematic analysis methodology, permitted a broad exploration of Black and Asian female identity constructions, and their experiences of psychosis and material lived realities. This was considered helpful in gaining a wide-ranging initial understanding of an under-researched topic area and also sufficient enough to answer the study's research questions.

2.6.3 Process of Thematic Analysis

The dataset was thematically analysed using the six stages outlined by (Braun & Clark, 2013). Thematic analysis is understood as a recursive process, rather than a linear one, hence movement across the stages below was expected and necessitated (Braun & Clarke, 2006).

2.6.3.1 Becoming familiar with the data
To initiate the process of becoming immersed in the data I transcribed all the interviews myself and repeatedly read all the transcripts. Annotations detailing initial ideas were made for each interview using the comment feature on Microsoft Word, an example of which can be seen in Appendix P.

2.6.3.2 Generating initial codes
To help manage the data sets, all transcripts were uploaded to NVivo qualitative data
analysis computer software. I then began to organise parts of my data into
meaningful groups (Tuckett, 2005). This involved developing 'codes', defined as, "a
succinct label that captures key analytical ideas in the data" (Braun et al., 2014,
p.100). I read through each transcript systematically, identifying aspects of the
interviews I thought were interesting, but also extracts which seemed inconsistent or
an exception to the rest of the data. An initial list of codes was generated with the
relevant interview extracts related to each code, all collated and managed in NVivo.
A sample of a version of the codebook can be found in Appendix Q and samples of
coded extracts in Appendices R and S.

2.6.3.3 Searching for themes
The existing codes were then further analysed, by considering how they may
combine to form possible themes and subthemes. Themes are defined as something
that catches important information about the data in relation to the research question
(Braun & Clarke, 2006). Searching for themes across the data involved extensive
mind mapping exercises, initial versions of which can be seen in Appendix T.

This phase was particularly overwhelming due to the sheer number of possible
themes and directions I felt the analysis could take. Supervision was utilised to
discuss these difficulties. Better grasping my role as an 'active' researcher, rather
than a 'passive' one attempting to 'discover' themes (Taylor and Ussher, 2001),
especially within a critical realist approach, took the ease off of trying to speak to
every single nuance referred to in the data. I acknowledge that the themes are both
data-driven and also a product of decisions I made as a researcher.

2.6.3.4 Reviewing themes
In order to further refine the themes, I firstly checked that they 'fit' with the collated
coded extracts. More developed thematic tables were then produced (Appendix U).
Next, I had to consider whether the tables reflected meanings evident across all the
interview data sets. The main aspects of each theme were reconsidered. Extracts
were also relocated if they seemed more relevant to other subthemes under other
subthemes. Additionally, transcripts were re-read, which resulted in coding additional
data missed from previous stages. The 'new' relevant coded extracts were included.

Themes were continually checked for internal coherence, consistency, and distinctiveness, i.e., through discussions with my supervisor, and through the writing process.

2.6.3 5 Defining and naming themes

Determining whether themes were clearly defined, involved establishing what each individual theme was supposedly capturing about the interview data. I reviewed, rearranged, and made a final selection of vivid extract examples, to produce a coherent and consistent story about the data. Each theme and subtheme was then given a short – yet impactful – name, which aimed to instantly provide the reader with a sense of what the themes were about, in relation to the overall research study (Braun & Clarke, 2006).

2.6.3.6 Producing the report

The analysis and discussion sections were written up in a way to provide a concise, logical, and interesting summary of the story told by the data, within and across themes. I aim to "go beyond description of the data" and "make an argument" in relation to the research question (Braun & Clarke, 2006).

2.7 Reflexivity

Reflexivity is an important aspect of qualitative research; it goes beyond simply reflecting on our study, and towards questioning 'our ways of doing' (Hibbert et al., 2010). It involves turning the researcher lens onto oneself, in order to examine, recognise, and take responsibility, for how one's identity, experiences and context may have impacted the study (Berger, 2013; Harper, 2011). The following questions, as suggested by Haynes (2012), were utilised to enhance reflexive engagement: 'How am I connected to this research?', 'What was the motivation for undertaking this research?', 'What underlying assumptions am I bringing to it?' and, 'What effect will this have on my approach?'.

At the time of writing this section, I personally felt the following aspects of my identity were particularly pertinent to the research:

- Mixed Asian racial background

- Female

- British

- Of Christian-Catholic faith

- Working Class

- Trainee Clinical Psychologist

It is acknowledged that my own personal and professional experiences have influenced the development of the research questions, interview schedule, conducting of interviews and data analysis. My own racial and gender identity inevitably informed the study topic and choice of participant sample, of which I shared similar characteristics. I can be described as having multiple ethnic and cultural influences, as I grew up in London raised by my parents of Filipino and Sri Lankan Malaysian heritage. I both experienced and witnessed what it was to be 'daughters of immigrants' (Lindenmeyer, 2001) in the UK, such as the intersecting of several worldviews, as well as expectations, demands and also silencing from multiple systems. Prior starting clinical doctoral training, I worked mainly in NHS acute and crisis mental health settings. I personally resonated with the women from similar backgrounds to myself, accessing these services in extreme distress. It felt lives and identities were often reduced to diagnostic labels, devoid of wider context, and utilised as justification for responses that were coercive in nature and medically-based. I wondered what it may mean for these women I worked with. To be subjected to such force, by agents of the state; the state we/our parents had sought protection and/or promises of prosperity from. In addition, I have been further influenced by critical psychology ideas in my work with BPS Minorities Group[4] and also during clinical training, which have both emphasised the impact of wider social context and inequality on the experience of distress. These have always encompassed the importance of considering power (Foucault, 2006) and multiple perspectives (Burnham, 2005). Such experiences have led me to question the

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[4] The Minorities Group is a committee part of the British Psychological Society's Division of Clinical Psychology. One of the group's main aims is to contribute towards a better understanding of the unique needs and experiences of minority groups within the profession.

usefulness of powerful, dominant and prevalent discourses about psychosis within mental health services, and how this may impact women similar to me and those I am close to.

Alongside personal reflexivity, the impact of epistemological reflexivity on aspects of this study was also considered (Willig, 2013). Adopting a critical realist position meant I viewed - participants' descriptions of their experiences and my consequent understanding of this as a researcher - to represent one possible interpretation of the data (Harper, 2011). The choice to utilise qualitative methodology, was partly informed by a desire to explore topics from subjective perspectives. The use of semi-structured interviews allowed participants some freedom to discuss topics that may naturally arise, and were important to them, while also permitting me to pose questions related to gaps in the literature. Taking a relativist epistemology, fit well with my view that psychosis, race and gender are socially constructed concepts, whereas holding a realist ontology, meant I was able to acknowledge the material impact of diagnosis, service access and disparities to resources, in my interview schedule and analysis. I realised I had to be mindful that my own position on psychosis as a construct may not be shared by participants even if they were from similar backgrounds, i.e., some women seemed to speak to psychosis in terms of 'direct realism' in their interviews; inferring they understood the concept as a discrete identifiable 'disorder'. This made me feel conflicted at times as I did not want to personally perpetuate a disease model of psychosis, i.e., if they used the word 'Schizophrenia'. However, I quickly realised the importance of honouring the language participants used during the interview process, rather than contribute to the silencing of their voices if this did not fit my own worldview.

In order to facilitate reflection on the impact of the research process, supervision, peer discussions and a reflexive journal (Appendix V) were utilised. Further reflexivity relating to the analysis of the data can be found in the discussion.

3. ANALYSIS

As part of the analysis process, the three main themes, their associated subthemes (Table 2), and supporting participant quotes will be presented and described here.

Table 2: Themes and Subthemes

Main Theme	Subthemes	Participants' quotes featured
Sense of Mistrust	Uninvited Intrusion Self-Blame	*Amanthi* *Ayaan* *Christiana* *Dami* *Dianne* *Sabina*
Navigating Unsafe Systems	Unjustified Consequences Hindered Help	*Christiana* *Dami* *Dianne* *Fahima* *Sabina* *Sylvia*
Impact of Adversity	Sense-Making of Suffering Unexpected Support	*Amanthi* *Ayaan* *Christiana* *Dami* *Dianne* *Fahima* *Sabina* *Sylvia*

3.1 Theme One: Sense of Mistrust

This first main theme explores Black and Asian women's talk of a '*Sense of Mistrust'*; a central feature of the data. Participants seemed to describe psychosis as an all-encompassing lived reality, characterised by doubt and fear. The women's feelings of suspiciousness of others, scepticism of one's own experiences, and apprehension about available support, is shown in the first subtheme, '*Uninvited Intrusion'*. Participants' talk suggesting that one could not be trusted to make wise decisions, seemingly holding themselves as partly responsible for their psychosis experience, is presented in the second subtheme, *'Self-Blame'*

<u>3.1.1 Subtheme One: Uninvited Intrusion</u>

This subtheme *'Uninvited Intrusion'*, describes participants' experience of psychosis as one's lived reality being significantly altered by unwelcomed, imposing others. As connected to the overarching theme, it conveys an **external '***Sense of Mistrust'***,** which is focussed on the untrustworthiness of others and the world. This appears to include experiences of 'paranoia', phenomenon others can't see, as well as unnecessary invasive services and peers.

Dami	*Like last year of uni, I was suffering from like, like hearing stuff, hearing and seeing stuff that wasn't there… I got like really paranoid… I started seeing cameras everywhere, and I was thinking people were following me.*
Dianne	*I had a complete, uh breakdown, or psychotic episode is what the doctors call it? … it's really hard to explain, but I wasn't um, in reality at all. I became really paranoid, that was the main thing…have you ever watched the 'Truman show'? That was basically me for like three months. I thought they were following me, and I was on the Truman show. I dunno I felt like other people could read my thoughts, or hear my thoughts. So anything that they would do, I would interpret it as they're reacting to what I'm thinking.*

Both women here speak to experiences of their actions being watched and monitored without their consent. Dianne explicitly refers to 'The Truman Show', a film from popular culture, involving a plotline in which the entirety of the main character's life is recorded for a hidden-camera TV show. She describes an intrusion, that is not just of her external world being tracked like Dami, but extends to an invasion of her internal world too, where she felt others were able to gain access to her personal thoughts too.

Another participant also spoke to experiences of unwelcomed interference, when describing what events had led her to accessing services:

> **Sabina** *When this lady comes to me, I could not divert myself - she only came to me… It's visual. I can see, nobody else can see… For example, that time my baby was 2 years old. So the lady kept telling me, "Oh keep him outside. Keep him on the balcony. Lock the doors. Slap him." She was instructing me to hurt my son. Obviously, this is my miracle baby you know? …I have endometriosis and was told before I could not conceive… It's not normal obviously, because she was just giving me wrong instructions.*

Unlike the women above, Sabina speaks about a more direct experience with an untrustworthy 'other', rather than feeling targeted by a generally unsafe wider world. Sabina appears to draw on her own personal life experiences to explain why she did not trust the childcare instructions being imposed upon her by the 'lady' no one could see but her, i.e., it seems she felt her own historical issues with fertility, did not fit with the commands to harm her only son.

The experience of intrusion on their lives, was also spoken in relation to their contact with services. In the next extracts, the women refer to particular challenges they encountered during/following hospitalisation:

> **Jennifer (Interviewer)** *How did you first find out about the Early Intervention Team?*

> **Dami** *Erm, they admitted me into hospital, well first I got arrested… During one of the last ward meetings, they just told me like I was going to get a social worker when I was discharged. Erm and I didn't want a social worker at first. Like someone who's just there. Just constantly. Just watching over you. I didn't want that.*

Christiana	*When I came out everyone was just talking about it… I didn't tell people I went to hospital, they found out… 'Oh my gosh Christiana was in a mental health hospital', this this that. I went off social media, coz I didn't want anyone to come and ask me, "Oh Christiana did you..?" And then they PRETEND that they care, but they just wanna find out information.*

Both participants speak here to aspects of receiving unwanted attention following hospital admission. It seems they anticipated that interactions with others on discharge would be detrimental to their lives - rather than of benefit. The women's talk focusses on two different groups; professionals and peers. Dami speaks of the planned input from EI services as a decision imposed upon her ("*they just told me*") and it seems she felt this would involve constant monitoring. For Christiana, it seems going *"off social media",* was an action she took to avoid attention from disingenuous others prying into her experience with acute mental health services.

3.1.2 Subtheme Two: Self-Blame

This subtheme speaks to the role many women seemed to feel they played in their psychosis experience, and the effect this believed this had on the support they were offered. 'Self-Blame', in relation to the overarching theme, highlights participants' apparent **internal** 'Sense of Mistrust', present across many women's accounts, when describing their understanding of how the psychosis experience came to be.

The following women talk to an act of distancing themselves from others:

Christiana	*Umm.. Coz.. How it started, my mental health started, is by me not wanting to be around people. I was isolating myself from people… just being in my room. I started not wanting to be around my family… I cut off all my friends. I just started not feeling myself properly...I was not acting myself.*

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Jennifer (Interviewer)	*So, when you said didn't have anyone to talk to when this all started, was that about something specific? Or in the sense of what you were going through? Or just in general?*
Dami	*Just in general, but that was my fault like, I pushed everyone away… It didn't like happen straightaway. It was like over a period of time. So first it was like I was distancing myself from everyone, I was like alone by myself kinda thing.*

In the lead up to working with mental health services, they appear here to describe an experience of physical and emotional disengagement across all relationships. Both women seem to locate blame within themselves, with Christiana stating this as particularly uncharacteristic of her usual behaviour.

In explaining what she had felt was helpful from services, this next participant also seemed to refer negatively to the role of the self:

Jennifer (Interviewer)	*You said, if you didn't have the support of the Early Intervention team now, you would've been hospitalised, you don't know how many times. What kind of things do they support you with, do you think? That helps you to stop from going to hospital again?*
Ayaan	*Talking. That's very important. Talking about your problems. And not bottling up like I do, which is unhealthy. I bottled it up all those years. My fault… When I was 13, I, there was a period of depression I was going through. I was going through a LOT in that year.*

Ayaan seems to highly regard the intervention of *"talking about your problems"* offered by her EI service. She contrasts this with previous methods she had utilised to manage challenges over her life (*"bottling up"),* and like the women above seems to speak about herself as blameworthy for this.

Just as what appeared to be references to being *too* isolated from others in participants' talk, describing oneself as being *too* angry was also present. A number of participants spoke specifically to experiencing emotions of anger:

> **Dami** *Well I was smoking a lot of skunk as well, so that made me more like, angry as well. So, like the people who were talking to me, I was just like switching out at them, and just angry for no reason. And like my mum kinda saw like a difference in me kinda thing. And she's the one who called the um, the hospital.*

> **Amanthi** *I did feel that people could like hear me, what I'm thinking, at one point when I was going through the psychosis. Which made me quite erm, violent as well, angry. And at one point I just couldn't take it. I started being really violent at home… That's when I was taken to the hospital… Like, for example, if I asked my mum for chicken and chips, I used to get angry. You told me it was 5 minutes, so why are you bringing it in 2 minutes? And then chuck the food away. Like, I broke whatever I found in my house, including my laptop, iPad... I never used to be like that.*

Dami seems to describe cannabis ("*skunk")* use as the main contributor to her feelings of anger, while Amanthi draws on specific features of *"the psychosis"*, such as, others accessing her internal thoughts, as reasons for her angry emotions and experiences of irritability. Their talk appears to describe that presenting as *"angry",* was experienced as a presentation pre-empting one's hospital admission.

Another participant who also described herself as displaying angry-type behaviours, spoke about this in relation to initial interactions with professionals:

Dianne   *The police came to the train station and they were just asking*
me questions that were just going round and round in circles…
Um.. and the ambulance came.. and looking back I was actually
quite rude to them. And I was quite aggressive. Like in my
manner. Um, so I see why they took me to the hospital. Looking
back that was the right decision. I don't think I was safe for
myself and for other people so …the police used quite a lot of
force though? Um, but again I was quite aggressive myself.

Just as participants above seemed to speak of how expressions of anger were potentially connected to their admission process, Dianne also appears to consider her *"rude"* and *"aggressive"* presentation as linked to her being sectioned. She seems to feel conflicted about the intensity of the approach used towards her by the police, wondering if it was excessive, or potentially proportionate to the situation at the time.

3.2 Theme Two: Navigating Unsafe Systems

This second main theme explores Black and Asian women's talk of particular interactions with services, highlighting their experiences of, *'Navigating Unsafe Systems'*. Many women spoke to the difficulties they faced at multiple points in their journey to accessing support for a FEP. This included accounts of feeling services were experienced as unfair and dismissive to/of one's mental state, race, gender, religion, beliefs and live experiences. The first subtheme, *'Unjustified consequences'* brings attention to participants' accounts of physical and verbal force used during the sectioning process. The second subtheme, *'Hindered Help',* focusses on the challenges women described when accessing support from services for psychosis prior sectioning, and also after - when engaging with EI services in the community.

3.2.1 Subtheme One: Unjustified Consequences

The subtheme 'Unjustified Consequences' presents one of the key features of participants' talk; experiences of negative interactions with professionals at the point of being detained under the Mental Health Act. Encounters with mental health staff and police at the point of acute care for a psychosis presentation, were described by

a majority of women as intense and highly-charged. As part of the overarching theme of, 'Navigating Unsafe Systems', staff's actions during the sectioning process seemed to be experienced by the women at best as, unsuitable and unnecessary, and at worst, as abusive and racist.

Following the process of being sectioned at her local A&E, Sylvia speaks here to the experience of being transferred to hospital by mental health staff:

Sylvia   *When I was being sectioned… they, yeah, used like FORCE - to put me in the van.. But it wasn't the paramedics that came to my house… these were the people trying to coax me in the van from A&E to [name of local mental health hospital]… I didn't like that…I just felt the force was extreme. Like, they could've just like, done it in a nicer way. I just remember them grabbing me and putting me in the van. And I was like, woah.*

Sylvia appears to describe the physical approach used towards her by the mental health team as excessive and inappropriate. She seems to have felt shocked by their actions and speaks to a preference for a gentler approach considerate to the situation.

Other women also talked about their experiences with professionals during the sectioning process, and in particular, encounters with the police:

Sabina   *When the police arrested me, I was screaming for my mum. And I remember she was crying, and she was held back by my sister. For me, being sectioned, all that experience just felt like prison. Because of the WAY, you know, I got taken away from my mum and family, just to be sectioned and stuff for my mental state.*

> **Dami** *When the police came, I was calm. I was talking to them and they were asking me about what happened with my brother. And then for no reason they told me they're gonna put handcuffs on me. So that's when I got kinda like, 'What you doing?', kinda thing. They treated me like I'd just killed someone! I got angry, and I threw my drink in the police officer's face. I thought it was unfair… like I wouldn't have assaulted them, if they didn't put handcuffs on me.*

Participants described encountering unfair treatment from the police, referring in their talk to feeling treated like criminals. Both women here seem to explain their experience with the police as unreasonable and disproportionate to the situation. The sectioning process with police involvement appears to be as a highly emotive one; Dami talks about feeling *"angry"*, Sabina states she was *"screaming"*, and that her mum also *"crying"*. Dami also talks to her behaviours and actions towards the police at the point of sectioning (*"I threw my drink in the police officer's face"*), as an active response to the treatment she received from them first.

Furthermore, participants also spoke to the relationship between the police and the black community, in the context of their experiences:

> **Jennifer (Interviewer)** *Do you think from being a woman from a Black background, had any impact on any of the experiences you've shared with me today?*

> **Dami** *With the police, yes. With hospital, no. The police, they took me to court for assault, for indecent behaviour. They tried to get me done for all of it, but I got let off all of it. One of them actually called me a black b**ch! When I went to court about it, they showed me a recording of it on the screen. When they arrested me, the policewoman was like, 'oh that black b**ch she's so annoying' or 'she's so difficult' or something like that… The police have always been like that. It happens all the time.*

Dianne	*Erm, the train guy was handling it quite well. He was really calm. Really polite. He was like, 'could you please sit back on the bench', and I was like, 'yeah course, whatever'. But when the police came, they didn't make me feel like that. I just, I didn't like it. I didn't wanna talk to them. I felt like I was already paranoid and I already felt people could read my thoughts and were against me. And obviously as a black person in England, I don't like the police, and having to be like dragged - I was dragged out of the station.*

Both participants seem to talk to the negative approach of police towards black people (*"the police have always been like that", "obviously as a black person in England, I don't like the police"*), as common, well-known and established practices. Alongside her identity as a Black person, Dianne also refers to her mental state at the time of being sectioned; and how these together seemed to influence her experience with police. For Dami, in addition to her Black identity, it seems her female gender was also of significance with the police – recalling a hostile remark made about her – combining skin colour and a derogatory term for females – caught on body-worn police camera. Both women here also speak to experiences of being physically handled by the police against their will.

