Changing Patterns of Incidence, Service Engagement and Outcomes Among Black African and Black Caribbean Patients With Psychotic Illness

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Changing Patterns of Incidence, Service Engagement and Outcomes Among Black African and Black Caribbean Patients With Psychotic Illness

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Abstract

Strong and consistent evidence of higher incidence of psychosis, crisis pathways to care and poor outcomes following first episode of psychosis (FEP) in ethnic minority populations have been reported particularly among Black African and Caribbean populations in the UK. Further, there is ongoing debate about the role of early intervention services which have shown promising effects on reducing treatment delays and a range of outcomes following FEP. This study aimed to estimate ethnic differences in the incidence of psychosis, pathways to care and two-year service use outcomes in three ethnic groups (namely, White British, Black African and Black Caribbean). An investigation of pathways to care and clinical outcomes comparing early intervention service (EIS) and non-EIS users was also conducted.

An administrative incidence study design with a follow up cohort study of outcomes of psychoses was employed to investigate the aims of this study. First episode psychosis cases were identified and their data were drawn from the South London and Maudsley NHS Foundation (SLaM) Biomedical Research Centre case register. Pathways to care, sociodemographic and clinical information were collected using the Personal and Psychiatric History Schedule (PPHS, WHO, 1996) the Medical Research Council Socio-demographic schedule (Mallett et al., 1997) and the Life Chart schedule (WHO, 1992) respectively for the purpose of case note data extraction. Data on 558 FEP patients were analysed using standardised incidence rate (SIR) / Poisson regression, logistic regression and negative binomial regression.

Higher incidence rates were found among Black African (adj. IRR =3.59; 95% CI 2.8 – 4.55) and Black Caribbean (adj. IRR = 2.81; 95% CI 2.15 – 3.68) ethnic groups compared with the White British group.

At first contact for psychosis, Black African (adj. OR = 3.23; 95% CI 1.57–6.63) patients were more likely to be compulsorily admitted, but there were no differences between Black Caribbean (adj. OR = 1.78; 95% CI 0.75–4.24) and White British patients. Comparison of pathways to care between the AESOP study and this study data showed that there were no ethnic differences in GP or criminal justice agency referral in this study compared with the AESOP study. However, there was evidence that Black African (adj. OR = 7.34; 95% CI1.15–

46.74) and Black Caribbean (adj. OR = 48.89; 95% CI3.49–684.71) patients were more likely to be referred by the accident and emergency department.

At two-year follow-up Black African patients experienced worse service use outcomes, as well as higher rates of compulsory admissions (adj. IRR =3.01; 95% CI1.33–6.80) and hospital admissions (adj. IRR = 1.98; 95% CI1.12–3.48). Ethnic differences were not evident between Black Caribbean and White British patients on compulsory admission or hospital admission outcomes at follow-up. Further, compared with patients who accessed early intervention service, patients in the non-EIS group were more likely to be hospitalised (adj. IRR = 3.30; 95% CI 1.98–5.49), and compulsorily admitted (adj. IRR = 2.22; 95% CI1.18–4.18).

This study provides a novel insight into the associations between ethnicity and incidence of psychosis, pathways to care and outcomes of two-year follow-up service use, and hints at a possibility that the service engagement disparities between Black Caribbean and White British patients may be diminishing.

Abbreviations

AESOP Aetiology and Ethnicity in Schizophrenia and Other Psychoses study

ARMS At Risk Mental State

BME Black and Minority Ethnic groups

BRC Biomedical Research Centre of the SLaM NHS Trust

BRCID Unique identifying number for each record of the Case Register

CI Confidence Interval

CRIS Case Register Interactive Search system of the Biomedical Research Centre

EI Early intervention

EIS Early intervention Service

ELFEP East London First Episode Psychosis study

FEP First episode psychosis

ICD-10 WHO International Classification of Diseases (10th/11th edition)

IoPPN Institute of Psychiatry, Psychology & Neuroscience

IQR Inter-quartile range

IR Incidence rate

IRR Incidence rate ratio

MHA Mental Health Act

MRC Medical Research Council

N Number / sample size

ONS UK Office of National Statistics

OPCRIT Operational Criteria Checklist for Affective and Psychotic Disorders

OR Odds Ratio

RCT Randomised Control Trial

RR Relative Risk

SLaM South London and Maudsley NHS Trust

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1 Chapter 1: General Introduction

1.1 Synopsis

The aetiological role of social factors in the onset of psychosis has been extensively studied, with particular attention paid to the role of ethnicity. Several studies have consistently reported a higher incidence of psychosis among black and ethnic minority populations in the Western nations (Harrison et al., 1997, Fearon et al., 2006a, Veling et al., 2006).

As the proportion of people living outside their country of birth is increasing globally, recognising the health needs of minority ethnic groups in the host society is paramount. For instance, compared to the 2001 census, data from the 2011 census suggest that 13% of the population in England and Wales are people born outside the UK (ONS, 2011b). In addition, with the passage of time, some ethnic minority groups and their succeeding generations are more integrated into the UK society than others. With the continuous social changes, it is unclear to what extent ethnicity still contributes to the onset and course of psychotic disorder.