3.2.2 Subtheme Two: Hindered Help

The next subtheme aims to highlight services seemingly restricted in their provision, models and delivery, thus participants' descriptions of receiving *'Hindered Help'* for a FEP. The women seemed to describe feelings of being dismissed in terms of the severity of their experience, as well as, their personal understanding of what psychosis is and how it came to be. Participants' experience of *'Navigating Unsafe Systems',* seems to be one in which certain voices, service models and dominant belief systems, were favoured over the women's own alternative understandings of psychosis.

In this first extract, Sabina describes what happened after she sought help from her GP for her difficulties, but had not yet received any follow-up care:

Sabina *So I explain to her, okay I have spoken with you, you know I am suffering the hallucination...getting worse. And she said you didn't get any reply or anything? Did anybody call you? I go, no, it's now nearly three weeks. And then my GP was saying, how come they don't come, it's nearly month now. So straightaway my doctor she sent me there to A&E… they did tests... And then they called my husband and said your wife needs to go into [mental health hospital name].*

Sabina describes how she felt concerned about the time that had passed without accessing support. Despite pro-actively sharing her experiences of psychosis with professionals ("*I have spoken with you, you know I am suffering the hallucination*"), it appears she encountered delays in receiving a timely mental health intervention, that did not avoid admission.

As for those already accessing the mental health system, it seemed participants felt services may not be sufficiently able to support the multiple meanings women had for their psychosis experiences. The following participants speak here to some of their spiritual beliefs:

Jennifer (Interviewer) *So you went into hospital, and the lady went away?*

Sabina *No no no. Hospital just put me in the Early Intervention team, giving medication, consultant, counsellor. It helps. But lady was still there, only went away just couple of months ago. After hospital, I have to go [name of South Asian country], and in the mosque, the Imam, they do the prayers. They give me blessings - these things <points to necklace>, this ring <points to ring>, I used to wear twenty-four seven. So, it's after that, the lady is not troubling anymore.*

Christiana   *I went to a church and they baptised me… After that, I just started not feeling myself, properly. I was acting not myself… I think it was two things… illness and a spiritual attack. The team don't think about it. Coz when you bring it up yeah, they feel like you're chatting, like rubbish. I feel like, they don't understand. Coz most of them are not Christians, so when you bring it up, they feel like, 'no, that can't be true' this this that. But I feel like they just put it ON, to try act like they understand you. But I feel like it's not talked about.*

Both participants seem to hold spiritual understandings for psychosis – Sabina described engaging in spiritual interventions, and Christiana felt she had experienced a spiritual attack. They were not entirely dismissive of other explanations – Sabina seems to have found psychological and pharmacological support useful, while Christiana seems to hold an illness explanation as equal to a spiritual one. In both cases however services were described as limited – either unable to offer interventions sufficiently able to reduce distress, or experienced as difficult, dismissive and disingenuous when it came to discussing spiritual meanings.

Similarly, another participant, also commented on feeling like certain understandings of psychosis were prioritised in services. She describes here attending an EI service group workshop, where the topic of why people might present with psychosis was discussed:

Fahima   *I think there was one of them where they were explaining about diagnoses, with people… who had it from smoking cannabis and stuff. I do feel like medically, I think maybe from their license, they're only allowed to give MEDICINE. Like, yeah I don't feel like they understand, that it could be from...Like they do understand a little bit. But I don't think they understand enough, that it could be from traumas where people have held… As in like I don't remember everything, in depth things from the rape. It was like something I bottled up. No one knew, not even my best friend at the time.*

This participant appears to offer an explanation for why there may be a service focus on particular explanations for psychosis. She's seems to understand the team's focus on medical interventions, as potentially due to statutory "license" rules and restrictions placed on them. Fahima describes feeling like services have limited knowledge of the possibility of trauma-informed explanations for psychosis, and how this is an explanation particularly significant for her as a survivor of a rape she could not speak to others about.

3.3 Theme Three: Impact of Adversity

This final main theme, *'Impact of Adversity'*, focusses on Black and Asian women's talk of multiple past and current difficulties in relation to understanding, and receiving help for psychosis. The term adversity is used here to convey multiple meanings - trauma incidents/events, early hardships/societal pressures, social inequalities, poor previous interactions with mental health services/authorities, and the distress of the psychosis experience itself. The first subtheme, *'Sense-making of Suffering'*, speaks to participants' attempts to understand psychosis in the context of sexual violence, childhood difficulties and ongoing stressors. The second subtheme, 'Unexpected Support', explores how women's negative lived experiences of the world/mental health services, seemed to have shaped their impressions of, and interactions with, EI services.

3.3.1 Subtheme One: Sense-Making of Suffering

Within participants' attempts to explain and understand their lived experience of psychosis, many drew on distressing incidents/periods in their lives, presented here in the subtheme, *'Sense-Making of Suffering'.* In relation to the main theme of*, 'Impact of Adversity',* all the women in this study seemed to feel that exposure to significant stressors, had an influence on their lived experience of psychosis.

Some women spoke to the significance of past traumas in their interviews:

Fahima:	*The rape was one of the main things that affected me, before I went to hospital…at the time that I was mentally unwell, all this was in my head. Like the rape and stuff, I felt like I was in the present of everything that happened. That's why I thought I'm probably in pain and these men in the hospital are trying to come after me, trying to abort my baby.*
Amanthi:	*The mental health people, they came to talk to me in the house. But I don't trust them at that time… So first I avoided it… I was fearing people when like men came over, I couldn't look.*

Jennifer (Interviewer): *Why do you think you were so scared of them?*

Amanthi:	*Um, I think because of my childhood times. So, um, I was abused… Police came as well… when I saw like men and stuff… I was like losing my consciousness. I really didn't like the men touching me. I was trying to get rid of them, their hands and stuff.*

Both participants speak here of being subjected to sexual violence prior service involvement. Fahima's talk appears to connect the experience of being subjected to rape, to phenomena she experienced when "mentally unwell", i.e., beliefs she was pregnant, and that others were intending to harm her and her child. Amanthi seems to understand her inability to trust and engage with professionals - particularly male staff - and links this to experiences of being abused by someone as a child. The police physically handling her is described as a distressing experience which she actively attempted to resist, due to this.

Participants also drew on multiple life stressors as potential explanations for their psychosis experience:

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Jennifer (Interviewer): *And if you feel comfortable saying, how do you make sense of what was happening?*

Ayaan: *When I was 13…I was getting bullied, my grades were falling down. I remember sitting on the chair just looking at myself. Am I shrinking, am I shrinking? I was so scared I might be, that this is actually happening to me. Is it, is it, is it the trauma? Because I, I had these friends. My friends left me. So I was thinking maybe, maybe that's how all this came to be.*

Dianne: *Um, I think, well I was taken substances first of all… Though I think it was building up from right back … Since I was little, I've never been able to make friends that easily. So, I think that started to build up into, oh people must not like me, they just want to use me and they're out to get me. Like I had a Polish friend and she would like make fun of my race a little bit, I'd joke and laugh about it, but it wasn't funny. I've also been a young carer for my mum, and I'm the only child. So it's been me and her for like my whole life. When I moved out for uni I had all this freedom. I kind of abused it and was just taking substances and not taking my education seriously.*

Both these participants speak of psychosis as something that had possibly developed over time and linked to early life stressors, i.e., relationship breakdowns and difficulties, bullying, racism, educational pressures. Ayaan recalls a frightening experience where she felt she was physically becoming smaller, and wonders if this was linked to her losing friends. In addition, Dianne spoke to her use of substances, explaining this as something she took advantage of when she experienced more freedom, following the role of being a carer most of her early life.

While all participants spoke about possible explanations they had for psychosis, they did not appear confident the experience could ever be adequately understood:

Dami: *I don't really understand it. Even though I went through, it's kind of, I don't know, it's crazy. It's not just seeing things and hearing things, it's a lot.*

Sabina: *I really don't know. Just no idea. Because, the situation is going sometimes worse to be honest. Now, I always I see this shadow. Example I'm watching TV, someone is just passing all the time it's not any specific. I'm feeling still small disturbance.*

Ayaan: *When I was in hospital, I was scared. I remember I was like okay, what's gonna happen? Is the shrinking gonna go away?... Hospital helped with my anxiety.. it helped with my depression.. But what it didn't help me with was the shrinking… My family, my friends they think that this is unreal. They don't get the fact that I'm still going through shrinking. I don't even understand. It's confusing.*

Dami speaks to psychosis as overwhelming and complex, while the other women describe confusion over their ongoing experiences of distress. Sabina reports she now sees a continuous shadow, while Ayaan feels she continues to feel troubled by her experiences shrinking, despite finding aspects of hospital helpful generally for her mental health. Furthermore, Ayaan talks not just to her own lack of understanding, but also refers to others in her support network, who do not seem to empathise, nor trust the authenticity of, her ongoing experiences.

3.3.2 Subtheme Two: Unexpected Support

While several of the women described having poor expectations of service-input, many spoke to opinions changing once they received direct interventions from EI services, as presented here in subtheme, *'Unexpected Support'*. Participants' prior encounters with mental health services, lack of access to finances, one's social identity and status, illustrated how significant the *'Impact of Adversity',* can shape service engagement for this particular group of women.

Participants in these next extracts describe their thoughts on accessing care from mental health services:

Ayaan: *Um...I thought maybe.. I thought at first I'm just gonna go home from hospital and stay at home. They're just gonna give me medication, stuff like that, that's what I was thinking.*

Dami: *I never wanted to work with mental health services in the first place - my family's always been supportive so, I've always been someone that likes to do stuff on my own.*

Ayaan describes thoughts that mental health teams in the community may be somewhat detached and medicalised in their approach. Dami states she had no interest in service input. She describes valuing her strong support network, as well as her own independence, as reasons to why she felt mental health provision was not required.

Later in her interview, despite initially holding seemingly negative views of mental health provision, Dami spoke positively about her experience with the EI team:

Dami: *Um, I do think they do like, the best they can for people. They actually care about their patients… they do all they can.*

Just as she talked favourably about the care she received, so did other participants:

Amanthi: *Like, they support in every way they can. Whether it's psychologist, employment, benefits… So, when I came out of the psychosis, I was blank… After my dad's death, after he passed away, things had changed. Like all the benefits and stuff that we had to sort out, was on me. And I had too much responsibility, which I couldn't take on my own. So they suggested to me, universal credit… I didn't even know about universal credit! I didn't know where to get my answers.*

> **Sylvia:** *They gave me support in like all areas of my life, you know. First thing we got sorted was, what was it? Like getting me on the housing list, then Freedom Pass. She's helped me with so much, I can't even remember.*

Participants in the extracts above, describe the EI team's ability to support their immediate social and material needs, i.e., access to financial support and suitable accommodation, as a function of the service they highly appreciated. Amanthi describes life after hospital as a time of difficulty *("I was blank"),* but alongside this speaks to previous longer term challenges in managing access to funds. It seems she found service support with this as particularly helpful. Sylvia speaks here about the help she received with accommodation, also inferring in her talk that she had lost count of how much support she had received.

Alongside the range of interventions on offer, women also described encountering caring professionals attuned to their needs:

> **Sabina:** *Care coordinator was very nice. She used to go with me to get the benefit, and with my husband in the carers' centre. This information, that information. Freedom bus pass. ALL the information, she used to give to us… Even Psychologist, she IS so lovely, young lady. And every week, spend time with, just talking, just expression of feelings.*

> **Christiana:** *Um well they supported me in like, helping me to take my medication. And, um one of them supported me with my self-confidence. 'Cause she NOTICED that I was a very shy, person. When she would be like talking to me, I'd be looking like down, I won't give her eye contact. She'd be like, 'You need to think highly of yourself, you're fearfully and wonderfully made'. And then it just, boosted my confidence up high.*

Sabina talks to feeling supported both practically and emotionally, describing how she received help not only for herself, but her husband too. Both women speak here to experiencing positive interactions with staff members. Christiana refers specifically

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to her "self-esteem" and "confidence", describing an encouraging experience she had with a care co-ordinator.

The women also spoke to what it was like to experience this type of help from services. Many seemed to express gratitude for the unanticipated quality of support received:

Sylvia: *I think it's the best thing that could've happened, after being sectioned, just to have someone who's dedicated to like working with you. And you know every week, this time or whatever, you go there, and you have a space to like, to talk about whatever's bothering you. Because of my experience with CAMHS, If I had gone to see a counsellor and she had just told me like before, 'you've done this to yourself', I would've just withdrawn from services… Like they knew I was on drugs. They didn't pass ANY judgement you know.*

Amanthi: *They've actually helped me out, because we don't expect people to do things for us.*

Dianne: *I'm still getting used to it. Like people, supporting me... I'm used to looking after my mum and even in my friendship groups. I was like the listener for them... So, I'm not used to people being interested in what I'm doing. And they will ask me like.. do I want to go back to uni and work? And I was just, erm, I was quite flattered. That they were interested and wanted to help me. Like my care coordinator is really lovely and, I felt quite supported. Like I'd come to a psychology appointment just to talk about myself and my difficulties, so that was weird. But that was really nice, and they guided me through it over time.*

Sylvia speaks here to previous interactions with mental health services; how she felt this differed from experiences with the team now. She describes an appreciation for their non-judgemental approach. Like Dianne, Sylvia also expresses valuing a space

to talk, focussed on her own personal adversities and needs. However, receiving such a dedicated level of help, may be experienced as a surprising and uncommon occurrence, as indicated in Dianne and Amanthi's talk. Dianne describes how not taking up her usual role of caretaker for others, was an unusual but pleasant experience. She seems to appreciate the gradual navigation through the therapy process.

The final participant in this subtheme, also speaks to the experience of accessing psychology within an EI service:

> **Fahima:** *It took like 6 months for me to understand what a psychologist is and what I'm meant to share with her. She then helped me go forward to report the rape to the police the first time. The second time I had to do it myself - but you know, only coz my time with her and the team is finishing. It's disappointing, coz NOW is the time I NEED a psychologist… I need all that support, whereas in the beginning I didn't use it properly, because I just didn't know how to.*

Following receiving initial psychological support under the EI service, Fahima describes feeling dissatisfied with the plan of discharge. She speaks to an awareness that her time with the team is limited, however feels it is "disappointing" this is happening now - alluding to the current emotional impact of engaging with police to report the rape perpetrator. Similar to Dianne, who talks to the significance of time in understanding the function of psychology, Fahima speaks to a similar experience of going through a somewhat lengthy process to grasp how to utilise therapy sessions in EI services best.

4. DISCUSSION

This chapter starts by discussing findings from the analysis, followed by a summary of how these answer the study's research questions. Implications for practice,

research and policy are discussed, followed by a critical review of the study and then discussion of personal and epistemological reflexivity.

4.1 Summary of Findings

The themes gathered from the analysis are further summarised and referred to in the context of the existing research.

4.1.1. Theme: Sense of Mistrust

4.1.1.1 Uninvited Intrusion
For the participants in this study, psychosis was an experience which involved an *'uninvited intrusion'* in their life from others, leading to feelings of suspiciousness and an overall '*sense of mistrust'*. While the way people intruded on their lives varied, i.e., being followed, thoughts intercepted – the experience of their safety and wellbeing as under threat, seemed to be shared. Previous research with Asian women has also spoken to an experience of psychosis characterised by invasion and suspicion (Corin, et al. 2005). This study goes further to explore how this specific feature of psychosis may impact relationships with services. Those who experience intrusion as part of their experience, may be wary of engaging with an intensive service model. An example of this is when a participant described not wanting to work with EI services, as she did not want someone "watching over" her. The experience of feeling watched by staff, has been reported previously by women hospitalised and diagnosed with psychosis (Hagen & Nixon, 2011), however it seems this experience may also be relevant when Black and Asian women are expected to interact with community teams such as EI services. In addition, the experience of *'uninvited intrusion'* was also extended to personal relationships. The stigma associated with hospitalisation for psychosis, seemed to also lead to a prevailing sense of mistrust towards peers. This resulted in experiences of withdrawing from social media, to avoid seemingly disingenuous others, intruding on details of experiences with services. Of the few qualitative studies exploring the experience of psychosis with a focus both on race and gender, the women in Loganathan and Murthy's (2011) study, also referred to the impact of societal stigma. While their sample involved those with long-term service use, the participants in this study were entering services for the first time, suggesting the impact of stigma can

also have fast and immediate effects on one's social network. Professionals need to consider how to support Black and Asian women, in services which may mirror distressing experiences of intrusiveness, and in addition may have lost previous sources of support due to the stigma associated with service use.

4.1.1.2 Self-Blame
Participants' 'sense of mistrust' was directed not only towards others but themselves too. They seemed to engage in *'self-blame'* (subtheme two), feeling they were responsible in the deterioration of their own wellbeing. Psychosis seemed to be an experience where the self could not be entrusted to make good decisions. This included self-isolating, where participants described detaching themselves from others, as unwise choices they had consciously made. This is a finding which has not been spoken to in previous literature. Being able to discuss personal problems with EI services, was outlined as something the service successfully facilitated, which was otherwise a challenge outside their intervention. It seems the women held themselves accountable for not sharing. This could be informed by prevalent messages in the media, such as the 'Time To Talk' campaign', which may position people as wholly responsible for help-seeking when in psychological distress (Malla, et al., 2015). However, this understanding may be devoid of wider context. Services need to consider what may be the barriers to meaningful help-seeking for Black and Asian women, which goes alongside – or beyond, an individualised explanation. As part of the experience of 'self-blame', participants also spoke to presentations of aggression, often in the context of their behaviour just before, or during, involvement from acute mental health services. The cause of anger was often assigned to something inside the participant, i.e., cannabis-use, the 'psychosis' itself; described as uncontrollable, baseless, and having a significant impact on interactions with others. Participants alluded to this being a reason for service involvement and a possible justification for forceful approaches; as a response to manage one's presentations of anger. While anger has been previously reported as an emotional response to living with psychosis for women (Chernomas, et al., 2017), this study's description of subjective accountability in pathways to care, has not been reported in previous literature focussed on Black and Asian women. Such experiences of *self-blame*, may also partly be influenced by wider gendered-racialised discourses, such as the 'strong black woman' or the 'subservient Asian', which may position women to

not seek help from others, as they are expected to hold it together themselves and/or focus on taking care of others first. Additionally, discourses such as the 'angry black woman' and 'meek Asian', may also partly explain why expressions of anger are problematised. For Black women, the stereotype suggests their anger is unjustified despite the circumstance, and for Asian women, the associated stereotype suggests anger is an unexpected abnormal reaction; both speak to pathologising the emotion of anger for these groups. Services need to consider that Black and Asian women may feel guilty and blameworthy at the point of service access, as well as endeavour to develop an awareness of the wider identity discourses that are involved in help-seeking for these groups.

4.1.2. Theme: Navigating Unsafe Systems

4.1.2.1 Unjustified Consequences
Participants described negative encounters with professionals at the point of being sectioned. As part of the experience of *'navigating unsafe systems',* police and mental health services were described as harsh, extreme and heavy-handed in their approach at the point of acute care. Such encounters were described as highly emotional negative events, which resulted in *'unjustified consequences'* that made participants feel like they had broken the law. Previous research with women - without a specific lens on race – have similarly reported encountering 'violence' and feeling 'violated' at the hands of the system (Hagen & Nixon, 2011), however references to one's actions being criminalised, seems to be a new finding specific to this study. Participants described attempts to defy police power, i.e., throwing a drink, not speaking (see also Amanthi's extracts in section 3.3.1. *sense-making of suffering*), often explaining this as a response to how professionals treated them first. As previously identified, women often report experiencing a loss of control at the hands of professionals while being sectioned (Chernomas et al., 2017), which may explain behaviours to resist the police, partly as a way of exerting control, in a situation where participants possessed limited power. Furthermore, participants in this study also made references to a complex and unsafe relationship between police and Black communities. Behaviours of resistance during interactions with the police, could also be understood then as behaviours of defence - and even survival,

see incident with Michelle Cusseaux[5] (Locke, 2016). This is reminiscent of the 'circles of fear' which talks to experiences of fear and mistrust between Black men (considered dangerous by services), and mental health services (considered racist, unfair and punitive by Black men), often utilised as an explanation for why help-seeking is delayed and access to mental health care via coercive routes at crisis point is common (Keating et al., 2002). It is possible that these experiences could also be extended to racialised women impacted by prevailing stereotypes. For example, that the 'angry' or 'strong' black woman presenting in distress is not to be considered vulnerable and weak (Ashley, 2013), thus allowing for more coercive approaches. And additionally, that the 'meek Asian woman', should present as quiet and nonaggressive, and by not complying with this is abnormal, again justifies the use of coercive interventions (Kwok, 2014). Research with BME groups, have reported police involvement in pathways to care for FEP can often deter further service engagement (Myers et al., 2019). Considering Black and Asian women seemed to report negative interactions with police in this study, it would be important not only for EI services to consider how to best to support those who have experienced coercive care journeys, but also how to prevent this, by acknowledging the potential impact of gendered-racialised discourses on practices, processes and pathways to care.