Furthermore, there have been major mental healthcare provision changes in the UK. In the last two decades, early intervention services (EIS) were introduced specifically to detect symptoms, reduce the duration of untreated psychosis and improve access to care and treatment (Craig et al., 2004a, Birchwood, 1995, Kuipers et al., 2004, McGorry et al., 2009). Further, psychiatric hospital beds have substantially reduced, community-based crisis services; home treatment and crisis resolution teams were introduced and there is greater emphasis on inter-professional working culture (Johnson et al., 2001, Priebe et al., 2008, Peck and Norman, 1999). These changes are likely to have an impact on mental health of the overall population and in particular ethnic minority populations.

The overall purpose of this thesis is to describe the incidence rates of psychosis, pathways to care at first contact and service use outcomes at two-year follow-up by ethnicity with a focus on three ethnic groups (namely, Black African, Black Caribbean and White British) in two well-defined catchment areas of south London.

Before outlining the structure of this thesis, it is important to consider the exposure and outcome (ethnicity and psychosis) variables that are under investigation in this study. These are briefly discussed below.

1.1. Ethnicity

The terms ethnicity, race and culture are often used interchangeably and so it is important to disentangle them. Fernando (2002) provides a summary of the interplay and connections between the three in Table 1.1 below.

Table 1.1: Race, culture and ethnicity (from Fernando, 2002)

	Characterised by	Determined by	Perceived as
Race	Physical Appearance	Genetic Ancestry	Permanent (genetic / biological)
Culture	Behaviour Attitudes	Upbringing Choice	Changeable (assimilation / acculturation)
Ethnicity	Sense of Belonging Group Identity	Social Pressures Psychological Need	Partially Changeable

The distinctions of race and ethnicity are socially constructed, as the question of who belongs to which groups and the status attached to different groups are matters of social convention (Blakemore and Boneham, 1994). Race may be considered as externally

motivated, stemming more from the need of human beings to categorise each other than the need to form inclusive social groups (Karlsen et al., 2006). It becomes important to maintain group boundaries and group identity around the perceived similarities of members of the group. And so, more emphasis is placed on the process of stereotype by others which inherently contains a judgement of value (Karlsen et al., 2006). Physical appearance, such as skin colour, hair colour etc. become important in categorising racial groups particularly in the Western states. These racial judgements are in turn shaped by folk-myth and beliefs about the intrinsic features of 'Black' and 'White' (Blakemore and Boneham, 1994). These characterisations originated during the voyage of Europeans to West Africa in the 1500s, and the striking characteristic they discovered was the African peoples' skin colour (Jordan, 1974). However, the 'Black' and 'White' characterisations are emotionally loaded in the West, particularly in the English language, not only because of the contrast that one denotes the polar opposite of the other, but because the two have been argued to carry a connotation of hierarchy (Jordan, 1974, Mason, 1995). Therefore racism is a form of biological reductionism, which stems from an observation of physical features and preconceived stereotypes about a racial group (Blakemore and Boneham, 1994). The use of racial categories has largely reduced in scientific research and been replaced by the use of ethnicity, a more acceptable term. However, researchers often categorise people into 'ethnic' categories in such a way that it is difficult to discern them from racial categories, e.g. the crude dichotomy between Black and White is used in some research studies' ethnic categorisations. People from diverse cultural and ethnic backgrounds are consequently often grouped together on the basis primarily of skin colour, with the underlying assumption that this marks an important and meaningful distinction that might explain an outcome of interest, for example, rates of psychosis, compulsory admission and hospitalisation.

Ethnicity is not an easily definable concept, because it is subjective and includes a range of factors in its definition. These include physical appearance, geography, language and cultural systems (Fernando, 2002). According to (Karlsen et al., 2006), an ethnic group implies a categorisation which may be defined by personal choice, establishment of common identity as well as certain shared economic, social or cultural characteristics at a given time. Ethnic identity may be a resource; it is also another way for 'outsiders' to make

judgements about a group (Blakemore and Boneham, 1994). These may be positive stereotypes (for example, the outgoing, extended Black family) or terms of abuse. So to put it simply, ethnicity can be described as a fluid concept encompassing an individual's sense of belonging to a particular group on the basis of geographical origin, skin colour, physical appearance, language, religion and cultural practice (Sewell, 2009, Fernando, 2002). Ethnicity is flexible and shifting on different levels according to situation and context. This is particularly important as far as minority status is concerned because opinions vary as to whether ethnic loyalties fade over time as migrants adjust to their adopted country, or whether they are retained (Blakemore and Boneham, 1994).

Culture on the other hand provides a set of socially shared guidelines or rules that shape and constrain beliefs, attitudes and behaviour. Like ethnicity, culture is not static or homogenous. As Blakemore and Boneman (1994) note, 'culture itself is an umbrella term referring broadly to a way of life: distinctive social institution (marriage, religion), social norms, manners, attitudes and ways of thinking' (p.6). Beliefs, attitudes and so on inevitably undergo modifications as individuals are exposed to and experience other cultural systems and ideas. Although cultural heritage may form a significant component of ethnic identity (as above), it does not define it and those who perceive themselves as belonging to an ethnic group may well differ markedly in terms of the cultural orientation that informs their beliefs and actions (Fernando, 2002). This highlights caution against confusing culture and ethnicity.

For the purpose of this thesis, capitalising on the key component of ethnicity, i.e. a sense of belonging, suggests that ethnicity can only be accurately ascertained by self-ascription. While this is true, it is nonetheless recognised that cultures vary considerably across the Caribbean Islands as well as in sub-Saharan Africa. Therefore, sense of identity, sense of belonging and self-ascription themselves will be influenced by the cultural context of the individual. In clinical practice, information on ethnicity is routinely collected and recorded in clinical records. However, it is acknowledged that the information may not be available or is incorrectly recorded. Therefore it is important to ensure that ethnicity is assigned consistently across the sample in this study. To do this, in addition to the routinely recorded ethnic groups, myself and colleagues manually checked and assigned ethnicity for individual patients included in the study. Ethnicity was ascribed independently by researchers using all

available information from the clinical records including country of birth, nationality, language spoken at home, parents' country of birth in conjunction with country of birth, geographical region (e.g. Saharan and sub-Saharan Africa), racial groups and religious groups (ONS, 2003). For the three ethnic groups under investigation in this study, 'Black African' includes people born in sub-Saharan Africa and people whose parents and grandparents were born in Africa. Similarly, 'Black Caribbean' includes people born or whose parents and grandparents were born in the Caribbean. Individuals of mixed parentage (e.g. Caribbean and other parentage or African and other parentage) were not included in the Black African and Black Caribbean groups. Instead, they were included in the 'Mixed' ethnic group. For the White British group, this includes people born in the UK (i.e. England, Wales, Scotland and Northern Ireland) to White parents. People born in rest of Europe or elsewhere to White parents were excluded from the White British group.

1.2. Psychosis

Psychosis is one of the most challenging psychiatric conditions to define due to the subjective nature of its clinical presentation which is often self-reported and as yet there is no objective test or validated biological marker for the condition (Jones, 2011). Recent studies show that men are 1.5 times more likely to develop psychosis than women, although later onset is reported in women with better course and outcome (WHO, 2005, Fearon et al., 2006a, Kirkbride et al., 2012a). It is a costly condition both to sufferers, their family and the economy (van Os and Kapur, 2009). Incidence rates ranging between 0.7 to 1.4 per 10,000 per year have been in reported in studies where schizophrenia is narrowly defined (Jablensky et al., 1992b) and a median of 1.5 per 10,000 per year in a recent meta-analysis (McGrath et al., 2004).

1.2.1. Diagnosis and Classification

Psychotic symptoms include delusions (firmly-held, false beliefs about external reality despite alternative evidence), hallucinations (false perception in any modality in the absence of eternal stimuli) and thought disorder (disturbance in conscious thoughts, shown through verbal processes). The International Classification of Disease (ICD-10) (World Health Organization, 1993) provides groups of diagnoses that come under the auspices of psychosis as shown in Table 1.2 below. These diagnoses are used in clinical practice and research and

they are at times referred to in two broad terms: schizophrenia spectrum disorders (F20-29) or affective disorders (F30-33).

For the purpose of this thesis, a broad and pragmatic definition of psychosis was employed, using the Psychosis Screening Schedule to determine whether a person screens positive. Individuals screened positive if they experienced at least one of the following:

- Hallucinations or pseudo-hallucinations in any modality
- Delusions
- Marked thought and speech disorder (e.g. incoherence, irrelevance, thought blocking, neologisms, incomprehensibility of speech) other than simple retardation or acceleration
- Marked psychomotor disorder (e.g. negativism, mutism or stupor, catatonic excitement, constrained attitudes or unnatural posture maintained for long periods) other than simple retardation or acceleration
- Emergence of marked exacerbation of bizarre and grossly inappropriate behaviour (e.g. talking or giggling to self, acts incomprehensible to others, loss of social constraints etc.)

Or two of the following:

- Marked reduction or loss of interests, initiative and drive, leading to a serious deterioration of the performance of usual activities and tasks
- Emergence or marked exacerbation of social withdrawal (active avoidance of communication with others)
- Severe excitement, purposeless destructiveness or aggression
- Episodic or persistent states of overwhelming fear or severe anxiety
- Gross and persistent self-neglect

Table 1.2: ICD-10 classifications of psychotic disorders

ICD-Code	Disorder	ICD-Code	Disorder
F20-F29	**Schizophrenia, schizotypal and delusional disorders**	**F30-F39**	**Mood (affective) disorders**
F20	Schizophrenia	F30	Manic Episode
F20.0	Paranoid Schizophrenia	F30.2	Mania with psychotic symptoms
F20.1	Hebephrenic Schizophrenia	F31	Bipolar affective disorder
F20.2	Catatonic Schizophrenia	F31.2	Bipolar affective disorder, current episode manic with psychotic symptoms
F20.3	Undifferentiated Schizophrenia		
F20.4	Post-schizophrenic depression		
F20.5	Residual Schizophrenia	F31.5	Bipolar affective disorder, current episode severe depression with psychotic symptoms
F20.6	Simple Schizophrenia		
F20.8	Other Schizophrenia		
F20.9	Schizophrenia, unspecified		
F21	Schizotypal Disorder	F32	Depressive episode
F22	Persistent Delusional Disorders	F32.3	Severe depressive episode with psychotic symptoms
F23	Acute and Transient Psychotic Disorders	F33	Recurrent depressive disorder
F24	Induced Delusional Disorder	F33.3	Recurrent depressive disorder, current episode severe with psychotic symptoms
F25	Schizoaffective Disorders		
F25.0	Schizoaffective Disorder, manic type		
F25.1	Schizoaffective Disorder, depressive type		
F25.2	Schizoaffective Disorder, mixed type		
F25.8	Other Schizoaffective Disorders		
F25.9	Schizoaffective Disorder, unspecified		
F28	Other Non-organic Psychotic Disorders		
F29			

1.3. Objectives, Aims and Hypotheses

As mentioned above, the overall objective of this thesis is to describe (at baseline) the incidence rates of psychosis, pathways to care at first contact and (at follow-up) the service use outcomes by ethnic group at two years following first episode of psychosis.