4.1.2.2. Hindered Help

Elements of service provision were considered restrictive by many participants, resulting in experiences of *'hindered help'* (subtheme two). Participants who did request help, seemed to only gain access to services when presenting in acute mental health crisis. This seems to be consistent with previous findings where women report being dismissed and denied access to support for FEP at an earlier stage for presenting as 'too functional' (Ferrari et al., 2016). Unlike other studies which have reported individuals from BME groups access EI services through a crisis due to fears of 'shame' and 'social stigma' (Islam, et al., 2015), this was not the case for all the participants in this study. It seemed for some Black and Asian women who did seek help, services did not seem to respond to their needs in a timely way.

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[5] Michelle Cusseaux was a Black woman in America who had received a psychosis diagnosis. She was fatally shot by police during a mental health callout in 2014.

Furthermore, for those who described their experiences while under service care, 'hindered help' was related to certain models of psychosis prioritised in services, to the detriment of others. Participants in this study spoke to holding spiritual and trauma explanations for psychosis, and felt EI services did not always value these to the same extent as the medical model for psychosis. This echoed findings with other qualitative research conducted with Black and Asian women diagnosed with psychosis (Cheng, 1985; Nxumalo-Ngubane, et al., 2019), as well as research reporting individuals from BME groups find it difficult to discuss spiritual beliefs with EI staff due to fear of judgement (Islam, et al., 2015). In addition the experience of psychosis being understood as biological disorder, rather than a response to trauma, was a finding echoed in previous research with women accessing psychosis services (Hagen & Nixon, 2011). It is also important to mention, participants did not hold strongly to one understanding, with many drawing on multiple models co-currently for explaining FEP, for example, "*I think it was two things… illness and a spiritual attack".* This mirrors research which indicates Black and Asian women accessing services over longer periods of time, also report multiple conceptualisations of psychosis (Sosulski, et al., 2010; Corin, et al., 2005). This could indicate Black and Asian women's personal explanatory models of psychosis related to one's ethnic or religious culture, may intersect with more dominant models prevalent in the societies they live in, and thus cannot be easily separated. Services need to thus consider how service access may be improved for Black and Asian women who do seek help, and also consider engaging in wider explanations for FEP that go beyond the dominant Western construct of diagnosis.

4.1.3 Theme: Impact of Adversity

4.1.3.1. Sense-making of Suffering
Participants spoke to significant experiences endured to explain the psychosis and engage in 'sense-making of suffering'. While quantitative studies have consistently suggested strong correlations between sexual violence and receiving a psychosis diagnosis for women (Morgan & Fisher, 2007; Riecher-Rössler et al., 2010; Fisher et al, 2009; Heins et al, 2011; Elklit & Shevlin, 2011), this study offers a qualitative insight into this. The experience of being subjected to sexual violence was understood as a trigger for the psychosis experience as well as informing its content,

i.e., the experience of rape was connected by one participant to her experience of falsely believing she was pregnant and that others were trying to abort her child. This speaks to previous studies in which beliefs are considered meaningless 'delusions' by services, actually have meaning for women (Chernomas et al., 2017). Trauma experiences also had an impact on participants' motivations to engage with services, i.e., not wanting to interact with male staff who reminded them of the abuse. This is also reminiscent of previous studies with women diagnosed with psychosis, who also described that the way they were treated by professionals in acute mental health services reminded them of their past experiences of violence, abuse and trauma (Chernomas et al., 2017; Hagen & Nixon, 2011). Mental health services' approaches may be inadvertently retraumatising women, but also the trauma itself for the women in this study may have informed decisions to not engage, not trust, and to resist/protect oneself from dominant others. Women also spoke to early life experiences of lacking control, power and trust, experiences, such as early friendship breakdowns, bullying, educational setbacks and racism, as potentially having a role in their psychosis experience. Psychosis was also considered as something participants still did not fully comprehend. It seemed the lived reality of psychosis was so intense and complex, that many of the women did not feel any explanations were satisfactory to make sense of it fully. A previous study has also reported how women have struggled to find rational explanations for psychosis, due to the very nature of the experience (Corin, et al., 2005). These findings imply that services need to consider how the following impact engagement with Black and Asian women; how current approaches may be reminiscent of past abuses, how early stressors experiences related to one's roles and responsibilities may help to understand the psychosis experience, and how not having an explanatory model for psychosis may not be a priority, and on the flip side – may be an ongoing source of distress.

4.1.3.2. Unexpected Support

Many participants described having low expectations of EI Services, which led to the experience of receiving '*unexpected support'*. This seemed to be based on previous negative encounters during the sectioning experience, or simply having no interest in the need for service input. Participants spoke to feeling surprised about the range of support they were able to access in EI services, a feature of psychosis services

women have previously valued, but not always received according to previous research (Chernomas et al., 2017). A major need the service met for the participants in this study, included access to social and financial support, indicating needs beyond the psychosis diagnosis were being met, again something previous research has indicated women have lacked access to (Hagen & Nixon; 2011). In addition, staff were described as caring and non-judgemental a finding which contrasted with experiences of women accessing psychosis services for longer periods of time reported in previous research (Kwok, 2014; Nxumalo-Ngubane, et al., 2019). The Black and Asian women in this study also seemed to place high value on the provision of talking therapies – a finding which did not corroborate with interviews completed with a sample of Black and Asian individuals accessing EI, which did not have an additional lens on gender (Islam, et al., 2015). However, this study goes further and speaks specifically to how women from these groups felt they benefited from this particular intervention, although shared it took time to understand how to utilise psychology sessions best. This was experienced as particularly difficult to when it came to discussing trauma. Participants spoke to EI provision as if this was something underserved, i.e., *"we don't expect people to do things for us".* This may imply that the Black and Asian women's previous experiences of powerlessness and lack of control, both in their personal lives as well within interactions with services, had made them feel like they were not deserving of, entitled to, or used to, receiving genuine care and support for their needs. This possibly speaks again to discourses of the 'strong black woman' or 'subservient asian', which may place expectations on these women to present as resilient and rely on oneself and/or focus on the needs of others before one's own (Reynolds-Dobbs et al., 2008). Services need to acknowledge and respect Black and Asian women may need some time to build and develop trust, which may be hindered by previous experiences of poor care as well as their own lived experiences.

4.2 Answering the Research Questions – Summary Statement

My first research question sought to explore Black and Asian women's personal descriptions of FEP. In this study psychosis was an experience characterised by a mistrust of intrusive others, involving a presentation of particular behaviours, and

explained by multiple models. However, these understandings were not always held by services. In relation to the second research question, which explored Black and Asian women's descriptions of mental health services for FEP, the approaches used at the point of sectioning, as well as the intensive model offered by EI services, intertwined and impacted distressing feelings of mistrust and intrusion already being experienced. Furthermore, while the medical model of psychosis seemed to be prioritised to the detriment of other personal understandings, Black and Asian women appreciated the holistic provision offered by EI services, describing this as a novel experience, which required time getting used to.

4.3 Study Implications

4.3.1 Clinical Implications – Professional Practice

4.3.1.1 Police involvement in acute mental health care
The involvement and impact of having the police involved in the Black and Asian women's psychosis service pathways was talked to extensively in the data. The approach and force used was experienced as unjust, unfair and unsafe; making participants feel like they were criminals, contributed to aspects of re-traumatisation from past upsetting incidents in their lives, and also highlighted the impact of historical injustices towards certain racial communities. The police as an institution was experienced as threatening, positioning participants as powerless which potentially explained acts of resistance from the Black and Asian women at the point of sectioning. While the police may be dominantly understood as an institution that keeps people safe, this was not necessarily experienced by the participants in this study. The experience of psychosis itself as described in this study, is one that is characterised by mistrust and intrusion. Therefore, if an already existing mistrustful relationship exists between the police and one's community, this may make police involvement in pathways to psychosis services, a particularly difficult, and even dangerous interaction for Black and Asian women.

The mental health system's expectation of police involvement in mental health crisis infers high quality training, which includes how to approach vulnerable groups such

as Black and Asian women. A mental health crisis 'street triage' model, launched by the Department of Health in 2013, involves mental health staff – including clinical psychologists - working collaboratively with police officers to attend scenes where a potentially more tailored and reflective approach can be utilised (Sweeney, 2015). Someone ideally with professional or lived experience of FEP, may be helpful. They may be able to hold in mind the experiences of mistrust and suspiciousness this particular group holds and/or become involved in training. It has been suggested that police would benefit from training and views from people with lived experience of police involvement during a mental health crisis (Her Majesty's Inspectorate of Constabulary and Fire & Rescue Services [HMICFRS], 2017), which I would argue should also include the voices of Black and Asian women. Hart & Waddingham (2018) have suggested statutory bodies involved in the MHA should be inspected by the Care Quality Commission [CQC][6], to ensure employees receive training which address issues of racial bias and cultural competence. While the authors were referring to mental health staff, as evidenced in this study police are also involved in mental healthcare, and thus the same expectations and standards for training could be applied to this group of professionals. However, what might be considered sufficient or acceptable training - and if teaching about racial bias can even help to shape discriminatory practices - is debated. Unconscious bias training for example, is a well-known workplace diversity initiative, which aims to increase one's awareness of the unconscious views they may hold about certain groups, for example, based on race or gender. Its' goal is to 'reduce explicit bias towards members of a group denoted as having a protected characteristic; and change behaviour, in the intended direction, towards equality-related outcomes' (Atewologun et al., 2018). Approximately 17,000 officers in the London Metropolitan Police Service have received a version of this training (Mayor of London, 2019). It is hoped training police officers on how to manage unconscious bias, may help to reduce the potential for stereotyping, and unfair treatment of racialised groups (Walden, 2019). To avoid this intervention becoming a 'tick-box' exercise, embedding regular follow-

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[6] Care Quality Commission – The independent regulator of all health and social care services in England.

up sessions which encourage continued learning, and-unlearning, may help to reinforce the internal process of change expected from unconscious bias training.

There is however limited evidence in general to suggest that awareness of personal biases can result in lessening of those biases (Kellough & Naff, 2004; Kalev et al., 2006). A one-off exercise could be considered too short-term to implement real change, potentially even making employees more complacent about their own biases, as they give organisations a false sense of confidence in their anti-discrimination programmes (Doben & Kalev, 2018). Such training could also be considered to individualise racial/gender bias, rather than the organisation taking accountability of discriminatory practices embedded within a complex system. Where initiatives are focussed on the organisation, rather than on individuals, Kaiser et al. (1999) suggests employees may be better able to approach that system with a critical lens, identifying where bias may be impacting the outcomes of the organisation's systems and processes. Dobbin & Kalev (2006) assert anti-discrimination initiatives need to be multi-pronged, and always engage decision makers who can enforce change. Those in roles of power should be held accountable to, and responsible for implementing meaningful change for marginalised communities accessing their organisations. Psychologists for Social Change (2020) have developed a poster communicating concrete ways services can begin to embed anti-racism within their organisations. It includes action points such as, appointing an 'anti-racism guardian' who is allocated an appropriate workload, and that 'representation from marginalised groups are embedded within internal structures'. They also highlight the importance of organisations acknowledging intersectionality – highly relevant to the participants in this group who experience multiple marginalisations. Although aimed at the NHS, it could be argued many of the proposals are appropriate for all statutory services. Leadership teams could also take actions such as, inviting people within the organisation to share experiences/observations of bias, empowering employees to be part of the 'design of the solution', and encouraging 'change champions' as valuable approaches to tackling institutional discrimination and racism, which go beyond training (Gulley & Liesch, 2020). Practically this may look like, 'acute mental health', 'anti-racism' and/or 'anti gender-discrimination' champions employed within the force, highlighting the experiences of Black and Asian women entering the mental health system via

the police, exploring harmful and positive practice, and advocating for change to a system that is willing to listen. Importantly, such champions would involve consultations with women's, BME or service user groups funded appropriately for their expertise and input. Just as Clinical Psychologists, as part of both their clinical and consultation work, assess difficulties, formulate problems, deliver interventions, and review outcomes – the same should be asked of wider professional systems implementing actions aimed at tackling systemic racism, gender discrimination and mental health stigma. While an intended outcome of unconscious bias training is that individuals become more aware of their biased beliefs and therefore this may reduce them acting unfairly to certain groups, outcomes of a system-wide approach would need to be devised carefully, i.e., X number of 'champions', X number of collaborative goals met devised with community groups etc. Alongside this, holding inappropriate practice to account, would be important in developing an anti-racist and anti-sexist culture. As Psychologists for Social Change (2020) writes; the awareness of structural inequalities, demands a structural response. Racism, sexism and discriminatory attitudes towards psychosis, are long-standing societal problems in the UK (see sections 1.5, 1.6, 1.7); organisations require multiple approaches, which are regularly reviewed by committed bodies across the health, social and justice systems, as these all impact a Black and/or Asian women's journey to accessing services for acute psychosis.

4.3.1.2 Clinicians in Early Intervention for Psychosis Services – Holding Awareness of Journeys to Care

It may be important to consider the impact of being sectioned under the Mental Health Act on Black and Asian women's pathways to care and how this might impact engagement. Prior distressing experiences with aspects of the system may be damaging to future relationships with care professionals (Reder & Fredman, 1996), including beliefs about EI staff and how much they can help, rather than harm. The experience of psychosis was described by participants as one where they feared others intruded upon their lives without consent. EI service's care model may be felt to reinforce this experience - their intense approach understood to improve support people for people in the 'critical period' of early psychosis and avoid long-term use of care (Norman & Malla, 2001; Marshall & Rathbone, 2011) – may be reminiscent of Black and Asian women's experiences of intrusive others, and impact initial levels of

engagement. They may understandably be suspicious of EI services, may want to resist their input, or even feel they have to unwillingly comply to avoid further unwanted interventions, i.e., increased length of stay in hospital.

Professionals should consider how they can facilitate more autonomy, offer Black and Asian women more explicit choices of how they would like to access the service, e.g., at home or in clinic, or any ethnic/religious/gender preferences of clinician. Of course this will not always be feasible, but where unavailable could open up more ideas on the kind of support Black and Asian women may need and inform further interventions, i.e., rebuilding networks, linking in with chaplaincy services, and /or signposting to relevant support groups beyond EI provision. Furthermore, maintaining a genuinely caring and persevering approach are not to be minimised, these are experiences that may have not been made available to Black and Asian women during initial experiences with services.

In light of this, professionals should consider opening up dialogue about past experiences with mental health services, acknowledging potential situations of injustice that may have made women feel confused, scared and conflicted about mental health provision altogether. These conversations should not be enforced however; talking about experiences of sectioning could potentially feel re-traumatising. However even the *offer* to talk about negative journeys into services, can validate the impact this may have had/continues to have on the person, and help to equalise conversations around collaborative crisis planning, which includes how services can support Black and Asian women to avoid the likelihood of accessing acute services for psychosis again. Additionally, providing support for accessing complaints procedures, should they wish to go down this route, which may feel difficult as a clinician of the NHS, is within our duty to highlight questionable practices and possible injustices.

4.3.1.3 Clinicians in Early Intervention for Psychosis Services – Working with multiple concepts of psychosis

The findings from this study suggest Black and Asian women held multiple concepts to explain psychosis, including biological explanations. However additional explanations, such as those informed by personal trauma, early life adversity and

spiritual beliefs, were felt to be less held and spoken about in EI teams. Such understandings may be seen to challenge dominant service models in the UK, which consider psychosis an underlying medical disorder, rather than as a response to one's interpersonal, historical and social context. Alongside this, 'not knowing' should also be accepted as a valid experience; that Black and Asian women may not always feel able to draw on an adequate model to explain their experience. Providing purely diagnosis-led or biological explanations, may limit the extent to which Black and Asian women can maintain a sense of hope or agency. Additionally, professionals may not always see the way their own knowledge and experience (i.e., own understandings of psychosis, race and gender) is culturally specific rather than universal and natural (Helman, 2007). This may be experienced as dismissive and oppressive by service users, whose world views may differ from those with relatively more power working in mental health services. Supporting discussions about personal ideas about one's experience, does not aim to dismiss medical understandings of the experience, but instead acknowledge psychosis as a construct with multiple meanings. Clinicians reflecting on the social differences between themselves and service users, '*assist practitioners in being mindful about a range of differences, and generating a desire to extend their practice beyond their current abilities'* (Burnham et al.,2008,). By practicing reflexivity, staff may come to acknowledge their own biases about psychosis and how this might impact professional practice (Pelechova, et al., 2012). By respectfully normalising differences in opinion where they exist, may contribute to feeling listened to and validated in EI services, avoiding a paternalistic service approach, and potentially reduce the risk of disengagement from services (Terkelsen, 2009). Wider dissemination of these ideas could be to include multiple theories about psychosis via service leaflets to highlight its contested, rather than 'scientific' nature.

In addition, the positives of EI services cannot be minimised. The Black and Asian women in this study expressed appreciation for the level of social and psychological support received. At the beginning of the journey with EI Services, allowing space to hear the person's experience alongside supporting one's social needs, may be key to enhancing engagement, rather than a service focus on defining psychosis.

4.3.1.5 Psychological Interventions and Early Interventions for Psychosis Services

While CBT models are advocated for in working with presentations of psychosis, with the possibility of adapting interventions to consider the impact of disadvantage and racism (Rathod et al., 2015), some argue that these can minimise people's experiences, getting them to challenge their lived realties. While this can be helpful to reduce some people's experiences of distress, other types of interventions which work *with* people's 'unusual' beliefs, rather than trying to reject them have been advocated (Romme & Escher, 2010; May, 2012). Developing a, 'Believe it or Not!' group (May, 2010) in EI services, aimed at exploring multiple beliefs about psychosis, may be helpful for discussing Black and Asian women's experiences of distress without pathologising them. Additionally narrative therapy approaches, which externalise the problems people experience, rather than insisting it is due to a default inside of them, have been found to be valued by young women diagnosed with FEP (Newman et al., 2018). Connecting with other like-minded peers, also interested in models outside the dominant realm of CBT would be important to seek.

As described in the introduction, intersectionality refers to when two or more discriminatory characteristics intersect, i.e., female gender and a marginalised racial background. In the case of this study, the participants may also be subjected to an additional label with potentially oppressive implications – 'person with psychosis'. This can have a cumulative negative impact on people's lives. The concept was originally considered in relation to the oppression of Black women in society (Crenshaw, 1989). Intersectionality reminds us that oppression cannot be reduced to one fundamental type, and that oppressions work together in producing injustice (Hill Collins, 2000). Acknowledging interlocking systems impacting Black and Asian women's lives, recognises the role of structural power on people's ongoing struggles. It leads us to question the way racial structures work, how they are influenced by patriarchy, and how this intertwines with material structures such as the mental health system. Rosenthal (2016) writes that some of the ways psychologists can incorporate intersectionality into their work more widely to contribute to tackling social injustice includes: engaging and collaborating with marginalised communities, addressing and critiquing societal structures, teaching social justice curricula and attending to resistance as well as resilience. As captured in the subtheme 'Self-Blame', Black and Asian women may potentially internalise wider societal racialised

stereotypes (Hooks, 1992; Lowe, 2008). In therapy, it has been suggested clinicians should develop an awareness of the potential racialised discourses impacting women, who they may benefit, what purposes they serve, as well as, a willingness to explore – and potentially even dismantle – such stereotypes safely and sensitively at the client's pace (Ashley, 2013).