At baseline, cross-sectional data on sociodemography, clinical presentation, compulsory detention and pathways to care at first contact were collected. In addition, a comparison of pathways to care is made between data from this study and the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ASEOP) study. Two questions will be addressed at this stage: (a) is the discrepancy in incidence rates between ethnic groups any larger (or smaller) now than 15 years ago? and (b) are there any differences in the duration of untreated psychosis (DUP) and pathways to care for FEP cases compared to 15 years ago and is this associated with the introduction of EIS?

The aims of the first phase (baseline) are:

1. To estimate the incidence of psychosis by ethnic groups during a two-year period May 2010 – April 2012 in a well-defined catchment area in south London.

2. To compare pathways to care, hospital admission (compulsory vs. non-compulsory) and source of referral (GP, A&E and others) at first contact for psychosis by ethnic groups.

3. To compare these pathways to care (compulsory vs. non-compulsory) and source of referral (GP, A&E and others) with those reported in the earlier AESOP sample and between those using early intervention service or not in the current study sample.

In relation to these aims, the following hypotheses will be tested:

Compared with those of White British ethnicity:

Incidence

1.1 The incidence of all psychoses will be higher in those of Black Caribbean and Black African ethnicity.

1.2 The magnitude of relative risk will be smaller for the minority ethnic groups (Black African and Black Caribbean) compared with those reported in previous studies (e.g. AESOP study, Fearon et al. 2006).

Pathways to care at first contact for psychosis

2.1 Higher rates of hospital admissions will be associated with Black African and Black Caribbean ethnicity.

2.2 Increased risk of compulsory admissions will be associated with Black African and Black Caribbean ethnicity.

2.3 Higher rates of police involvement will be associated with Black African and Black Caribbean ethnicity.

2.4 Lower levels of GP referral will be associated with Black African and Black Caribbean ethnicity.

2.5 Higher rates of accident and emergency referral will be associated with Black African and Black Caribbean ethnicity.

2.6 Compared with 15 years ago (i.e. AESOP vs. CRIS FEP samples), among patients aged 18-35 years old, ethnic differences in GP referral and crisis source of referral (criminal justice agency, accident and emergency) and compulsory admission at first contact for psychosis will be smaller for Black African and Black Caribbean patients.

At follow up, data relating to service use (i.e. number of hospitalisations, number of compulsory admissions and total number of days spent in hospital) were collected longitudinally during the two-year follow-up period. Two questions were the addressed: (a) are there differences by ethnic group in the rate of admission, compulsory admission and length of time patients spend in hospital during the follow up period? and (b) are there differences in rates of hospital admission, length of hospital stay and compulsory detention by early intervention service status during the follow up period?

The follow-up phase aims are:

1. To estimate rates and rate ratios of hospital admission and compulsory detention during the two-year follow-up by ethnic group.
2. To estimate differences in length of hospital stay by ethnic group during the two-year follow-up.
3. To compare service use (hospital admission, compulsory admission) between those using early intervention services and standard community care during the two-year follow-up.
4. To determine whether there are ethnic differences in service use outcomes during the two-year follow-up in relation to early intervention service use status.

Course and outcome

The following hypotheses will be tested:

3.1 Over the two-year follow-up period, worse service use outcomes (characterised by increased rates of hospital admissions, compulsory admission and longer duration of hospital stay) will be observed among those of Black Caribbean and Black African ethnicity compared with White British patients.

3.2 Over the two-year follow-up period, worse service use outcomes will be associated with non-EIS use compared with EIS use and these will vary by ethnic groups.

1.4. Structure of Thesis

This thesis is structured as follow:

Chapter 2 presents a review of literature and methodological consideration of research studies that have examined the relationships between ethnicity and the incidence of psychosis.

Chapter 3 presents an overview and critique of research studies that investigated associations between ethnicity and pathways to care and source of referral. It also considers the role of early intervention services in the pathways to care and help-seeking during first episode psychosis.

Chapter 4 reviews and reports on studies that have investigated the associations between ethnicity and course and outcome of psychosis.

Chapter 5 gives a contextual overview of the population at risk within which this thesis study was conducted. It provides an in-depth detail of the case register from which psychosis cases were identified. It also discusses the sociodemographic and socioeconomic characteristics of the population at risk.

Chapter 6 presents the general methodology of the study from which the data for this thesis were drawn (Section 6.5). Section 6.5.3 provides an in-depth detail of the screening process for identifying first episode psychosis cases. Section 6.5.5 gives details of the measures used to assess sociodemographic characteristics, pathways to care and service use outcomes.

Chapter 7 describes the results of the screening procedure, sociodemographic characteristics and findings from the analysis of incidence of psychosis by ethnic groups (Hypotheses 1.1 and 1.2).

Chapter 8 presents the findings of the associations between ethnicity and various sources of referral, compulsory and hospital admissions during first contact for psychosis (Hypotheses 2.1 to 2.5).