Some women's talk included accounts of sexual violence committed against them, appearing to describe trauma as something which led to their experience of psychosis, as well as a barrier to trusting services (see subtheme: sense-making of suffering). Black, Asian and Minority Ethnic women subjected to violence, report coping with multiple, intersecting issues including financial difficulties, racism, unstable living conditions, immigration status, as well as sometimes feeling judged or blamed by professionals (Imkaan, 2016). As Black and Asian women's experience of gender inequality intersects with issues such as race, mental health services need to recognise and respond to these intersections, particularly as funding for specialist BME-led groups are strained (Larasi & Jones, 2017). Clinical psychologists should attempt to understand sexual violence in its' social and political context, to abstain from non-neutrality and address blame and responsibility. Violence against women is set on the social context of patriarchy, systematic discrimination, marginalisation and oppression. Clinical Psychologists working in EI Services with Black and Asian women who may report trauma, may also experience vicarious trauma, and should access appropriate supervision for this. While Clinical Psychologists may favour talking therapies for trauma, this could be considered a Eurocentric approach and it would be important to consider offering other approaches where available, i.e. trauma-informed yoga (see Epstein & González, 2017), or collective narrative approaches which rather than emphasising an individual focus on trauma, privileges preferred stories of women's identities within a group setting (Ncube, 2014). It appears it takes time for Black and Asian women to trust professionals, so it may be worth considering providing additional time with EI services, that go beyond the traditional three years. Alternatively, at least transitions/discharged need to be collaborative and carefully planned and collaborative.

4.3.1.6 Clinical Psychologists as Leaders within Early Intervention for Psychosis Services

Clinical psychologists are in leadership positions of power and hold a privileged position to support the implementation of the above suggestions through training, consultation, supervision and co-working with other professionals (BPS, 2007). While it can be difficult to function in services where the medical model may be dominant, it is possible to raise alternative perspectives to stimulate discussion and debate. Furthermore, offering supervision to care co-ordinators in teams, developing good working relationships with service managers, may help to open up ways of thinking in the system, that may offer additional and alternative ways of thinking about psychosis, which may benefit Black and Asian women.

Reflective practice groups within teams may support the deconstruction of taken for granted language in interactions with service users (Finlay, 2008). Advocating for certain questions to be included in assessments, i.e., what was the pathway to the EI team, could help to inform team case formulations, when discussing Black and Asian female service users. They could encourage services to be sensitive and considerate to the issues during MDT meetings. Furthermore, they could invite and offer paid work to Black and Asian women who have been given a label of FEP and accessed services, to be part of teaching future clinical psychologists (as well as other professions) about their experiences and how different aspects of social identity can shape experiences with mental health services.

4.3.2 Clinical Implications - Alternatives to Detention under the Mental Health Act

4.3.2.1 Support Before a Crisis

Public bodies – which include the mental health system and police - have a duty to develop mechanisms which guard against the discrimination of anyone accessing services (MacPherson, 1999; Government Equalities Office,2011). The disproportionate number of racialised minorities subjected to the Mental Health Act, as well as the lived experiences of this highlighted in the present study, suggest the imminent role of the state to improve and develop, legislation, policies, and practices which better serve the needs of BME groups (see section 4.3.3 for further discussion). An assumption that seems to prevail during service-planning and amongst policymakers, is that issues of race and ethnicity falls within the remit of

third-sector organisations, as an 'add-on' with limited ways of 'influencing mainstream provision' (Patel & Fatimilehin, 2005 p.21). The state has been accused of perhaps 'appropriating' such organisations as part of its response to discrimination within our society, and holding an unhelpful assumption that BME voluntary and community organisations are simply how race equality gets 'done' (Afridi, 2009). Hart & Waddingham (2018), in their alternative review of the Mental Health Act report, discuss the state's role and responsibility in developing services that BME communities *want* to use when they're struggling – as opposed to subjecting these groups to coercive treatment at the acute point of care.

While this study was focussed on the experience of participants whose routes into services were via the sectioning process, it would be useful to contemplate what alternative interventions may have meant it did not get to the point where compulsory treatment was proposed. As indicated in the results, psychosis was characterised by a 'Sense of Mistrust' (see section 3.1), and within this, 'Self-Blame' (see section 3.1.2). The former suggests that due to the lack of trust it may be difficult to ascertain what existing interventions participants would have been comfortable/open to approaching for the distress that was being experienced. The subtheme of 'Self-Blame', suggests the women may have held themselves responsible for the distress, thus seeking external support may be considered futile, and perhaps even undeserved. Additionally, the conceptualisation that certain communities are 'hard to reach', tends to locate the problem within certain groups, putting the onus on said communities to make contact with services that do not meet their needs, rather than services adapting their methods to those who need it (Matthews, et al., 2012). While self-referrals to EI services are starting to become more widespread, participants in this study may not have necessarily identified themselves as experiencing a FEP, nor have wanted to engage explicitly with a mental health service. Other ways of engaging/supporting people when at an earlier point of a FEP experience, should be further explored. For example, just as search engines promote the Samaritans[7] information helpline, when someone types in "I am suicidal", it may be worth developing a similar link to a non-stigmatising/supportive website if someone types

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[7] Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide. This includes 24 hour helpline.

in, "I feel like I'm being watched". These may be useful types of algorithms for search engines to consider collaboratively with services. Additionally, in response to the theme, 'Unexpected Support' (see section 3.3.2), where participants spoke of how novel it was to receive help, as they were usually the one caring for others, seeking support may have to be phrased in a way that focusses on others, i.e., 'If it feels like no one believes what is happening to you, and your parents/friends seem to be worried about you, or perhaps not even on your side – do contact us as we are still here to talk.'

Imperative to this would include EI/mental health services engaging with local communities, as well as service-user/survivor-led organisations, which advocate for practices to reduce coercion and ambitious change in service provision (Keating, et al.,, 2003; Gooding, et al., 2018). A key relationship to be further developed may be with university student unions, counsellors, GPs and Improving Access to Psychological Therapies (IAPT[8]) services. For example, equipping some of these professionals with the skills and confidence to work with early signs (self-isolating, expressing anxieties about the intentions of others) and clear advice on how to refer on when necessary, i.e., increase in risk of harm to self/others. Potentially normalising some of the experiences associated with FEP could be trialled, i.e., mental health 'pop-up' events stating the commonality of hearing voices, and how to get help if this is distressing and impacting relationships/studies. Additional sentences on IAPT posters placed on campus such as, 'Do you often have worries that no one believes what's happening to you, and would like to chat to someone about this?', may help women access for anxieties and low mood during much earlier phases. Professionals from EI could also offer 'virtual clinics' to GP practices and other groups, to offer guidance on possible FEP presentations and referral pathways.

Also in relevance to this participant group, help related to particular adversities/trauma could be offered/advertised in relevant work/public spaces, i.e., 'Do you feel that unfair experiences that have hurt you as a child/adult woman, that

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[8] IAPT is a primary care service especially created to provide accessible psychological therapies primarily for those experiencing low mood and anxiety

have been difficult to talk with your family, friends or community, and continue to affect you now? If so, please see our website to see if we can help'. This could possibly lead to a source of resources which reference information/services for sexual trauma, miscarriage, racism, bullying to name a few. Where funding is made available this may even include a holistic assessment of needs, with the clinician trained in holding an intersectional lens, to inform appropriate signposting. This may potentially help Black and Asian women access support for difficulties, prior to the point of needing acute mental healthcare.

Another 'local community' that was demonstrated to be relevant to some of the participants in this study were faith institutions. Byrne et al. (2017) describe how mental health services can engage in joint working with the local Muslim centre, in the hope of 'increasing trust and understanding' and, 'think about ways of working together'. In the 'Hindered Help' subtheme (see section 3.2.2), some of the women described experiences of their faith not being attended to. Thus EI services actively building relationships with local faith groups relevant to the area may help to further support Black and Asian women engaged in these communities, via collaborative working. Psychological interventions which allow space to discuss one's culture, faith and religion, such as the tree of life (Ncube, 2006; Mustafa & Byrne, 2016), may be seen as more acceptable and relevant to this participant group, particularly as psychology has been traditionally quite secular in its' approach (e.g. Bergin, et al., 1996). Service models based on community psychology principles, which aim to build on and strengthen existing community resources, may also lend itself to exploring the development of self-help and peer support groups. Just as 'Hearing Voices' groups exist, it is possible supporting Black and Asian women to create and access such groups if they wish, may help to normalise psychosis and potentially prevent acute presentations at crisis point.

4.3.2.2 Support During a Crisis

While it is advocated that services which help to avoid an acute mental health presentation, should be developed, it is recognised that crises may not always be avoided. The NHS Long Term Plan for Mental Health (2019), refer to aims of developing 'universal mental health crisis care for everyone' (p.70) including alternatives to admissions, such as crisis houses and sanctuaries. The Alternative

Review of the Mental Health Act document, informed predominantly by members of the Hearing Voices Network group, do not call for an absolute end to sectioning, instead advocating for the possibility of a 'short term admission (under 72 hours) in extreme circumstances', as a last resort when all other options are exhausted (Hart & Waddingham, 2018). The report goes on to suggest a proposed culture of alternatives to compulsory admission, which includes the offer of a range of options, that are less restrictive and help keep people safe, as opposed to the often default position of detention under the MHA. This could potentially include Soteria-based houses; mental health services based on a social rather than medical model, created to support clients in the acute phase of psychosis (Calton et al., 2007). The model aims to support clients in finding meaning in their subjective experience of psychosis, using the least amount of restraint and coercion. This approach may be well suited for Black and Asian women who do not conceptualise psychosis as purely an illness, and experiences of coercive approaches, can be retraumatising of past traumas and racial injustice. Soteria homes have been run in the USA Switzerland (Calton et al., 2007; Ciompi & Hoffman, 2004), and while there is interest for such approaches in the UK (see soterianetwork.org.uk), there does not seem to be any funding for developing the model here currently. Other suggestions include drop-in crisis cafes, peer run respite houses, and residential spaces which are open to working with different voices and beliefs. How acceptable any such provision would be dependent on a meaningful commitment to consulting and collaborating with Black and Asian women (and their families) 'to create the services people want to use when they are in distress – rather than continue to create ones they either avoid or run away from' (Hart & Waddingham, 2018). Another model for working with crises presentations based in the community is the Open Dialogue approach (Seikkula et al., 2001a). The intervention utilises a systemic, language-based network approach to mental health care, where all discussions about the person's care happens with them and their support network. The Open Dialogue approach has shown good outcomes for FEP compared to the 'treatment as usual' groups; individuals spent less time in hospital, showed a reduced likelihood of readmission, reported less distressing psychosis-like experiences over time, and were more likely to return to studies and work (Seikkula et al., 2001b; Seikkula et al., 2011; Bergström et al., 2018). The model involves a mobile crisis team responding within 24 hours to a referral, in which a dedicated team of professionals and peer-workers, organise frequent meetings to give all

members a place to speak, so the system does not feel alone in a crisis (Seikkula, & Olson, 2003). Risk is also discussed, and even if admission is indicated, network meetings would continue to run (Razzaque & Stockmann, 2016). Key decisions would occur in meetings all with the service user present; this may help to manage some of the difficult experiences presented in the themes within this study, such as, 'Sense of Mistrust' (see section 4.1.1) and 'Unjustified Consequences' (see section 4.1.2.1). Offering an Open Dialogue intervention may mean Black and Asian women more included in processes and able to develop trusting relationships with their mental health team. This may also help to negate some of the power imbalances that can be quite stark in services for psychosis, especially for racialised woman. It is reported that up to six NHS Trusts have been involved in setting up Open Dialogue services (Razzaque & Stockman, 2016). One Trust has reported positive outcomes so far, such as service users sharing positive experiences of 'equality' with practitioners in the meeting space, however there are also reported difficulties integrating such an approach within the pre-existing NHS mental health service structure (Hendy & Pearson, 2020). Where Open Dialogue has been successful in other parts of the world, it has been part of a larger cultural transformation of services, i.e., embedded within a standard crisis and admissions format, involving intense training/supervision in the Open Dialogue methods for all staff groups (Seikkula, & Olson, 2003). Potential challenges include implementing 'continuity of care' in a fragmented NHS environment, where hierarchy and authority for decision-making in relation to managing acute psychosis is the norm, and where service user, family, and peer worker autonomy and involvement is often unheard of (Razzaque & Stockman, 2016). Exploration into staff and service user views of the Open Dialogue approach being implemented in the UK has been positive, but not without doubts, with one service user stating – 'The National Health Service is built on the foundations of the medical model and needs a radical shift to make room for Open Dialogue' (Razzaque & Wood, 2015). Current service provision in the UK for psychosis views the phenomena within a medicalised and individualised approach, contrary to the Open Dialogue framework. Further evidence of positive outcomes, i.e., the potential effectiveness of the model to improve engagement with individuals and families impacted by FEP, and thus reduce likelihood of forced pathways, may help to justify a radical, less-hierarchical and collaborative, system-wide change in approaching acute psychosis.

4.3.2.3 The Mental Health Act, Psychosis as 'Disorder' and Human Rights

To consider alternatives to the MHA, a discussion about the basis of this unique legislation, I would consider necessary. Spandler & Calton (2009), state that the Act essentially permits professionals to recognise psychosis as an 'illness resulting from a bio-chemical imbalance in the brain' with risks. This conceptualisation is used to justify the state's decision to remove one's rights to liberty, in the name of risk management and enforce compliance of (primarily) medical, 'treatment'. The current medical model underpinning services, seems to convey particular understandings and approaches of psychosis, as necessary and non-negotiable, i.e., 'medication always fixes illness', and others as either secondary, i.e., 'trauma might make the psychosis illness worse', or even absent, i.e., 'spiritual explanations for psychosis are not valid'. However, as this research has shown, Black and Asian women may view their experience within alternative frameworks that go beyond the dominant medical model. The current mental health system's focus on compulsion could be seen to contradict the right to patient choice outlined in the NHS Choice Framework (DHSC, 2020), and on a wider scale, 'psychosis' could be considered a human rights issue, particularly in relation to enforced treatment and choice (Spandler & Calton, 2009). Given that racialised communities are more likely to be sectioned, this may be seen to tie in with human rights violations, in which states are obliged to prohibit discrimination in access to health services, to eliminate racial discrimination, and to guarantee the right of everyone to public healthcare (International Covenant on the Elimination of all forms of Racial Discrimination (ICERD), article 5 – see Banton, 2015). In addition, human rights human rights principles state the need for gender and culture appropriate provision in state services (United Nations, 2000, para.12(c)). For many Black and Asian women accessing mental health services for a FEP, 'recovery' could be seen as much more than a 'personal' one, but also a socio-political one against racism and discrimination (Fernando, 2008).

Spandler & Calton (2009), advocate that a human rights approach to psychosis and the MHA, would involve making explicit the power imbalance that exists within current mental health provision and the public, and how thses ultimately underpin clinical guidelines and policies. There is a call for psychologists to use our knowledge and status as professionals familiar with the social injustice that impacts

our service users, as opposed to simply locating the responsibility for change within the individual (Mallinckrodt et al., 2014; Patel, 2003). Partly informed by Patel's (2013, 2019) papers, in this sense our roles may look like: acknowledging how wider social injustices such as racism and gender discrimination directly impact experience of distress, engaging directly with policymakers about the impact of the MHA in its current form, i.e., how institutional racism and gender discrimination effects Black and Asian female service users, engaging with and contributing to independent think tanks and charities dedicated to shaping policy in health and social care (i.e., King's Fund strand focused on race equality/mental health), creating opportunities for services users to change their material and political realities (i.e., supporting/developing user-friendly complaints procedures, co-creating interventions which may help Black and/or Asian female service users find a 'collective voice', see Holland, 1990), as well as engaging in other forms of social action in which the authority of the Clinical Psychologist role can be used to highlight injustice (i.e., questioning discriminatory practice in sectioning rates, querying the client demographics that are typically referred for therapy, writing advocacy letters to those in power, etc.). At the heart of this would be prioritising the needs explicitly stated by the Black and Asian women accessing psychosis services themselves. As evidenced in the subtheme 'Unexpected Support' (see section 3.3.2), many women may not be aware of their right to be protected against threats to their fundamental human interests, and in addition may be weary of service input. Psychologists may need to think creatively and dedicate time in fostering genuine partnerships, with community groups potentially relevant to this particular participant group, i.e., Breaking Mad, Imkaan, International Society for Psychological and Social approaches to Psychosis UK (ISPS- UK), and the Hearing Voices Network [9] - not just to explore what possible service users might need, but also inform them of their rights to access safety and care from the state.

In addition to collaborations with Black and Asian women accessing services, mental health systems need to work with local authorities, a wide range of agencies and groups involved in planning infrastructure (Kinderman, 2014). Many of the recommendations above require supportive contexts, leadership, buy-in and funding

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[9] www.breakingmad.org, www.imkaan.org.uk, www.ispsuk.org, www.hearing-voices.org

in order to develop and thrive. There is a clear gap in service investment for this group of women. In order to create services Black and Asian women want to use when they are distressed and avoid overuse of the MHA, radical investment and restructure of mental health and its surrounding systems are needed.

4.3.2 Research

This is the first study to consider how Black and Asian women describe experiences of FEP and access to mental health services. The study indicates the need to fund further research which explores social-cultural influences on experiences of psychosis, that goes beyond the medical model. Dominant research into psychosis focussed on biological causes and medical interventions, could be considered a reflection of the mental health system's attachment to Western theories, over others (Fernando, 2017). Additionally, while EI services operate as an ageless service, meaning they serve adults of all ages – not just young adults, I note I did not recruit anyone that was visibly over 35, with only one of the participants reporting they were a parent/mother. Exploring the experiences of Black and Asian women across the age-span, would have further added insight into their needs for a FEP. As this study consisted of participants who were all sectioned prior coming into service, more qualitative work is needed to better understand the experiences of Black and Asian women who access services through less coercive routes, i.e., GP or self-referral pathways. Additionally, this study did not explicitly explore participants' experience of hospital nor Crisis Home Treatment Teams[10], which are likely to also inform participants 'relationship to help' with EI services. . Similarly having a more focussed participant sample, i.e., Black *or* Asian women, would be helpful further research to conduct. The participants were not a homogenous group, even though the commonly used term BME, would imply as such. This study also suggests research which considers other types of discriminatory characteristics and how this may impact/ intersect with the psychosis experience, i.e., disability, sexuality, would be imperative to explore how this is experienced in service interactions. Additionally, perspectives of those in the systems surrounding Black and Asian women, i.e., parents/carers,

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[10] Home Treatment Teams are an NHS secondary care service which support people going through acute crisis, often as an alternative to hospital admission, and often following discharge from an inpatient admission

professionals involved in acute care, including police, EI staff and commissioners, may be helpful to gain an insight into their perspectives on/awareness of, the needs of Black and Asian women diagnosed with FEP. This may help to improve service delivery and inform training.

<u>4.3.3 Policy</u>

Generally in the UK, mental health services, including those serving people presenting with FEP, seem to be underpinned by the medical model. A shift in policy could contribute to challenging dominant discourses such as these, which infer services may have a culture of offering 'paternalistic' rather than 'collaborative' support, with a perceived 'duty of care' to offer medical treatment (BPS, 2014). In support of the findings of this study, it has been suggested that there exists a dichotomy; services approach women's mental health from an individual pathology perspective, whereas service users consistently ask for a more holistic view of their lives (Williams & Scott, 2002). To overcome this fragmented view, service planning and delivery, informed by policy, needs to be firmly rooted in people's social experience. Services must be able to understand and work with the idea that expressions of mental distress and requests for help, will be affected by a range of aspects of women's identity, including their race, age and social class, and their previous experiences, including any previous stigmatising experiences when seeking support. This includes addressing women's needs for safety, such as those who have experienced traumas at the hands of perpetrators and also of the state. Developing policies for mental health services, which are underpinned by trauma-informed approaches acknowledging Black and Asian women's need for safety, collaboration and empowerment, are also strongly advocated for (Sweeney et al., 2016).

It has been proposed that discriminatory attitudes towards women's needs in services, are likely embedded in the structures and processes of most mental health services, rather than individual staff (Raine, 2000). While wider governmental initiatives such as the 'Time to Change' campaign aims to destigmatise mental health difficulties, they may in fact be reinforcing ideas of pathology (Malla et al., 2015) and the responsibility of managing difficulties is located solely in the individual

(see subtheme: self-blame). It is suggested that psychologists should be involved in working towards structural-level changes to promote social justice and equity for women from marginalised backgrounds accessing mental health services (Rosenthal, 2016). By acknowledging the material and psychological challenges Black and Asian women face, policy changes could feed into efforts to raise consciousness that presentations of psychosis are often meaningfully linked by service users to their lived experience of the world, i.e., adverse past experiences, discrimination, racism, ongoing material difficulties. This may help to validate Black and Asian women's experiences, reduce potential experiences of isolation, guilt, shame, and also possibly improve wider social acceptance of FEP.

Policy guidelines should aim to facilitate interventions that are truly preventative by addressing the known psychological and social factors that contribute to distress, such as poverty and abuse, and reducing inequalities across society (Wilkinson & Pickett, 2010). Funding, political interests and a focus on the illness model of psychosis may have prevented this so far. Black and Asian women in the UK, compared to their white counterparts, are reported to be more likely living in poverty, be unemployed/in lower positions even when acquired equivalent qualifications, and be subjected to both racism and sexual discrimination in the workplace (Runnymede Trust 2012; Alexander, et al., 2016; McGregor-Smith, 2017). Furthermore, women from marginalised backgrounds diagnosed with mental health difficulties, are rarely consulted when policies and services are determined (Sosulski, et al., 2010). 'Experts by Experience' such as Black and Asian women labelled with FEP, should be invited to be involved in all aspects of service development and policy (Millar et al., 2015). Clinical Psychologists may also have a role in contributing to government think tanks about these issues. Additionally contributing to, collaborating or being part of the Department Of Health and Social Care's Women's Mental Health Taskforce to advocate for intersectional issues, as well as in the development of the Mental Health Crisis Care Concordat - which brings together bodies involved in health, policing, social care, housing, local government and third sector to think about acute care – would be useful in highlighting and advocating for change for Black and Asian women accessing acute mental healthcare on a national level.

4.4 Assessment of research quality

Yardley's (2000) suggested criteria for assessing qualitative research were addressed. The criteria was determined to be consistent with the study's aims and critical realist epistemology (Willig, 2013) and detailed below.

4.4.1. Sensitivity to context

The initial background research into existing conceptualisations and service frameworks for psychosis, as well as the stereotypes that may be held about ethnically marginalised women in the West, spoke to the wider context this research was set in. This was followed by a scoping review of the existing literature around Black and Asian women's experiences of psychosis and services, which indicated a gap in the research. Existing qualitative studies had not previously focussed on the experiences of participants that were both female AND from racialised backgrounds, accessing services for the first time. This study attempted to attend to participants' cultural and socio-economic contexts, when analysing the data. I was aware that I specifically interviewed participants from London boroughs of high social deprivation, and how this may explain some of the findings in the data, i.e., appreciation of the attention to their social and financial needs by services.

I was aware that as the researcher and mental health professional, I likely held more 'power' and 'control' over the interview and research process. Attempts to decrease this imbalance included: the decision to not use a strictly structured questionnaire; being flexible to when and where potential participants could meet; using the same chairs; allowing space for further questions from the participant; as well as explaining the right to withdraw their data at any point in the research process. I also ensured to only use the terms that they used to describe their experience, i.e., avoiding the use of 'psychosis' if they did not say this, as well as being transparent in how this research would benefit myself .i.e. for qualification.

4.4.2. Commitment and Rigour

Commitment can be shown by the researcher through in-depth engagement with the study topic, analytical process and development of methodological competence

(Yardley, 2000). I embarked on a background and literature review of the study topics, attempting for this to be as thorough as possible within the time frame available. I created engaging powerpoint presentations and posters about the study to present to service user research panels and EI services, with the aim of receiving their feedback and aid with participant recruitment.

As for methodological competence, I immersed myself in the data by transcribing all interviews myself. Rigour was achieved through developing competence in conducting thematic analysis; I spent three months analysing the data, using Braun and Clarke's (2006) process (see Methodology section).

4.4.3. Coherence and transparency

Coherence describes the 'fit' between the research questions, epistemological stance, and choice of methodology and analysis (Yardley, 2000). From a critical realist stance, a thematic analysis of the interview data, felt well suited to answer the broad research questions. In terms of transparency, each aspect of the data collection process through to analysis has been documented including the development of codes and how these led to the themes (see section 2.6).I have presented interview extracts to ensure accountability to the analytic procedure, as well as allowing readers to recognise for themselves the potential patterns and findings identified from the data. I have also detailed how my own assumptions, intentions and actions, may have impacted the research process and findings (see section 4.6).

4.4.4. Impact and importance

This is the first qualitative study to explore how Black and Asian women may understand the experience of FEP in the UK, alongside offering novel insights into their experience of accessing services. Based on the findings, efforts were made to suggest practical recommendations which could be applied at multiple levels, such as for clinical teams, additional statutory services, future research, policymakers, and other Black and Asian women. To ensure impact there are plans to disseminate the findings within the host trusts, in peer-reviewed papers and in mediums suitable for

practitioners and the wider public – especially women from marginalised groups as recommended by participant themselves (Appendix W).

In addition to the theoretical and practical importance of the study, as a qualitative researcher I was also concerned with its socio-cultural impact (Burman & Parker, 1993). Qualitative studies may sometimes complement quantitative studies by highlighting socio-cultural processes which explain the effects documented by quantitative research (Yardley, 2000). It could be said this study may offer some insights into findings from epidemiological studies which infer women from marginalised backgrounds given a FEP label are diagnosed at higher rates than other groups, and also more likely to access psychosis services via crisis pathways. Whether the findings and recommendations can improve the experiences of Black and Asian women receiving a diagnosis of FEP and their experience with services, will tell how useful this study is.

4.5 Study limitations

4.5.1 Participant Sample

A small sample was recruited in line with the aims of the study, suitable for collecting rich data about complex phenomena from a marginalised group of participants (Morse, 2015). While the study may seem to reflect only a few people's lived experience, a small sample size allowed sufficient time to commit to a detailed analysis of the interview data. A larger sample size, although more broad, may not necessarily have better captured the richness of the data or improved the findings' meaningfulness (Smith, Flowers & Larkin, 2009).

It could be said that the study's credibility was impacted by biases in who agreed to take part in the research. The women who did decide to take part may have: been those who were most interested in discussing the study's issues; had good relationships with staff who informed them about the study; those who were in less distress in relation to their psychosis experience, quite possibly those who had a more positive experience of EI Service. This was potentially evidenced in the

findings where most women reported satisfaction with the support they received from the team. The contributions of women with less positive interactions of services and more distressing presentations of psychosis, potentially may not be included in this research. That being said, there were a variety of challenging topics expressed in participants' interviews, including negative interactions with the police, understandings of psychosis which were not dominant in services and ongoing experiences of psychosis. This may suggest that participants felt comfortable to share to some extent. Potentially offering telephone/online interviews may have helped, and lessened my affiliation with the NHS.

Other limitations of the participant sample, involve issues around race, ethnicity, culture and language. The decision to interview both Black and Asian women together was based theoretically on the lack of research on either of these groups' experiences of FEP, their shared experiences of marginalisation, and to practically improve the ease of recruitment and access to participants. However, by doing so, I may inadvertently be perpetuating ideas that Black and Asian women are a homogenous group, just as many policies and services, within the NHS and beyond, refer to "BME groups" collectively. There may be problematically unknowingly implying that all non-white groups have the same needs and are impacted by structural discrimination and racism in the same way. While both Black and Asian women may have a similar experience of being impacted by racialised discourses, they do hold different social positions. In particular relevance to this study's topic, the background research suggests Black women are more likely to receive a psychosis label and experience more coercive mental health interventions than any other group of women. Furthermore, although this study endeavoured to recruit an equal number from each 'racial group', more participants were from Black backgrounds, suggesting these women's' experiences may be more represented in the findings. In addition, this study's lack of use of interpreters to explore the experiences of non-English speaking women – possibly also with refugee or asylum-seeking status – is a drawback of the research. By not taking into account the experiences of Black and Asian women who do not communicate primarily in the language this research is conducted in, may reflect wider inequalities and inequities to care potentially present in services for these groups. Despite these limitations, this does not invalidate the accounts of the participants who did take part. In addition to this being the first study

to consider how both race and female gender inform service users' lived experience of psychosis and services, the diversity across the accounts gave rise to rich data.

4.5.2 Study Design

This study employed cross-sectional semi-structured interviews to gather data, which relied on retrospective accounts of initial encounters with services, as well as past distressing and confusing events. While a longitudinal observation may have potentially offered me the opportunity to collect 'more objective' data around the topics I was exploring, for example, potentially observing the sectioning process or appointments with the EI team, this would not have been feasible within the time frame, nor felt ethical or necessary. Holding a critical realist stance, meant I understood participants' accounts as a reflection of the 'truth', whilst also attending to the psychological, social and cultural contexts that shape how these are made sense of. Therefore, this epistemological positioning, alongside my study's aims of exploring subjective experiences from women not traditionally included in research, felt well suited to a semi-structured interview study design. The potentially distressing and highly emotive topics this study explored through the interviews, may have felt particularly intrusive for participants taking part. A focus group may have helped the participants feel more comfortable sharing, discover others have similar experiences, and recognise their views as legitimate and valid; benefits especially described for using this methodology with women from marginalised groups (Rodriguez et al., 2011). While this may have serviced a dual function of potentially adding further richness to the data, as well as possibly fostering feelings of empowerment, I would be concerned that some of the women may have felt restricted to speak as freely as they did in individual interviews. Some of the reasons include many of the women had diverse views about the conceptualisations of psychosis, some spoke about psychosis being in the past, while others reported it was an ongoing experience – participants' may have felt wary of sharing experiences that differed from others. In addition participants' proficiency in English varied, and this may have had an impact on the length of time focus groups would take.

<u>4.5.3 Service User/Participant Involvement</u>

While this study's proposal was presented to a research panel of service users and carers, to access consultation before data collection began, I did not have any active service user involvement beyond this. This would have offered a valuable contribution to ensuring the relevance of the research. Difficulties in the recruitment process itself, suggest meaningful co-production would have required extensive planning and commitment - somewhat restricted by the academic requirements and timescale for the study, Other considerations may include, proportionately funding co-researchers for their time as experts-by-experience and designing protocols supportive of their wellbeing. However, this is not an excuse, and much further thinking is needed to include and support marginalised voices in short scale research design, i.e., research in relation to academic qualification.

As the analysis is a synthesis of all the interview data, interpreted using selected theoretical frameworks and my own subjective lens, I could conclude that a participant is unlikely to recognise their own story clearly in the combined text, and thus I am the best judge of my analytical findings (Morse, 2015). The credibility of the study's findings may have been further enhanced by member-validation, particularly since the voices of this group of participants whose have reportedly traditionally been excluded, silenced and dismissed both in services and previous research.

4.6 Reflexivity

Reflexivity is an ongoing process (Dowling, 2006) and considered as central to the development of this study and its' reported findings. It is understood as the researcher's interrogation of their own influences on knowledge production and claims (Willig, 2013). It is unlikely that we are always aware of the range of factors that influence our experience as researchers (Harper, 2011), thus dedicated time to attend to this after the interviews and analysis had been completed felt crucial to explore.

As mentioned in the methodology section, the main explicit similarities between myself and the participant sample, were the shared identities of gender and racialised background. I wonder if that allowed women to feel more comfortable to speak about certain experiences, i.e., sexual trauma. As I also shared the identity of 'ethnic minority' in the UK, this may have allowed women to speak more freely to topics directly related to ethnicity or culture (Papadopoulos & Lees, 2002). However, I was aware that appearance wise I present as a lighter-skinned woman of East Asian descent, and therefore did not visibly seem to be an exact 'ethnic match' with the participants. This visible difference was most marked between myself and the Black female participants. I wondered if it felt uncomfortable – and even particularly painful - for some of the Black female participants to speak to a researcher from a different racial background who would very likely not have faced the same severity of racialised-gendered injustices. This may also extend somewhat in a different capacity to participants of South Asian descent, for example, I noted one participant, made a reference to 'people in my community', not knowing that I too was part of the same community. I wonder if this had any impact on what and how women chose to speak with me, and whether having researchers visibly from Black and South Asian backgrounds may help to manage this in some ways and reduce the power differential. That being said, this should not be tokenistic, may come with its own difficulties for researchers themselves, and issues of racial injustice is everyone's 'business' and responsibility. It could also be possible participants may have felt more comfortable speaking about aspects of their experience, as assumed I was not part of the cultural groups they referred to.

As someone who has not been diagnosed with FEP or accessed acute mental health services via coercive pathways, I was aware I was in a relative position of power compared to the participants. Although efforts were made to reduce the imbalance as much as feasibly possible, i.e., flexibility in interview times, offering a small gesture of appreciation, I did feel some uneasiness that the women shared intimate details of their experiences – and although gave consent – this data would ultimately contribute to my career progression. This has made me more determined to disseminate the findings in ways that appeal both to professional systems (i.e., peer-

reviewed papers, NHS trusts), but also using methods that are easily accessible to/engage the wider public, i.e., via a short animation, a website (see Appendix W).

4.6.2 Interviews

The use of semi-structured allowed for some flexibility in interviews (However, it is possible that at times, women may have wanted to talk more about certain aspects of their experience, but due to fears about going 'off topic', I may have limited these discussions, instead focussing on questions from the planned interview schedule. While it felt important to gather data thought to more likely to answer the research questions, I wonder if at times I may have perpetuated past experiences of being dismissed or silenced by those in power, as described in the women's accounts. Furthermore, as interviews were carried out in the EI Service offices, this may have made it difficult for them to speak more critically about the care they received, as well as having an awareness that I was employed by the NHS while conducting the study. This may have prevented participants from discussing experiences or beliefs that may be viewed by mental health professionals as 'lacking insight'. I note many participants spoke highly of EI services, but negatively of other services - and there may have been a pressure to provide 'socially desirable responses' due to the setting. However, it seems an array of views were shared that did not necessarily align with the medical model nor always speak highly of services, suggesting participants did feel somewhat comfortable to speak truthfully. Participants were offered the choice to be interviewed at the university base as an alternative, but they decided to be seen at their team's offices, presumably for reasons of convenience.

4.6.3 Analysis

The analysis was often emotionally difficult to engage with. Even from the beginning stages of the analysis, i.e., interview data collection and transcription, immersion in participants' accounts at times was upsetting. Primarily, this was linked to women's descriptions of sexual trauma. While I anticipated some of the descriptions of distress associated with a psychosis diagnosis from previous clinical work, I found it particularly difficult engaging with the topic of sexual assault. During some revisions of the themes (Appendix U), I noticed I had completely omitted any reference to

trauma. It appeared that I may have unconsciously limited the voices of the participants, in order to avoid discomfort and protect myself from experiencing and speaking to their pain. Throughout the analytic procedure I had to question whose interests my interpretations were made, which resulted in refining themes and the selected quotes to include in the analysis. In addition, I reflected on whether the choice to highlight unfair treatment from the police experienced by the Black and Asian women (see subtheme: unjustified consequences), was primarily informed by personal political/ideological beliefs about police 'brutality' and institutional racism, as well as past research I had read about strained relationships with black communities and statutory services, i.e., 'circles of fear' (Keating et al., 2002). It could be possible, that a grounded theory methodological approach, where literature is not reviewed beforehand, may have helped to avoid this dilemma. However, I took the position that as the researcher, I am part of the research process and part of the findings that get reported. There were choices I made about what themes to report on and what I saw was important, and I take ownership of the choices I made in order to answer the research questions, led by the research data (Liamputtong & Ezzy, 2005). To me police intervention seemed to be a significant part of many womens' journeys to EI services, while I feared possibly going 'against the status quo', it felt more important to shed light on and potentially discriminatory and oppressive practices and the impact it had on Black and Asian women experiencing First Episode Psychosis. It has been said to, "treat the process of reflexivity as an opportunity to enrich your own research and improve the lives of people" (van der Riet, 2012).

4.6.4 Epistemological reflexivity

As well as my own assumptions and positions, there are methodological and epistemological assumptions which have influenced the findings from this research (Willig, 2013). As a trainee clinical psychologist with an interest in critical psychology and social constructionist approaches, I hold a view that the wider social context has relevance to the mental health difficulties people experience and present with. Taking a critical realist epistemology allowed me to take what people said as a reflection of their own thoughts and experiences, whilst exploring how this may have been influenced by wider social and cultural context. Despite holding the view that certain concepts such as psychosis, race and gender, are not definitive, objective

constructs with biological bases, I did not adopt a social constructionist position. A critical realist position was felt to be the right selection; FEP can have very real material and social consequences for Black and Asian women accessing mental health services, as evidenced in this study - even if the labels themselves are not considered to be "real" or socially constructed.

<u>4.6.5 The Research Topics</u>

When I embarked on this study I set out to amplify the voices of Black and Asian women, regarding experiences of a FEP diagnosis – a presentation rarely explored in existing literature with this particular group. I felt I held some level of responsibility to highlight marginalised experiences, particularly as a woman of mixed-Asian descent, embarking on a funded clinical psychology doctoral programme, known for its competitiveness, as well as disproportionate access to the profession for Black, Asian and Minority Ethnic groups, and use of Eurocentric therapeutic models. However, I think this did put a lot of pressure on me at times, to "get things right", i.e., to not perpetuate racist discourses which portray Black, Asian and Minority ethnic groups as 'the problematic other' (Kalathil & Faulkner, 2015), as well as fears of contradicting models and ways of thinking currently dominant in mental health services and associated systems. I found myself occasionally paralysed by the weight of the research topics, including the multiple experiences of injustice the participants in this study recalled in their accounts. I often felt I had taken on the responsibility of 'trying to solve' a complex systemic problem; an impossible task, way beyond the scope of this thesis and my own capabilities. I wondered if this is sometimes why people choose not to explore topics around power, injustice and inequality. Through the use of supervision, personal therapy and discussions with peers, I came to understand this research as a way of simply 'opening up' important discussions about women, race and mental health services, often neglected in the field of Clinical Psychology.

4.7 Final Reflections

To summarise, this study has sought to explore the experiences of Black and Asian women diagnosed with FEP, and sectioned on their pathway to accessing services

in the UK. Psychosis was an experience characterised by a mistrust of the self and others, understood to involve a presentation of particular behaviours, and explained by multiple models, not always favoured by services. It is proposed racialised-gendered discourses have an impact on both seeking help from services, and how services give help. As Patel (2003) writes, there is a role for psychology in challenging practices and providing healthcare in a way which does not neglect socio-political contexts of conflicts and reinforce inequalities. This study reinforces the call for services to attend to current practices around risk management and mental health interventions for racialised communities. The findings indicate a need for the mental health system, police force, and, field of clinical psychology to engage with intersectionality at multiple levels; Black and Asian women accessing services for psychosis through forced pathways, deserve for their stories to be heard, by psychologists, systems, and a society, that are willing to listen, reflect, and respond accordingly.