Chapter 9 presents the results of the early intervention-stratified associations between ethnicity and pathways to care comparing data from the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ASEOP) study and data from this thesis (Hypothesis 2.6).

Chapter 10 presents findings of the relationships between ethnicity and service use outcomes at the two-year follow-up (Hypothesis 3.1).

Chapter 11 explores associations between early intervention service and service use outcomes. It also describes early intervention services-specific ethnic variations in service use outcomes (Hypothesis 3.2).

Chapter 12 presents a summary of findings presented in the preceding chapters, alongside a discussion of methodological strengths and limitations of the study. It then offers suggestions for direction of future research and the implications of the findings.

1.5. Candidate's Distinct and Original Contributions

This thesis was formed as part of a larger on-going study, the Clinical Records Interactive Search-First Episode Psychosis (CRIS-FEP) led by Professor Craig Morgan. Within this study, I was involved from the outset in all aspects of screening clinical records of over nine thousand patients, identifying first episode cases and collecting data. I led on the follow-up phase of this thesis, whereby key variables of interest were defined and extracted from CRIS. In preparing data for analysis in this thesis, I was responsible for checking data integrity and completeness on key variables such as ethnicity, sociodemographic characteristics, pathways to care, DUP and service use. I contributed extensively to data entry and data cleaning. The aims and hypotheses of this thesis, which I believe are novel, were developed by me and I carried out all the analyses presented in this thesis.

2 Chapter 2: Literature Review – Incidence of First Episode of Psychosis and Ethnicity

2.1 Synopsis

Higher incidence rates of psychosis are consistently reported among black and ethnic minority groups particularly in Western countries (Bhugra et al., 1997, Fearon et al., 2006a, Chorlton et al., 2012, Kirkbride et al., 2012b, Fung et al., 2009). Several possible explanations have been put forward to understand the excess of psychosis in these groups, including biological, environmental and social factors.

Much attention has been given to biological risk factors and bio-markers in understanding the aetiology of psychosis, even more so because of the emergence of sophisticated technologies for studying the brain and genes (Morgan et al., 2008b). So far, biological risk factors alone have not been sufficient to explain the aetiology of psychosis; even attempts made at explaining psychosis through hereditary from the twins studies fail to fully account for the aetiology of the illness (Cardno and Gottesman, 2001). Similarly, other biological factors such as obstetric complication have been found to be associated with increased risk of schizophrenia in offspring (Clarke et al., 2006) and the prevalence of such complications tends to be higher in migrant groups (Sharpley et al., 2001). However, this evidence is not consistent as other studies have found no association of higher obstetric complication among migrant groups (Hutchinson et al., 1997, Morgan et al., 2010). Another biological argument for increased rates of psychosis in the migrant groups (particularly black migrants) is that of vitamin D deficiency, since moving to colder climates may reduce exposure to sunlight (McGrath, 1999). Morgan et al. in a review contextualised this notion and argued that the potential racial discrimination that individuals from Black migrant and minority groups experience, who are most visible in predominately white societies, may be equally plausible as low vitamin D (Morgan et al., 2010).

The role of social factors and experiences has been a controversial debate in understanding the aetiology of psychosis. However, social changes whether at societal, familial or individual level may be at play in providing some promising indication in understanding the aetiology of psychosis. In the past two decades many efforts have been spent examining the role of social factors in the onset of psychosis with evidence suggesting that there are strong

links between the environment and social factors and psychosis (van Os et al., 2010). For example, an excess of psychosis is widely reported among migrant populations in Western countries such as the UK, USA, Australia, Europe and also among migrants' children born in the host country (Selten et al., 2001, Veen et al., 2002, Cantor-Graae and Selten, 2005, Fearon et al., 2006a, McKenzie et al., 2008). This suggests there is something about living as a member of a migrant or minority ethnic group in a host context that increases the risk of developing psychosis.

The demographic profile of the UK population has undergone a noticeable change with the proportion of people born outside the UK living in England and Wales increasing and rising unemployment, but with the number of people without educational qualifications falling by around 6% (ONS, 2011b). These factors may impact on the mental health of the overall population and in particular migrant populations.

This chapter provides a detailed review of research from social perspectives, addressing specifically the question, is the discrepancy in incidence rates between ethnic groups any larger (or smaller) now than they were 15 years ago?

2.2 Examining the Role of Ethnicity and Social Risk Factors in the Aetiology of Psychosis.

In this chapter, I will review the literature concerning associations between minority ethnicity (namely Black African and Black Caribbean) and social factors through the prism of migration (section 2.2.1), ethnic density (section 2.2.2) and social disadvantage (section 2.2.3) as predictors of psychotic disorder. To clarify, this is not a systematic review, since a number of such reviews and meta-analyses have been carried out recently (McGrath et al., 2004, Kirkbride et al., 2012a). Instead, a careful search was undertaken to scope the main literature on the topic. Using bibliographic databases (including Embase, PsychoInfo, Pubmed and Web of Science) and search terms including 'ethnicity', 'psychosis', 'African', 'Caribbean', 'migration', 'social' and 'density', I have predominately considered studies conducted in the last decade, as studies in this time period employed more robust

methodology than earlier studies. For example, many recent studies defined ethnicity according to standardised categories of self-ascription (e.g. ONS census categories) and many have moved away from crude comparison of 'Black and White' ethnicities. I have also only included studies that have employed population-based epidemiological methods including those that identified first episode psychosis patients in both inpatient and community settings in well-defined geographical areas. Forty-seven studies were included and their key findings are outlined in Tables 2.1, 2.2, and 2.3 below. I have acknowledged some older studies that measure the rates of psychosis among minority ethnic groups compared to the native population because these studies provide underpinning evidence and theories upon which the review in this chapter is based. Limitations of current evidence are presented in section 2.3 and finally a summary of the review is outlined in section 2.4.