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6. APPENDICES

APPENDIX A: DSM-V diagnostic criteria for schizophrenia spectrum and other psychotic disorders – most common symptoms
(APA, 2013)

1. Two or more of the following for at least a one-month (or longer) period of time, and at least one of them must be 1, 2, or 3:
- Delusions
- Hallucinations
- Disorganised speech
- Grossly disorganized or catatonic behavior
- Negative symptoms, such as diminished emotional expression

o Impairment in one of the major areas of functioning for a significant period of time since the onset of the disturbance: Work, interpersonal relations, or self-care.
o The disturbance is not caused by the effects of a substance or another medical condition
o If there is a history of autism spectrum disorder or a communication disorder (childhood onset), the diagnosis of schizophrenia is only made if prominent delusions or hallucinations, along with other symptoms, are present for at least one month

APPENDIX B: Scoping Review One Database Search Strategy - Black and Asian Women's Conceptualisations of Psychosis

Databases:
Academic Search Complete, CINAHL Plus, PsycInfo, PsycArticles

Search Terms*:
Psychosis (n= 579, 674) AND race (n= 24,986) AND female (n= 10,675) AND explanatory model (n= 673)

Limiters:
None

Inclusion Criteria
1) English written
2) Adult only (>18)
3) Qualitative Methodology

Exclusion Criteria:
1) Quantitative methodology (n= 546)
2) Book reviews (n=2)

Remaining **127** abstracts were screened, informed by final exclusion criteria:
3) People with a diagnosis of psychosis not included in study (n= 58)
4) Study focusing primarily on caregiver experience (n= 23)
5) Poetry, fiction or other artistic literature (0)
6) Duplicates (n =5)

Studies where previous search criteria still not met, i.e, qualitative, must include female participants (n= 38)

Results remaining: 3

Grey Literature
Search via Google Scholar and Reference section of papers (n=2)

Final Number of Journal Articles: 5

* Specific terms used:
(psychosis OR "first episode psychosis" OR "early phase psychosis" OR "first presentation psychosis" OR "first episode of psychotic illness" OR "early psychosis" OR "first onset psychosis" OR "psychoses" OR "psychotic" OR "schizophren*") **AND**

("BME" OR "BAME" OR "minority ethnic" OR "black" OR "African American" OR "African Caribbean" OR "Asian" OR "Asian" OR "south Asian" OR "ethnicity" OR "ethnic minorit*" OR OR "race" OR "culture" OR "black and minority ethnic" OR "migrant" OR "immigrant") **AND**

("wom?n" OR "female*" OR "gender difference*s" OR "gender") **AND**

("conceptualisation" OR "construction" OR "narrative" OR "meaning" OR "discourse" OR "explanation" or "belief" or "explanatory model*")

APPENDIX C: Scoping Review Two Database Search Strategy - Women's Experiences of Psychosis Services

Databases:
Academic Search Complete, CINAHL Plus, PsycInfo, PsycArticles

Search Terms*:
Psychosis (n= 579, 674) AND female (n= 169,225) AND mental health services (n= 14,154)

Limiters:
None

Inclusion Criteria
   1) English written
   2) Adult only (>18)
   3) Qualitative Methodology
Exclusion Criteria:
   1) Quantitative methodology (n= 11,570)
   2) Book reviews (n=214)

Remaining 2585 – limiters further applied in relation to gender, and abstracts screened for relevance:
   3) People with a diagnosis of psychosis not included in study (n= 1242)
   4) Study focusing primarily on caregiver experience (n= 427)
   5) Poetry, fiction or other artistic literature (22)
   6) Duplicates (n =0)

Studies where previous search criteria still not met, i.e, qualitative, must include female participants (n= 889)

Results remaining: 2

Grey Literature
Search via Google Scholar and Reference section of papers (n=1)

Final Number of Journal Articles: 3

* Specific terms used:
(psychosis OR "first episode psychosis" OR "early phase psychosis" OR "early psychosis" OR "first presentation psychosis" OR "first episode of psychotic illness" OR "early psychosis" OR "first onset psychosis" OR "psychoses" OR "psychotic" OR "schizophren*") **AND**

("wom?n" OR "female*" OR "gender difference*s" OR "gender") **AND**

("Early Intervention Services" OR "Early Intervention Psychiatric Services" OR "Early intervention in psychosis services" OR "mental health services")

APPENDIX D: Scoping Review Three Database Search Strategy - Black and Asian groups' Experiences of Psychosis Services

Databases:
Academic Search Complete, CINAHL Plus, PsycInfo, PsycArticles

Search Terms*:
Psychosis (n= 579, 674) AND race (n= 24,986) AND mental health services (n=3200)

Limiters:
None

Inclusion Criteria
   4) English written
   5) Adult only (>18)

Exclusion Criteria:
   7) Quantitative methodology (n= 2846)
   8) Book reviews (n=1)

Remaining 354 abstracts were screened, informed by final exclusion criteria:
   9) People with a diagnosis of psychosis not included in study (65)
   10) Study focusing primarily on caregiver experience (n= 52)
   11) Poetry, fiction or other artistic literature (0)
   12) Duplicates (n =0)

Studies where previous search criteria still not met, i.e, qualitative, (n= 233)
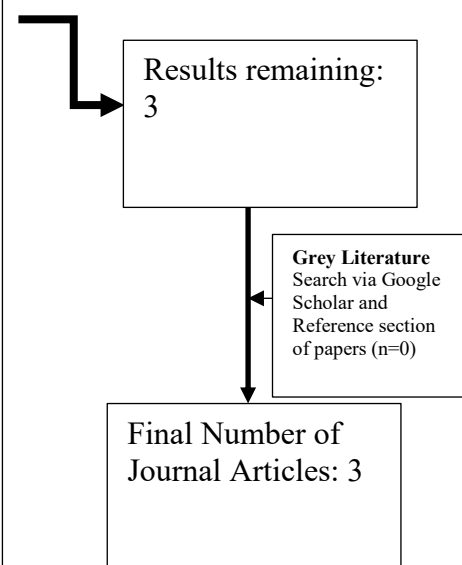
Results remaining: 3

Grey Literature
Search via Google Scholar and Reference section of papers (n=0)

Final Number of Journal Articles: 3
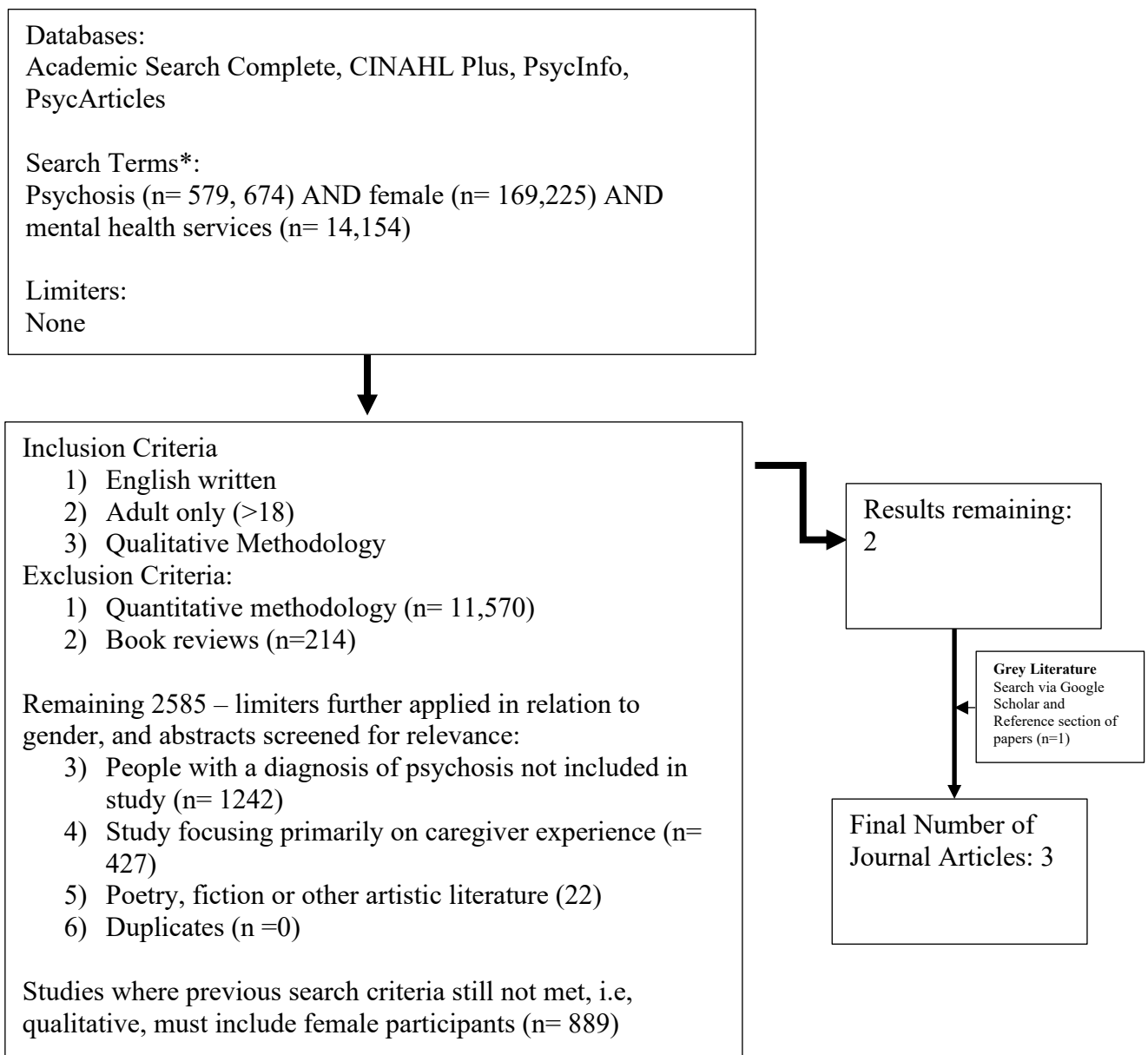
* Specific terms used:
(psychosis OR "first episode psychosis" OR "early phase psychosis" OR "early psychosis" OR "first presentation psychosis" OR "first episode of psychotic illness" OR "early psychosis" OR "first onset psychosis" OR "psychoses" OR "psychotic" OR "schizophren*") **AND**

("BME" OR "BAME" OR "minority ethnic" OR "black" OR "African American" OR "African Caribbean" OR "Asian" OR "Asian" OR "south Asian" OR "ethnicity" OR "ethnic minorit*" OR OR "race" OR "culture" OR "black and minority ethnic" OR "migrant" OR "immigrant") **AND**

("Early Intervention Services" OR "Early Intervention Psychiatric Services" OR "Early intervention in psychosis services" OR "mental health services"

Slide 1

MAKING SENSE OF PSYCHOSIS
AS A WOMAN OF COLOUR
Jennifer Nicholas | Trainee Clinical Psychologist, UEL
EIS - July 2018

Slide 2

The Project

I am interested in:

How do Black & Asian women **understand** their experience of "Psychosis"?

How do Black & Asian women make sense of why they were **hospitalised** for "Psychosis"?

How do these experiences shape their relationships with NHS "Early Intervention for Psychosis" **services**?

Slide 3

Early Intervention for Psychosis Services:

- For those who engage with the service:
  - Increased **employment**
  - Shorter **hospital** admissions
  - Lower **suicide** rates
  - Fewer '**negative** symptoms' of psychosis
  - Less likely to *relapse*/have another 'psychotic episode'

Petersen et al., 2005; Park et al., 2016

Slide 4

"PSYCHOSIS"

What is the most popular "explanation" about psychosis in this team?

Who taught this explanation? Where did it come from?

How does this explanation impact you? How do you benefit from it?

Do you think service users agree with this explanation? Why/Why Not?

What other explanations might be silenced/ignored, if we only focussed on this main one?

Slide 5

" WHY FOCUS ON BLACK & ASIAN WOMEN? "

Slide 6

Ethnic differences for women admitted to Psychiatric hospitals in Camden, Islington & Lambeth

(Lawlor et al., 2012)

Ethnic background				
White British(n = 146)	White other(n = 45)	Black Caribbean (n = 26)	Black African(n = 41)	Black other(n = 29)

Slide 7

What percentage of women from white British backgrounds were sectioned?

13%
a

32%
b

47%
c
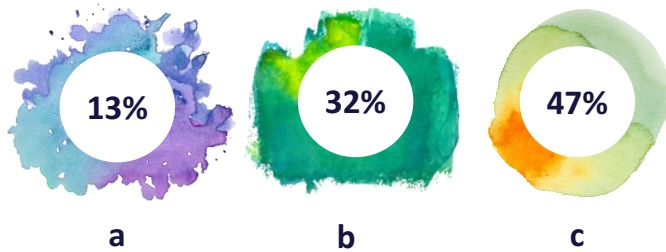
Slide 8

What percentage of women from black African backgrounds were sectioned?

25%
a

48%
b

67%
c

Slide 9

13% of white British women were admitted **COMPULSORILY** to the ward, compared to **48%** of black African women

Ethnic difference for women detained under the Mental Health Act in Camden, Islington & Lambeth

Lawlor et al., 2012
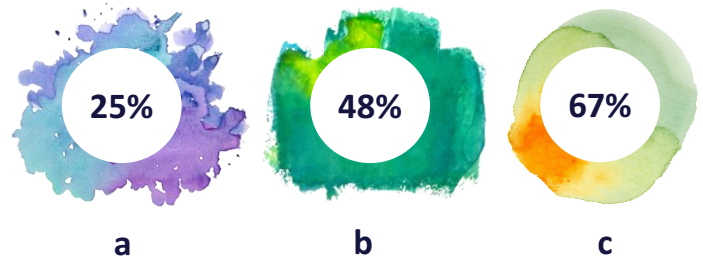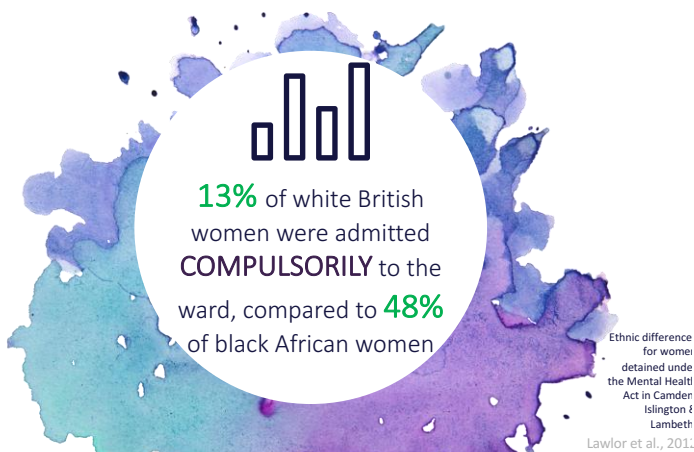
Slide 10

Ethnic differences for women detained under the Mental Health Act in Camden, Islington & Lambeth

Ethnic background

White British (n = 146)	White other (n = 45)	Black Caribbean (n = 26)	Black African (n = 41)	Black other (n = 29)
13%	36%	42%	48%	45%

Slide 11

Why focus on race & gender?

High Sectioning Rates

In Early Intervention for Psychosis Services:

Women are more likely to be forcibly hospitalised, compared to **men**.

Black African women more likely to be forcibly hospitalised, compared to **White** British women

Tseliou et al., 2017
Mann et al., 2014

Underrepresented in Research

Studies into Psychosis are typically focused on:

Men

Studies into Psychosis do **NOT** typically focus on:

Women AND Race together

Aitken, 1996
Longenecker et al., 2010

Slide 12

How does our identity shape us?

Gender
Race
Religion
Age
Ability
Class
Culture
Education
Ethnicity
Spirituality
Sexual orientation

1. **What part of your identity do you think people first notice about you?**

2. **What part of other people's identities do you notice first?**

3. **What part of your identity (or top 3) is the most important to you? Why?**

4. **What part of your identity do you see having the most effect on your interactions with service users?**

Slide 13

Why focus on race & gender?

Inequality

Black & Asian women in the UK, compared to white women are more likely to be:

- Living in **poverty**
- **Lone parents**
- **Unemployed**
- Victims of **racism**
- Victims of **violence**

Links have been found between psychosis & social inequality

Runnymede Trust, 2017
Ross et al, 1983

Stereotypes

"Asian women are **oppressed**"
"Asian (Muslim) women are **dangerous**"

"**Angry** black woman"
"**Strong** black woman"

Stereotypes can shape:
- How women see themselves
- Decisions on engaging with services
- How services see/treat women

Scharf, 2011
Woods-Giscombe, 2010
Donovan et al, 2014

Slide 14

HOW MIGHT THIS RESEARCH HELP?

1. Make the experiences of Black & Asian women more **visible**

2. **Service users'** perspectives on "psychosis"

3. Explore neglected aspects of **mental health care** important to this group

4. Understand what **social factors** may influence why someone may/may not seek help for "psychosis"

5. Explore the **experience** of Early Intervention Services as perceived by Black and Asian Women

6. Inform recommendations in relation to matters around the **Mental Health Act,** Race and Gender

7. Contribute to creating fairer & less forceful **pathways to mental health care** for Black & Asian women

Slide 15

Research Process

Research Proposal → Submit NHS Ethics → Interview 8-10 Women → Analyse Interviews → Share Findings

Complete by November 2018

Slide 16

Participants I'm looking for:

Female

Black, Asian and/or Mixed Heritage

Sectioned in the last 12 months

Slide 17

Recruitment Process

1) Study presented to EIS Team

2) Suitable person from caseload identified by EIS Key Worker

Best way to do this? CC meet with me to go through caseload? Frequency of reminders?

3) Key Worker presents poster/ leaflet/ information sheet to person

On an appointment day? What if no appointment soon?

4) Key Worker informs ▬▬▬ myself

5) I call/email/meet Person to explain study & answer queries

Come on an appointment day?

6) If consent given, appointment arranged

What may encourage/ put off people taking part?

7) Person attends & invited to read / sign consent sheet

8) Person takes part in one hour interview

9) Person receives £10 gift voucher

10) Person has right to withdraw their interview

Slide 18

Any Questions?

Thank You!

APPENDIX F: Participant Information Poster

APPENDIX G: Participant Information Sheet

Participant Information Sheet

Black and Asian Women's Conceptualisations of Psychosis and Compulsory Admission within an Early Intervention Service

We would like to invite you to participate in this study. Before deciding whether or not you would like to participate please take time to read the following information carefully.

What am I being asked to do?
You are being invited to take part in a research study exploring the experiences of Black and Asian women who have previously been sectioned and are now accessing Early Intervention Services.

People may have lots of different experiences that mean they might seek support from an Early Intervention in Psychosis service. Some examples include: Low mood, difficulties with thinking and concentrating, changes to behaviour such as lacking motivation or interest in things, hearing voices or sensing things that others do not, and holding strong beliefs that many others do not share.

What is the purpose of the study?
The purpose of the study is to gain a richer understanding of what being compulsorily admitted to hospital for your experience was like and how this may have shaped your relationship with Early Intervention services.

We are aware being hospitalised for your beliefs can be an upsetting experience and previous research appears not to have asked how women from certain backgrounds view this. We hope that this research will contribute to the knowledge of personal experience to the field and improve future service planning for women from Black and Asian backgrounds.

The study is being conducted as part the lead researcher obtaining a Doctorate qualification in Clinical Psychology at the University of East London.

Why have I been asked to take part?
We are inviting you as you have first-hand experience of being compulsorily admitted to hospital and are currently attending an Early Intervention Service. You have also been identified by your team as a woman from a Black, Asian and/or Mixed Heritage background.

What will happen to me if I decide to take part?
The study involves meeting with a researcher to complete a semi-structured interview, which should take around 60 minutes to complete. The questions you will be asked will be about your understanding of your admission to hospital and experiences with the Early Intervention Service. Your responses will not be shared with your team. You will also be asked how being a woman from a Black or Asian background may or may not have contributed to your experience.

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The lead researcher will contact you within two weeks of receiving this information, to see if you are interested in taking part. An appointment will be arranged to meet in a private room at the Early Intervention service you currently attend. A clinician from the team will meet you briefly before the interview, to ensure you have full capacity to agree to take part.

We will be asking for your consent to audio-record the interview and for anonymised quotations to be used in research publications and training. At no point will your name or identifiable be disclosed with your responses.

Do I have to take part?
No, you do not have to participate in this research. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw your contribution without giving a reason and the care you receive will not be affected. We ask that if you wish to withdraw to kindly let the researcher know by *1st of March 2019.*

Will my information be confidential?
All of your responses will be confidential and anonymous. A member of staff involved in your care at the Early Intervention Service will be aware of your involvement in the research, but they will not have access to any information you share with the researcher. With your consent, your GP will be notified of your participation in the research.

Interview scripts will be stored on a password protected computer and will be identifiable only by a number, not by your name. If you revealed an occurrence of harm or risk of harm to yourself or anyone else, the interview would be stopped and it would be necessary to breach confidentiality by referring the matter to an appropriate authority. We would contact the clinical staff relevant to your care following discussion with you to ensure you receive support to keep safe.

<div style="border:1px solid">

General Data Protection Regulation for health and care research information:

The University of East London is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of East London will keep identifiable information about you for 5 years after the study has finished.

███████████████ will collect some information from your records for this research study in accordance with our instructions, i.e. when you were sectioned. ██████████████████ will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of East London and regulatory organisations may look at your research records to check the accuracy of the research study.

The only people from the University of East London who will have access to information that identifies you will be myself, Jennifer Nicholas, the researcher, and my supervPSr Dr Chanelle Myrie. The University of East London will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

Your rights to access, change or move your information are limited after 1st of March 2019, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting *Catherine Fieulleteau [C.fieulleteau@uel.ac.uk].*

</div>

What are the possible risks of taking part?
We are aware that discussing your experience of 'psychosis', compulsory admission and mental health services, may be quite sensitive topics and potentially upsetting. The researchers would encourage potential participants to consider this and to ask us any questions prior to taking part. You can refuse to answer any questions, take breaks and have the right withdraw from the interview during any stage, with no impact on your clinical care.

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If discussions do lead to significant distress, the interview would be stopped straightaway and you would be referred to an appropriate professional for help.