2.2.1 Psychosis, ethnicity and migration

Migration is defined as the process of going from one country, region or place of residence to settle in another and there are three key stages to the process: pre-migration, migration and post-migration (Bhugra et al., 2011b). Migration has been recognised as an important factor in understanding the aetiology of psychosis for many decades. Evidence of its effects began to be observed in the 1930s when Odegaard examined the rates of hospital admissions among Norwegian migrants to Minnesota and found double the rate among the migrants compared to the indigenous Minnesotans (Odegaard, 1932). Since then, endeavours have continued in understanding the role of migration as a predictor of psychosis. Over the years, a number of hypotheses have been put forward as possible explanations for excess of psychosis in migrant groups. For example, Cochrane and Bal (Cochrane and Bal, 1987) argued for four key theories which research studies have attempted to test. They are reviewed below.

1. Countries of origin have higher rates of schizophrenia. A few older studies have compared rates of psychosis between Western and developing countries, but evidence shows no increase in rates in developing countries (Hickling and Rodgers-Johnson, 1995, Bhugra et al., 1996, Jablensky et al., 1992b, Hanoeman et al., 2002, Bhugra et al., 2000, Tafari et al., 1991). Yet the rate of psychosis among migrant groups to Western countries,

especially Black African and Black Caribbean (first and second generation), is higher (Fearon et al., 2006a, Kirkbride et al., 2012a). This may suggest that it is factors in the host counties that most explain the observed discrepancies.

2. Schizophrenia (or related precursors) predisposes individuals to migration; that is to say, individuals with schizophrenia or at risk of schizophrenia are more likely to migrate than people who do not. This is synonymous with the hypothesis of selection and drift, whereby people with schizophrenia either drift into or are selected into urban areas or lower social class groups because of disability or discrimination (March et al., 2008). Selten and colleagues (2002) tested this hypothesis by envisaging that the entire population of Surinam had migrated to the Netherlands. They calculated denominator population for the Surinamese by combining the Surinamese-born population in the Netherlands and that of Surinamese 1980 census figures and then compared incidence rates of schizophrenia to the native Dutch population. The result revealed a markedly increased relative risk of psychosis, adj. RR of 1.46 (95% CI 1.35 – 1.57) among the Surinamese (Selten et al., 2002). However, Lundberg and colleagues (2007) in a Ugandan study sought to examine the impact of psychotic-like experiences on the likelihood of migration. They compared prevalence of psychosis between those planning to emigrate and those with no intention to emigrate and found no difference between the two groups (Lundberg et al., 2007).

3. Migration produces stress. Cochrane and Bal argued that difficulties and traumas surrounding migration and the social disadvantage of being a migrant (e.g. experiencing discrimination) increases the risk of psychosis (Cochrane and Bal, 1987). Odegaard (1932) demonstrated that psychosis is at its peak during the post-migration phase. Indeed, post-migratory experiences such as securing housing, building social relationships/networks and understanding the way of life in the host country, which are often negative (Johns et al., 2004), may also increase stress and the risk of developing psychosis. Historically, migrants tend to settle in city areas of host countries and much effort has been spent in understanding the relationship between inner-city living (urbanicity) and psychosis. It is well documented that social factors such as stressful life events, social isolation, higher levels of crime, higher unemployment rates and overcrowding are more commonplace in inner cities and these disadvantages are often experienced by migrants (Boydell et al., 2012, Morgan et al., 2009, Reininghaus et al., 2008).

4. Misdiagnosis of schizophrenia (psychosis). Arguments have been put forward that migrant patients have psychological conditions which have been misdiagnosed as psychosis, and that the diagnosis of schizophrenia has been used to impose social control on minority groups. Hickling and colleagues' (1999) study compared diagnoses using the Present State Examination (PSE), a research diagnostic interview, made independently by a British psychiatrist and a Jamaican psychiatrist and showed a 55% agreement between the British psychiatrist and the Jamaican psychiatrist in the proportion of black patients diagnosed with schizophrenia by the British psychiatrist or the Jamaican psychiatrist. However, there was disagreement in the diagnosis of affective psychoses, where the British psychiatrist were more likely to diagnosed patients with affective psychoses as having schizophrenia. However, the overwhelming evidence in the last few decades shows stubbornly higher rates of psychosis among Black African and Black Caribbean patients in the UK, Europe and the USA (Fearon et al., 2006a, Cantor-Graae and Selten, 2005, March et al., 2008, Veling, 2013). Many of these studies have employed standardised scales for assessing symptoms, and even blinded to ethnicity they found elevated rates of psychosis in the minority groups. Therefore, misdiagnosis is unlikely to play a major role, given numerous well designed studies consistently show a higher rate of psychosis in black Caribbean and black African minorities, and migrants; but other social and environmental factors may be more relevant.

Considering research in the past ten years, a number of studies have reported various ways of assessing the discrepancy of incidence rates of psychosis between ethnic groups as shown in Table 2.1. A diverse range of incidence rates per 100,000 person-years were reported with incidence rates (IR) ranging between 16.4 (Tarricone et al., 2012) and 50.0 (Cheng et al., 2011a). Only two studies reported IR by ethnic group. Fearon et al. (2006) reported IRs of 20.2 for White British, 140.8 for Black Caribbean and 80.6 for Black African (Fearon et al., 2006a), while Cheng and colleagues (2011) reported IRs of 47.0 for White British and 94.2 for Black groups (Cheng et al., 2011a, Fearon et al., 2006a). Meanwhile, all studies reporting incidence rate ratios (IRR) among migrant groups compared to the native populations found higher rates in the migrant groups ranging between 1.2 (Veling et al., 2006) (Cheng et al., 2011a, Coid et al., 2008b) and 18.2 (Lloyd et al., 2005). Considering the variation of effect by ethnic groups, IRR were reported as follows: for Black Caribbean, IRRs ranged from 2.1 (Cheng et al., 2011a) to 18.2 (Lloyd et al., 2005); Black African IRRs from 2.6

(Kirkbride et al., 2008) to 11.9 (Lloyd et al., 2005); Other White from 1.2 (Tortelli et al., 2014) to 2.3 (Lloyd et al., 2005). Similarly, higher relative risks were reported in migrant groups particularly among Moroccan, RR= 2.3 (Veling et al., 2006) to 7.8 (Zandi et al., 2010), and Surinamese, RR= 1.46 (Selten et al., 2002) to 1.5 (Zandi et al., 2010).

In addition, the fact that excess rates are not confined to first generation migrants as new evidence, suggests that both first and second generation migrants are at risk. Cantor-Graae and Selten (2005) in a systematic review concluded that personal or family migration is a risk factor of psychosis among both first and second generation migrants. The relative risk of psychosis is highest 4.8 (95% CI 3.7–6.2) in migrants of Black ethnicity compared with other migrant groups (Cantor-Graae and Selten, 2005). Bourque and colleagues (2011) in a meta-analysis, also reported IRR of 5.4 (95% CI 3.2–8.8) among second generation migrants categorised as 'Black'. Two other studies reviewed in Table 2.1 below have also reported incidence rate ratios by generational status, for example Coid and colleagues (2008) reported IRRs of 3.2 and 3.7 among first and second generation Black Africans respectively. Meanwhile among the Black Caribbean group, IRR of 3.2 and 1.6 were reported respectively. This suggests that rates of psychosis are elevated in both generations but appears to be diminishing in the among second generation Black Caribbean group. Further, Veling and colleagues reported IRRs from 2.3 to 5.8 among first and second generation Moroccans and 4.0 to 2.9 among first and second generation Surinamese(Veling et al., 2006). Similarly, rates appear to be reducing among the second generation Surinamese in the Netherlands.

Other demographic factors have also been considered in estimating incidence of psychosis; one study looked at age of migration and reported that young migrants (aged 20 and below) are particularly at risk (Veling et al., 2011). Gender has also been reported as a contributory factor with Asian women reported to be more at risk compared with White British women, while first generation Black African men were reported to be at higher risk compared with White British men (Coid et al., 2008b). Furthermore, variation in magnitude of risk by diagnosis were reported, for schizophrenia IRR ranged from 1.5 (Smith et al., 2006) to 9.1 (Fearon et al., 2006a); affective psychosis IRR from 1.7 (Fearon et al., 2006a) to 18.2 (Lloyd et al., 2005); depressive psychosis IRR from 3.1 to 5.6 (Fearon et al., 2006a).

Table 2.1: Studies of incidence of psychosis, ethnicity and migration.

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
Selten et al. (2002) (the Netherlands)	10 yr retrospective Hospital admissions	697 Surinamese 10,726 Dutch	The Bureau of Statistics Netherlands and The Bureau of Statistics Paramaribo Country of birth	ICD-8 and ICD-9 Clinical diagnosis only	Schizophrenia	**Reference group: Native Dutch** **RR = 1.46(95% CI 1.35–1.57) Surinamese**
Lloyd et al. (2005) (UK)	Incidence and Case-control (AESOP)	75 FEP	MRC Socio-demographic schedule (Mallett 1997). 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	ICD-10 SCAN SCAN - IGC	Mania - with or without psychotic symptom Bipolar affective disorder	**Reference group: White** **IRR = 12.3 (95% CI 8.3–17.6) all BME** **IRR = 18.2 (95% CI 10.8–28.8) African-Caribbean** **IRR = 11.9 (95% CI 5.9–21.3) Black African** **IRR = 12.7 (95% CI 4.6–27.8) mixed ethnicity** **IRR = 2.3 (95% CI 1.6–3.2) White group**
Fearon et al. (2006) (UK)	Incidence and Case-control	568 FEP patients	MRC Socio-demographic	ICD-10 SCAN	**All psychoses:**	Adj. IR = 20.2 (95% 17.8 – 22.7) White British