You will also be signposted towards avenues to raise complaints about the treatment you received in hospital/Early Intervention Services, or distress caused by the research itself, should you wish to do so.

What are the possible benefits of taking part?
Taking part in the research may not be of immediate benefit, but could benefit service users accessing mental health services in the future. All participants will however receive a £10 Love2Shop gift voucher as a gesture and travel reimbursements can be arranged on request.

We hope taking part in this research will offer a space to talk openly about your experiences, which some participants may find beneficial. It is also hoped that the understandings offered by participants for this research will help to inform how mental health services and the wider community can better meet the needs of women from similar backgrounds as yourself.
You will also be provided with details of supporting agencies that may be helpful to access in relation to some of the topics we may discuss.

What will happen to my information once the study is complete?
Once the study is complete your interview audio-recordings will be immediately destroyed. The written transcripts of your recording will be kept for five years as evidence of the research findings to support publications of the outcomes of the research. This is outlined in the University of East London's data retention policy. You will be provided with the outcomes of the study and summary of the research unless you state you do not wish to receive one.

Who has reviewed the study?
The study has been approved by the University of East London. Additionally, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by XXXXXXXXXXXXXXXXXXXXXX, Ethics Code XXXXXXXX

Who do I contact if I wish to make a complaint?
If you are unhappy with the way you are treated by staff involved in the study or experience changes in your care which you perceive to be related to your participation in the study you are within your rights to complain to the relevant service. Details of the complaints procedures are available below:

██████████████████████; The Patient Advice and Liaison Service (PALS): ██
████████████████████████

University of East London: Dr Libby Watson: l.a.watson@uel.ac.uk; 020 8223 4220

How do I contact the research team?
If you would like further information about the research or have questions about taking part please contact the research team using the details below:
Researcher: Jennifer Nicholas, U1622892@uel.ac.uk
Local Supervisor: ████████████████████████
Research Supervisor: Dr Chanelle Myrie, C.Myrie@uel.ac.uk

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APPENDIX H: Service User and Carer research panel - Meeting Plan and Background Information

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NHS
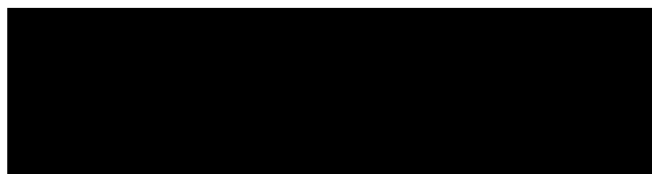
Meeting Plan for Thursday 22nd March 2018.

[black redaction boxes]

Please arrive by 10.50am for an 11.00am start

Times	Activity	People
11.00 – 11.15	**Welcome and check in.**	[redacted]
11.15 – 12.10	Black and Minority Ethnic Women's Conceptualisations of Psychosis and Compulsory Detention within an Early Intervention Service	Jennifer Nicholas UEL/[redacted]
12.10 – 12.20	**Break**	

*Text redacted to preserve anonymity of host trust

[Host Trust Name]'s Service User and Carer research panel:

- Aim to promote patient & public involvement in research
- Ensuring those with lived experience of mental health services contribute to research
- Approximately 50 minutes – 20 minute presentation, followed by discussion
- Researcher expected to provide a succinct overview of the study followed by specific, focussed questions for the group
- Members discuss and contribute to various aspects of research projects and the research process

NB. These slides were presented in addition to slides in Appendix E

What is "Psychosis"?

Hearing voices

Believing things that others find strange

Speaking in ways others find hard to follow

Experiencing periods of confusion where an individual may appear out of touch with reality

Typically attracts diagnoses such as "Bi-Polar Disorder" & "Schizophrenia"

Early Intervention for Psychosis Services (EIS):

- Community Mental Health Teams designed especially to work with people experiencing Psychosis for the first time

- Well-funded in the last 20 years, compared to other NHS services

- For those who engage with the service:
  - Increased **employment**
  - Shorter **hospital** admissions
  - Lower **suicide** rates
  - Fewer '**negative** symptoms' of psychosis
  - Less likely to *relapse*/have another 'psychotic episode'

Petersen et al., 2005; Park et al., 2016

Why SUGAR? *Your insight!*

ETHICS

1) As Service Users & Carers, what initial ethical **worries** come to mind about this study?

PARTICIPANTS

2) If you fit the criteria, would you **take part** in this study? Why/Why not?

3) Do you have any ideas on how I can **involve Black and Asian women** who have experienced **Psychosis** & their **carers** in the design, analysis or sharing of this study?

INTERVIEW

4) Do you have any feedback/ reflections on my **interview questions**?

5) How could I help participants **feel safe** about taking part in the interview?

SHARING THE FINDINGS

6) **Where/with whom** can I share the results, so that it is most likely to make a **positive change** for service users on the ground? For e.g:

- Networks/Groups
- Certain people
- Professional groups
- Organisations
- Events
- Websites

APPENDIX J: Interview Guide

INTERVIEW GUIDE

*Why did you decided to take part in this research today?

1. **My understanding is that most people attend Early Intervention Services, because they have had some 'unusual' experiences such as 'holding strong beliefs that many others do not share' and/or 'hearing voices or sensing things that others do not'.**

Does that fit with your understanding of why you're here?
Why? Why not? Can you tell me more.

2. **I am interested in what kind of experiences led up to you accessing Early Intervention Services, such as hospitalisation.**

What kind of experiences led up to your hospital admission?
How was it decided that you went into hospital? Did you feel like you needed to go into hospital?

3. **What happened as a result of being sectioned?**
Did things in your life change? Were there any consequences or not? If so, what?
Do you think being a woman from a Black/Asian/Minority Ethnic background had any impact?

4. **Following your admission, how did you feel about being referred to an Early Intervention Service?**
Did attending an Early Intervention Service make sense for you?
Did you feel it was appropriate for you as a Black/Asian/Minority Ethnic woman?
Would you have preferred to get support from anywhere else?

5. **Do you think Early Intervention Services are accessible to women from Black and/or Asian backgrounds who have been sectioned?**
- Have you found anything <u>helpful</u> from EIS in relation to working with you as a Black/Asian/Minority Ethnic woman?
- What might <u>prevent</u> Black/Asian/Minority Ethnic women who have been sectioned from engaging with Early Intervention Services?
- What would you <u>expect</u> Early Intervention Services to provide for Black/Asian/Minority Ethnic women who have been sectioned?

6. Where do you think it would be useful to share some of the experiences you've spoken about today?
Or who do you think it would be important for to hear? Professionals / lay people (specify if possible)? Why?

Closing
1. Review consent
2. Debrief, including concerns regarding information shared.
3. Discuss how participant experienced the interview, how they are feeling and whether they would like additional support. Ensure participant has researcher's contact details and answer any remaining questions.
4. Provide supporting agencies sheet

APPENDIX K: Participant Consent Form

Participant Consent Form
Consent to participate in a research study

Title of Project: Black and Asian Women's
Conceptualisations of Psychosis and Compulsory
Admission within an Early Intervention Service

Participant Identification Number:
      Please initial boxes:

1. I confirm that I have read the information sheet dated 27th August 2018 for the above
   study. I have had the opportunity to consider the information and ask questions.   ☐

2. I understand that my participation is voluntary and that I am free to withdraw, without giving
any reason, and that withdrawal from the study will not affect the care I receive in any way. I am
aware that I must inform the researcher by *1st of March 2019*, if I would like to withdraw from the
study.   ☐

3. I am willing for my meeting with the researcher to be audio-recorded and for anonymous
 quotations to be used in the results, write up, and research publications. I am also free to audio-
record the interview if I wish to do so.   ☐

4. I understand that my personal information and audio-recording will only be available to the
interviewer (Jennifer Nicholas), and that the anonymised interview transcript will be kept
confidential and will only be accessed by the research team.   ☐

5. I understand that relevant sections of my medical notes and data collected during the study
will be kept confidential and only be seen by the direct research team at the University of East
London. I give permission for these individuals to have access to my records.   ☐

6. I understand that my data will be stored securely and that the audio-file of my interview
will be destroyed once the study is complete. I give permission for the transcript of my interview
to be kept for five years after the study in line with the University of East London's data retention
policy, in order to publish the results.   ☐

7. I understand that if I become distressed or disclose information that raises concern about my
safety or the safety of others, the interview will be stopped and I will be referred to an appropriate
member of clinical staff or relevant authority.   ☐

9. I am willing for my care team (GP or Care Coordinator) to be informed of my participation in
this study. I understand that they **will not** have access to the information I give in interview.   ☐

10. I agree to take part in the above study.   ☐

_____   _____   _____
Name of participant   Date   Signature

11. I have explained the study to this participant and answered their questions honestly
and fully.

_____   _____   _____
Name of researcher   Date   Signature

When completed, 1 copy for participant, 1 for research

APPENDIX L: Transcription Conventions

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

(1) Length of pause in seconds

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

[inaudible] Inaudible section of transcript

[name/place] Confidential information changed with description.

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

/ Interruption

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

APPENDIX M: Health Research Authority approval letter

Miss Jennifer Nicholas
Doctoral Researcher
Camden and Islington NHS Foundation Trust
4 St Pancras Way
London
NW1 0PE

13 November 2018

Dear Miss Nicholas

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Black and Asian women's conceptualisations of Psychosis and Compulsory Admission within an Early Intervention Service**
IRAS project ID:	
REC reference:	
Sponsor	**University of East London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

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It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Catherine Fieulleteau
Tel: ▮▮▮▮
Email: researchethics@uel.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **244528**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Catherine Fieulleteau, University of East London, sponsor contact* ▮▮▮▮▮▮▮▮▮▮

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List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants [Copies of advertisement materials for research participants]	1	11 September 2018
Covering letter on headed paper [Covering letter on headed paper]		22 January 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance or indemnity - Part 1]		18 July 2018
GP/consultant information sheets or letters [GP/consultant information sheets or letters]	1	22 January 2018
HRA Schedule of Events [Validated SOE]	1.0	26 October 2018
HRA Statement of Activities [Validated SOA]	1.0	26 October 2018
Interview schedules or topic guides for participants [Interview schedules or topic guides for participants]	1	22 January 2018
IRAS Application Form [IRAS_Form_27092018]		27 September 2018
Other [Cover letter for conditions following favourable opinion]		10 November 2018
Other [Supporting Agencies sheet]	1	22 January 2018
Other [Evidence of Sponsor insurance or indemnity - part 2]	1	31 July 2018
Other [Evidence of Sponsor insurance or indemnity - part 3]	1	01 August 2018
Participant consent form [Participant consent form]	2	09 November 2018
Participant information sheet (PIS) [Participant information sheet (PIS)]	2	09 November 2018
Referee's report or other scientific critique report [Referee's report or other scientific critique report]		22 January 2018
Research protocol or project proposal [Research protocol or project proposal]	1	22 January 2018
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator (CI)]		22 August 2018
Summary CV for supervisor (student research) [Summary CV for supervisor (student research)]		22 August 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary, synopsis or diagram (flowchart) of protocol in non-technical language]	1	22 August 2018

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	Applicant has confirmed that ████████ ██████████████ Trust are no longer involved in this study
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The statement of activities confirms that there are no funds available to site from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will be recruiting sites; consent and interviews will be undertaken by the external researcher.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator is expected at participating NHS site.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

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APPENDIX N: Research Ethics Committee (REC) Favourable Opinion

NHS

Health Research Authority

London - Westminster Research Ethics Committee

4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8012

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

08 November 2018

Miss Jennifer Nicholas
Doctoral Researcher
Camden and Islington NHS Foundation Trust
4 St Pancras Way
London
NW1 0PE

Dear Miss Nicholas

Study title: **Black and Asian women's conceptualisations of Psychosis and Compulsory Admission within an Early Intervention Service**

REC reference:
Protocol number:
IRAS project ID:

The Research Ethics Committee reviewed the above application at the meeting held on 30 October 2018.   Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Favourable opinion

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The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

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

1. Ensure both the Participant Information Sheet and consent form give the same time frame for participants to withdraw from the study.

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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

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

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

[CTIMPs only]
Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

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

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Extract of the meeting minutes

Social or scientific value; scientific design and conduct of the study

The Committee was pleased to see that not only had there been public involvement in the study but that the researcher explained how that had led her to rethink aspects of the study.

The Committee was unclear on exactly how the Early Intervention Service (EIS) worked. For instance, was everyone assigned to an EIS after experiencing a First Episode of Psychosis (FEP)? Or was it something people went to if they experienced further problems? It was important for the Committee to understand the process in order to consider the vulnerability of potential participants and the potential for distress. The Committee requested an explanation of the role of the EIS in patient care.

> Miss Nicholas said anyone sectioned for an FEP would be referred to an EIS. They would be with the EIS for three years and have contact at least once a month. At the end of three years they would either be discharged to the community or to a different team.

The Committee discussed this and agreed this reduced their concerns about recruiting extremely vulnerable people since the researchers would be able to recruit from people who had not just left hospital.

The Committee asked what conclusions Miss Nicholas thought she would draw.

> Miss Nicholas said she had worked in the community and inpatients and the discourse was very medical. She wanted to know what the patient's version of events was. She hoped to open up the conversation to see if professionals needed to think about psychosis in different ways, such as it being a religious experience for some.

The Committee thought this was a laudable goal.

Recruitment arrangements and access to health information, and fair participant selection

The Committee asked if there was any knowledge on how many potential participants there were.

    Miss Nicholas said the teams had said they definitely had people who would fit the criteria, with each team leader saying they had 2 or 3 suitable people. Miss Nicholas said the contingency plan was to recruit people who had not been sectioned but who felt coerced into entering hospital.

The Committee asked if the coercion came from Healthcare Professionals.

    Miss Nicholas said the coercion could also have come from family members or a person's community.

The Committee thanked Miss Nicholas for the explanation.

The Committee asked if fluency in English might be a problem.

    Miss Nicholas said the EIS teams had said most of the people they engaged with did not use interpreters so it was not expected to be a problem. However, Miss Nicholas did think it a shame that there was no funding available for translators.

The Committee was pleased that the lack of translators was unlikely to exclude women from the study.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked if there had been any thought of sending the interview transcripts to participants for their review and clarifications.

    Miss Nicholas said she knew some studies that had done that but it was something that caused additional delays to the study. A summary of the findings would be sent to participants.

The Committee did not think there was a compelling reason for participants to receive a copy of the transcript and so did not require it.

Informed consent process and the adequacy and completeness of participant information

The Participant Information Sheet said participants could withdraw consent up to 01 March 2019. The consent form said they could withdraw for up to 2 weeks after their interview. The Committee understood why there had to be a limit and was content with either one but agreed the information to participants needed to be consistent.

The application mentioned that a simplified Participant Information Sheet might be created. One had not been submitted so the Committee wished to advise the researchers that if one was developed it would need to be submitted as a substantial amendment before it could be used.

Suitability of supporting information

The recruitment poster stated that participants would receive a £10 voucher. While the amount was small the Committee did not think it appropriate to include it on the poster. The Committee asked how the £10 voucher was being funded.

    Miss Nicholas said the university was funding it.

The Committee asked why it had been put on the poster.

    Miss Nicholas said she had just thought that was what should be done.

The Committee said there were two schools of thought on that as some thought it might mean people did the study purely for the reward.

    Miss Nicholas said the EIS teams had also been in disagreement about the amount, with some saying it was too little and others saying it was too much. Miss Nicholas said it was a gesture that she anticipated being appreciated.

    Miss Nicholas then said that the poster would not actually be put up anywhere. Rather, the care teams would have it and give it to people during visits if they met the inclusion criteria. The team member would also assess risk and capacity at that time, which was a standard part of care. Consent would then be taken for the researcher to contact the patient. Miss Nicholas said she contact the potential participant and then contact them two weeks later to see if they wanted to take part. If they did, the care team would reassess capacity prior to the interview. Only one call would be made to potential participants.

The Committee asked if the care team would be able to do that.

    Miss Nicholas said she had been concerned about that but her clinical supervisor had said it would be possible as long as everything was well scheduled.

The Committee considered the poster and concluded it was actually a leaflet and thus no changes were required.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Copies of advertisement materials for research participants]	1	11 September 2018
Covering letter on headed paper [Covering letter on headed paper]		22 January 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance or indemnity - Part 1]		18 July 2018
GP/consultant information sheets or letters [GP/consultant	1	22 January 2018

information sheets or letters]		
Interview schedules or topic guides for participants [Interview schedules or topic guides for participants]	1	22 January 2018
IRAS Application Form [IRAS_Form_27092018]		27 September 2018
Other [Supporting Agencies sheet]	1	22 January 2018
Other [Evidence of Sponsor insurance or indemnity - part 2]	1	31 July 2018
Other [Evidence of Sponsor insurance or indemnity - part 3]	1	01 August 2018
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Participant information sheet (PIS) [Participant information sheet (PIS)]	1	22 August 2018
Referee's report or other scientific critique report [Referee's report or other scientific critique report]		22 January 2018
Research protocol or project proposal [Research protocol or project proposal]	1	22 January 2018
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator (CI)]		22 August 2018
Summary CV for supervisor (student research) [Summary CV for supervisor (student research)]		22 August 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary, synopsis or diagram (flowchart) of protocol in non-technical language]	1	22 August 2018

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

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

HRA Training

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

	Please quote this number on all correspondence

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

Yours sincerely

Mr Robert Goldstein
Chair

E-mail: nrescommittee.london-westminster@nhs.net

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers"
Copy to:	Ms Catherine Fieulleteau, University of East London

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APPENDIX O: Supporting Agencies Sheet for Participants

Supporting Agencies

NHS Care

If you become distressed and concerned that you are no longer safe following the interview - please visit your **nearest A&E** to receive appropriate emergency support.

You can also contact your clinical team at the **Early Intervention Service** and/or your **GP**.

Support services/resources

Apart from the NHS, the following organisations provide support/information specifically for Black, Asian and Minority Ethnic communities and/or women.

- Nafsiyat Intercultural Therapy Centre

Website: www.nafsiyat.org.uk

- The Black, African and Asian Therapy Network

Website: https://www.baatn.org.uk/

- I Am Not Broken - Mental Health in the Black, South Asian and Muslim diasporas.

Website: http://iamnotbroken.light-inc.org

- 1000women – Minority Ethnic Women's Sexual & Mental Health Charity
  Website: http://1000women.co.uk

- Agenda – Alliance for Women & Girls at risk; Mental Health campaigns.
  Website: https://weareagenda.org

- Women's Mental Health Network – User-led platform giving women a voice.
  Website: https://womensmentalhealthnetwork.com

Complaints services:

If, following participation you wish to make a complaint about the **research** itself please contact Dr Libby Watson at the University of East London.

- Dr Libby Watson Tel: 020 8223 4420 Email: l.a.watson@uel.ac.uk

If you wish to make a complaint, or give feedback on the care you received in **hospital or from your current NHS service** please contact the patient advice and Liaison service:

- ███████████████████████████ The Patient Advice and Liaison Service (PALS) Tel: ███████████████████████

APPENDIX P: Example of Annotations - Initial Thoughts, Feelings, Reflections on original transcript MS Word

P: Erm, they admitted me into hospital (1) well first I got arrested <I: Okay> by the police, for lashing out at the police. I was yeah (1) I assaulted a police officer. And then I went into hospital, erm (2) yeah [laughs] what was the question?

I: Yeah, what happened I guess, the process. When that was all happening, if you can remember, I know it's ages ago <P: mm hmm> but when – because I know you said looking back it makes sense, because I wasn't myself <P: yeah>. But when the police did come, what was your understanding of what was happening?

P: Well it started because, erm I like, I wouldn't say I attacked my brother, but I kinda like, coz I was hearing voices and stuff, like I thought everyone was against me, so, I thought that my brother was like, erm [makes sound as if lost her words], I just thought he was against me. Basically so he gave me his phone and his phone was like low battery and I said, I said to him, oh your phone is low battery. You told me that your phone was full, but it's low battery. And then he was like, no I didn't say that, kinda thing. So then I lashed out at him and I threw a bag at him <I: mm>. And it wasn't like, on like, proper threw a bag at him, kinda like [gestures throwing a bag], you're lying. And then attacked me and then we ended up having a fight. And this is like my brother, my little brother, so we don't like fight or nothing, so my mum was like really shocked about it, and she called the police. <I: mm> So when the police came, and I was calm, and I was talking to them and they were asking me about what happened, and then erm for no reason they told me they're gonna put handcuffs on me <I: Okay> So I that's when I got kinda like, what you doing kinda thing, I got angry, and I threw my drink in the police officer's face, and then I ended up getting arrested (1) and then I went to the cell (1) for assaulting a police officer.

I: And when you think about that now, do you feel like that was fair, do you feel it was unfair?

P: I thought it was unfair yeah, because they didn't arrest me for assaulting my brother, like what they came there, for, to do, they arrested me for assaulting them. But it wouldn't have been, like, for me to, like I wouldn't have assaulted them, if they didn't put handcuffs on me.

I: Yeah, so they, originally, mum called because you were having a fight with your brother <P: yeah> then the police came, because you reacted to the police, that's why they, arrested you. So it just felt like <P: Yeah> you're not even arresting me for what happened with my brother <P: Yeah>. So it just sounds like you felt really unsafe?

P: Yeah I was (2) Yeah.

I: And then, after the cell, what happened after that?

P: Erm, I went into the cell, erm I was really really, just agitated. And angry, and just, I was trashing the whole cell. I was like putting food on the walls. But I guess I was a bit of like (2) erm a nuisance, I

Annotations (right margin):

Jennifer NICHOLAS
Lies, mistrust, betrayal

Jennifer NICHOLAS
Different genders, different power, does not judge brother, behaviours of "anger" out of character for females?

Jennifer NICHOLAS
Emphasis on family member's position – expectations of older siblings to look after younger?

Jennifer NICHOLAS
Leading Q?

Jennifer NICHOLAS
• I note she says the police treated her unfairly but she didn't say mental health professionals did.
• Is it possible that the complex relationship between police and black communities is well known, so easier to speak to?
• Compared to voicing out unfair treatment from mental health professionals?
• She does go on to say hospital was abusive, but does not spend as much time expanding on this. Too painful?
• Is it because I was a mental health professional associated with the NHS?
• Or too much happened? Conflicts with a profession who are supposed to care for you, unlike the police who are expected to be unfair towards people from your community.

• Thought - Police more likely to be white. Hospital staff in the P's area more likely to be from Black and Minority Ethnic backgrounds.

Be aware of my own knowledge, experiences and biases in around mental health inequality during the analysis.

Jennifer NICHOLAS
The physical act of putting handcuffs on P led to her reaction

Jennifer NICHOLAS
Coercion from people in authority, responding incorrectly, blamed, scapegoated, not fulfilling their role accurately

Jennifer NICHOLAS
Judgement of self

KEY:
Name – Name of code
Files – No. of transcripts code appeared in
References – No of times code appeared in interview transcripts

APPENDIX **Q: Initial Codes – Nvivo Codebook**

Name	Files	References
Abuse	6	28
Acceptance	7	14
Alternative to statutory	5	12
Ambulance staff	4	10
Anger	4	18
Black men	3	5
Blames self	7	23
Boredom	1	2
Choice	7	24
Colonisation	1	3
compassion empathy	7	20
Compliance	4	6
Confidence	2	2
Coping	5	11
criminal not patient	4	15
culture	7	42
Decisions made by others	8	77
Defending self	3	6

Name	Files	References
Delays	3	5
Depersonalisation	1	2
Development of 'psychosis'	8	50
Accumulation of events	5	18
Anxiety	3	9
Change in behaviour	6	29
Distrust	8	34
Drug use	4	24
Disempowered	8	50
Dissemination	8	24
Duty	5	25
Early life experiences	5	29
Education	6	20
EIS staff relationships	8	52
Feeling Held	6	15
Employment	4	24

Name	Files	References
End life	3	11
Erratic behaviour	6	11
Escapism	5	12
Excessive attention	7	22
Expectations	6	12
Failing	1	1
Fear of safety	6	30
Fed up	5	7
Finances	4	8
Freedom	3	5
Friendships	6	36
Generational differences	6	18
good cause	4	6
guilt	5	5
Hopelessness	6	10
Ignorance	2	4
Impact of family	8	107
Impact of race on treatment	5	17

Name	Files	References
Impressions of hospital staff	7	31
Independence	6	19
Individualised	7	32
Injustice and Unjustified	6	36
Institutional racism	4	23
Interactions with police	5	30
Isolation	7	38
Judgement	7	20
Justified	3	5
Lack of general awareness	4	13
Lack of understanding	6	28
Lies	6	9
Limited use low expectations	3	3
Listened to	6	18
Literacy	3	5
Loss of liberty	7	32

Name	Files	References
Magnitude of experience	7	17
Medical Model	8	68
Migration	1	9
Mystery	5	9
Not belonging	7	28
Not working correctly	2	4
Ongoing difficulties	6	20
Other service users	6	17
Others noticing change in behaviour	6	26
Paranoia	4	13
Part of life	4	8
Patience	4	6
Permanency	2	4
Physical health	3	18
Positive intentions	5	6
post-hospital	8	79

Name	Files	References
Power of Media	2	3
Preoccupation	3	5
Previous MH experiences	6	20
Protecting Self	7	12
Psychosis as an episode in time	6	14
Racism	4	6
Range of support	7	17
Realisation of being in hospital	4	6
Realness of hospital	6	23
Reconnection	4	12
Recovery	8	46
Rejection	5	8
Reluctance to work with services	6	15
Respect	4	5
Retrospect	6	29
Rights	4	7
Romantic	3	24

Name	Files	References
Secrecy	5	25
self reliance	8	25
Senses	8	35
Shock	4	6
Silenced	3	5
Social Context	7	25
Social Media	5	13
Socialising	7	25
Spirituality	6	43
Stress	8	24
Stigma	4	7
Strong identity	6	20
Suffering	6	17
Talking about your difficulties	6	40
Talking about Trauma	3	21
Trust	8	25
Unclear	7	33
Unexpected	7	24
Unmanageable	5	8
Unsure	7	35

Name	Files	References
Unwanted attention	8	25
Using the experience	7	14
Utility of EIS	8	54
Violence	5	27

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APPENDIX R: Examples of Coded Extracts Part 1 - N-Vivo

Home   Create   Data   Analyze   Query   Explore   Layout   **View**

Close All   Close   Zoom   Detail View   Coding Stripes   Highlight   Node   Node Matrix   Classification

Application   Window   Coding   Detail View

Thesis v2 (2)

DATA
- Files
- File Classif..
- Externals

CODES
- Nodes

CASES
- Cases
- Case Class.

NOTES
- Memos
- Annotations
- Memo Links

SEARCH
- Queries
- Query Res..
- Node Matri.
- Sets

MAPS
- Maps

OPEN ITEMS

Name
- TRANSCRIPT 1
- TRANSCRIPT 2
- TRANSCRIPT 3
- TRANSCRIPT 4 cop
- TRANSCRIPT 5
- TRANSCRIPT 6
- TRANSCRIPT 7
- TRANSCRIPT 8

TRANSCRIPT 1   Code   Annotations   Edit

was your understanding of what was happening?

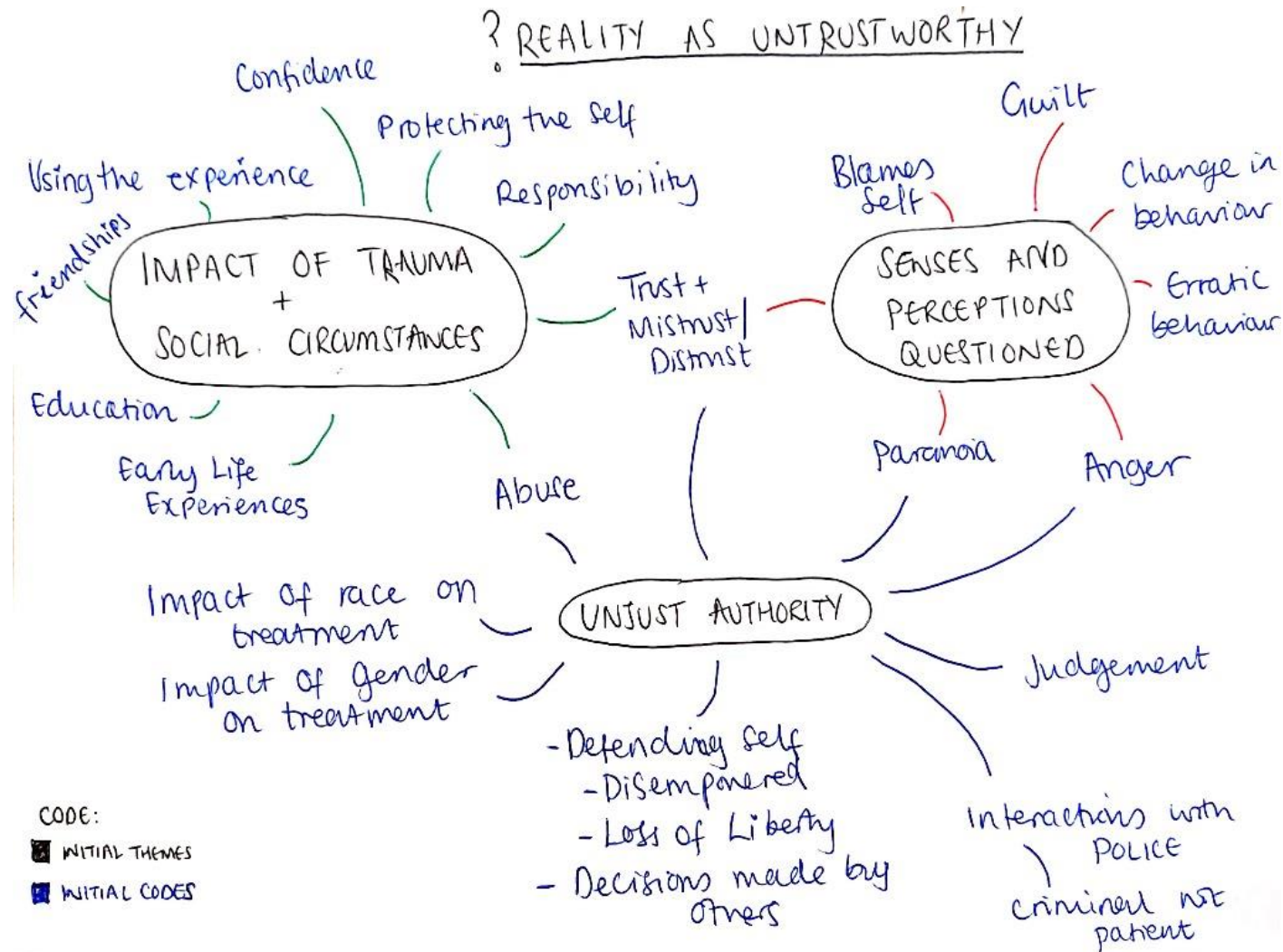P: Well it started because, erm I like, I wouldn't say I attacked my brother, but I kinda like, coz I was hearing voices and stuff, like I thought everyone was against me, so, I thought that my brother was like, erm [makes sound as if lost her words], I just thought he was against me. Basically so he gave me his phone and his phone was like low battery and I said, I said to him, oh your phone is low battery. You told me that your phone was full, but it's low battery. And then he was like, no I didn't say that, kinda thing. So then I lashed out at him and I threw a bag at him <I: mm>. And it wasn't like, on like, proper threw a bag at him, kinda like [gestures throwing a bag], you're lying. And he like, attacked me and then we ended up having a fight. And this is like my brother, my little brother, so we don't like fight or nothing, so my mum was like really shocked about it, and she called the police. <I: mm> So when the police came, and I was calm, and I was talking to them and they were asking me about what happened, and then erm for no reason they told me they're gonna put handcuffs on me <I: Okay> So I that's when I got kinda like, what you doing kinda thing, I got angry, and I threw my drink in the police officer's face, and then I ended up getting arrested (1) and then I went to the cell (1) for assaulting a police officer.

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I: And then, after the cell, what happened after that?

P: Erm, I went into the cell, erm I was really really, just agitated. And angry, and just, I was trashing the whole cell. I was like putting food on the walls. But I guess I was a bit of like (2) erm a nuisance, I think. But I was like calling them on the speaker thing to like, could I have a cup of tea or something, and they were ignoring me on the speaker. They weren't like, they weren't attending to me at all. Like, they would tell me, oh we will be there in ten minutes, then two hours would pass, and they're still not there. Um, then they told me like that I could go stay at my cousin's house, her sister [points to cousin in the room], and they was like would you wanna stay there? Would you wanna go? We can let you go and you can stay there. <I: Okay>

Coding Density

Development of 'psychosis'
Accumulation of events
untrustworthy reality
Decisions made by others
Injustice and Unjustified
Institutional racism
Interactions with police
Loss of liberty

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APPENDIX S: Examples of Coded Extracts Part 2 - N-Vivo

This page on NVivo goes on to list all the interview/transcript extracts linked to the 'Blames Self' code

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APPENDIX T: Example Initial Mind Maps

? REALITY AS UNTRUSTWORTHY

Confidence

Protecting the self

Using the experience

Responsibility

friendships

IMPACT OF TRAUMA + SOCIAL CIRCUMSTANCES

Trust + Mistrust/Distrust

Education

Early Life Experiences

Abuse

Blames Self

Guilt

Change in behaviour

SENSES AND PERCEPTIONS QUESTIONED

Erratic behaviour

Paranoia

Anger

Impact of race on treatment

Impact of gender on treatment

UNJUST AUTHORITY

Judgement

- Defending self
- Disempowered
- Loss of Liberty
- Decisions made by others

Interactions with POLICE

criminal not patient

CODE:
■ INITIAL THEMES
■ INITIAL CODES

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APPENDIX U: Development of Thematic Tables

Version One

Main Themes	Subthemes
Reality as Untrustworthy	1. Impact of Trauma and Social Circumstances 2. Senses and Perceptions Questioned 3. Unjust Authority
Depersonalisation and Re-Personalisation	1. Criminal vs Patient 2. Behaviour as Unacceptable 3. Ownership of Decisions
Duties of Self, State and Society	1. Demands of Social Identities • Womanhood • Ethnicity and Migration 2. Unaccustomed Support 3. Privileged Explanations

Version Two

Main Themes	Subthemes
Extreme Surveillance	Being Monitored Denied Autonomy
Trust of Self and Services	Self-Accountability Unjustified Consequences
Navigating Intersecting Identities	Unexpected Support Community Constraints Silenced by Services

Version Three

Main Themes	Sub-themes
Under Extreme Surveillance	Being Monitored Denied Autonomy
Trust of Self and Services	Self-Accountability Unjustified Consequences
Navigating Intersecting Identities	Expectations of Support Acceptance & Unacceptance Multiple Models of Meaning Silenced by Services

Version Four

Main Themes	Sub-themes
Under Extreme Surveillance	Being Monitored Self-Blame
Trust of Self and Services	Unjustified Consequences Silenced by Services
Disentangling Trauma	Sense-Making of Suffering Unexpected Support

Final Version

Main Themes	Sub-themes
Sense of Mistrust	Uninvited Intrusion Self-Blame
Navigating Unsafe Systems	Unjustified Consequences Hindered Help
Impact of Adversity	Sense-Making of Suffering Unexpected Support

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APPENDIX V: Reflexive Diary

<u>Reflections after First Interview with 'Dami':</u>
I finally completed my first interview with a participant today, and first of all this has made me feel hopeful for more women coming forward to take part. I am firstly grateful and so relieved!

As for the interview process, I think I underestimated how nervous I would be! I noticed my questions were a bit clumsy at times and I would speak in long sentences/paragraphs, that I think confused the participant at times! Nevertheless, with some clarifying as we went along, I noticed there were certain topics already coming up, i.e., the way the police treated her while she was being sectioned. I found this quite shocking, and I think this showed in my facial expressions when we were talking. I wonder if as a researcher I am supposed to be more 'neutral', but I guess at the end of the day I am a human, part of the research process, who will be impacted by the 'data' participants share. Personally, I wonder if maybe it would have even been somewhat disrespectful to not acknowledge how upsetting the experience sounded? But I did have to find the balance, as I obviously was not there in a 'therapist' capacity. Also, the topic of police brutality being brought up, it has started to make me feel a bit nervous about how this research may even be able to help, with such a huge systemic problem? Since completing the interview, I am really curious to why she decided to take part today. The gesture of appreciation is not a large amount (purposefully!), so I do wonder what motivated her to come to speak to me about her experiences.

For Dami she used the word "Schizophrenia" to describe her experience, and as something she "suffered" from. She talked about social isolation, uni pressure and skunk, and how the anger that came out of these were all out-of-character for her. Psychosis was talked about as a sort of blurred reality. I found myself asking clarifying questions at times about her experience, but then I realised by pushing this, that for her, psychosis was extremely complex – and could not simply be explained by me asking about it. I think this was a slight revelation for me! I assumed that people weren't being asked about their understandings of psychosis – which may be the case, but that also people don't necessarily have a complete explanation for first episode psychosis, even when they are asked. It seems as EIS was offered to her after hospital, she didn't necessarily want to engage with this service as she didn't want to feel like she was continuing to be monitored by someone. It seems the EIS intervention made her feel like she was STILL being restricted and watched, as before hospital she felt like people were monitoring all her actions via cameras. It seems she found EIS eventually mobilising and not restricting however? Her account has made me think about the role of clinical psychology when it comes to the relationship between the police force/emergency services and Black women presenting with acute psychosis?

I really like I used clarifying talk, "How do you make sense of that?". I think slowing down the pace of the session, with a statement like, "I might pause at times, just to give you some time to think if there's anything else you want to add", would be helpful, rather than me being completely focussed on moving on to the next question. Additionally, adding the question, "Why did you decide to take part today?", I think would be useful in gauging why this group of women have voluntarily decided to share such a personal – and likely distressing – part of their lives, and additionally, what hopes they may have for this research. This is likely to also make this study even more meaningful for me.

APPENDIX W: Reason for Participation & Dissemination Recommendations

Why did you decided to take part in this research today?

Dami	N/A. Only included this question after this (first) interview was completed.
Dianne	I think making more awareness about mental health would benefit a lot of ethnic minorities who suffer from mental health issues. Because there's not enough information about why it can happen, what can go wrong.
Sylvia	Being sectioned does happen to quite a few minority, ethnic minority women. So, if I can help their experience, you know any ones that come after me, um, yeah, that's why.
Christiana	I just wanted to let people know about like what I went through. And to let them know about the experience and stuff like that yeah. Like wow..I've actually, like gone through. I've conquered like mental health. Yeahhh. I've actually overcome it.
Amanthi	I just thought that you're doing something good, it's for a good cause. So I thought I'd take part in it.
Ayaan	I think...what helps me to..What helps ME personally is..the fact that my voice is being heard. It's, it's encouraging to take part in this.
Sabina	So if I was to have like my own rape campaign, or you know share my, my bits of my story, that would probably help others. Just the way I explain it like, confidence in sharing it in the future. Just being heard, kind of, and being understood if that makes sense.
Fahima	I know it's really hard as a student to find out someone for research, and even lots of people they don't agree to do it you know? So I want to help you, honestly number one as a student. Number two, I know it's really important to discuss the mental patient, why they become a mental patient.

Where do you think it would be useful to share some of the experiences you've spoken about today?

Dami	- Separate. Like separate audiences. Like with schizophrenia you have mental health audience for that. With police, you got audience for that. - Magazines - Ones that empower women, so female empowerment.
Dianne	- I think social media is a really good platform, coz people can...listen or watch something, without having to get involved. They can just scroll past it, and maybe it would've you know, stuck in their heads. - My mum doesn't have social media, but she watches YouTube a lot. A lot of them watch YouTube. And they use WhatsApp, that's what they go on. So maybe on YouTube. - And the police. It would be great if it was like part of their training or something. How to handle someone who is suffering from mental illness and how that's different from someone committing a crime.
Sylvia	I think...everyone that's working with mental health, should, yeah. If it's done right, they can help improve people's lives. Mental health diagnosis does not have to be the end of someone's life.
Christiana	Like certain groups of community. Like, I feel like, Black girls. And Asian girls. Should hear it.
Amanthi	I think my doctors, psychologist and like for research purpose, I think it would be useful.
Ayaan	The nurses. Care coordinators. Erm, support workers. People, doctors, psychiatrists. They should know that. Basically everyone who's involved in your care. Family. The parents.
Sabina	Mainly people who have faced rape. OR bad relationships that didn't last, I dunno. Relationships basically. And just someone that's had a mental health problem where they've bottled something up I think.
Fahima	Mental patient or their family. Especially their family or the carer.