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
	(AESOP)		schedule (Mallett 1997) 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	SCAN - IGC		Adj. IR = 140.8 (95% 114.4 – 167.2) Black Caribbean Adj. IR = 80.6 (95% 60.0 – 101.2) Black African Adj. IR = 31.6 (95% 16.7 – 46.5) Asian Adj. IR = 55.0 (95% 30.9 – 79.1) Other Adj. IR = 45.9 (95% 26.4 – 65.5) Mixed Adj. IR = 33.1 (95% 22.0 – 44.2) Other White Adjusted IRR for gender and age Reference group: White British **Schizophrenia:** **IRR = 9.1 (95% CI 6.6 – 12.6) African Caribbean** **IRR = 5.8 (95% CI 3.9 – 8.4) Black African** IRR = 1.4 (95% CI 0.7 – 3.1) Asian **IRR = 3.5 (95% CI 1.9 – 6.5) Other** **IRR = 2.6 (95% CI 1.2 – 5.3) Mixed** **IRR = 2.5 (95% CI 1.6 – 3.9) White Other**

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						Manic psychosis: **IRR = 8.0 (95% CI 4.3 – 14.8) African Caribbean** **IRR = 6.2 (95% CI 3.1 – 12.1) Black African** IRR = 2.7 (95% CI 0.9 – 7.6) Asian IRR = 3.0 (95% CI 0.9 – 10.0) Other **IRR = 6.2 (95% CI 2.6 – 15.0) Mixed** IRR = 1.7 (95% CI 0.6 – 4.3) White Other **Depressive psychosis:** **IRR = 3.1 (95% CI 1.5 – 6.1) African Caribbean** IRR = 2.1 (95% CI 0.9 – 5.0) Black African **All Psychoses** IRR = 6.7 (95% CI 5.4 – 8.3) African-Caribbean IRR = 4.1 (95% CI 3.2 – 5.3) Black

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						African IRR = 1.5 (95% CI 0.9 – 2.4)Asian IRR = 2.6 (95% CI 1.7 – 3.9) Other IRR = 2.7 (95% CI 1.8 – 4.2) Mixed IRR = 1.6 (95% CI 1.1 – 2.2) White Other **IRR = 3.0 (95% CI 1.3 – 7.1) Asian** **IRR = 5.6 (95% CI 2.5 – 12.4) Other** **IRR = 4.0 (95% CI 1.6 – 10.2) Mixed** IRR = 1.3 (95% CI 0.5 – 3.2) White Other **Other psychosis:** **IRR = 5.5 (95% CI 3.8 – 8.0) African Caribbean** **IRR = 2.7 (95% CI 1.6 – 4.5) Black African** IRR = 0.6 (95% CI 0.2 – 1.9) Asian IRR = 0.3 (95% CI 0.1 – 2.2) Other IRR = 1.3 (95% CI 0.5 – 3.5) Mixed IRR = 0.8 (95% CI 0.4 – 1.7) White Other

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
Kirkbride et al. (2006) (UK)	Incidence and Case-control (AESOP)	568 FEP patients	MRC Socio-demographic schedule (Mallett 1997). 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	ICD-10 SCAN SCAN- IGC	All psychoses Schizophrenia: Substance-induced psychoses: Affective psychosis: Other psychosis:	**IRR = 2.3 (95% CI 1.7 – 3.1)** Schizophrenia **IRR =3.6 (95% CI 3.0 – 4.2)** All psychoses among BME No ethnic difference in affective psychoses **Variation by study centre** **IRR = 49.4 (95% CI 43.6 – 55.3)** Southeast London **IRR = 23.9 (95% CI 20.6 – 27.2)** Nottingham **IRR = 20.4 (95% CI 15.1 – 25.7)** Bristol
Veling et al. (2006) (The Netherlands)	Cohort incidence study	197 FEP patients	The Municipality of The Hague classification Country of birth Country of parents' birth	CASH IRAOS DSM-IV	Schizophrenia	**First generation** **Adj. IRR = 2.3 (95% CI 1.7 – 3.0**) Moroccans **Adj. IRR = 4.0 (95% CI 2.5 – 6.3)** Surinamese Adj. IRR = 1.4 (95% CI 0.7 – 2.6) Turks Adj. IRR = 1.2 (95% CI 0.5 – 2.5)

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						Immigrants from other non-Western countries **Second generation** **Adj. IRR = 5.8 (95% CI 2.9 – 11.4) Moroccans** **Adj. IRR = 2.9 (95% CI 1.6 – 5.0) Surinamese** **Adj. IRR = 2.3 (95% CI 1.0 – 5.4) Turks** **Adj. IRR = 3.5 (95% CI 1.8 – 6.8)** Immigrants from other non-Western countries
Veling et al. (2007) (the Netherlands)	Cross-sectional survey	361 first contact patients	The Municipality of the Hague classification Country of birth Country of parents' birth	CASH DSM-IV IRAOS	Depressive disorder Bipolar disorder Brief psychotic disorder	**Positive symptoms Moroccan vs. native Dutch** **Adj. OR = 3.44 (95% CI 1.49 – 7.93) Persecutory delusion** **Adj. OR = 3.14 (95% CI 1.43 – 6.87) Bizarre behaviour** **Adj. OR = 3.08 (95% CI 1.36 – 7.00) Visual hallucinations** Adj. OR = 0.29 (95% CI 0.08 – 1.06) Religious delusions

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						Negative symptoms Moroccan vs. native Dutch **Adj. OR = 2.69 (95% CI 1.23 – 5.90) Anhedonia** **Adj. OR = 2.61 (95% CI 1.12 – 6.09) poverty of speech** **Adj. OR = 2.31 (95% CI 1.04 – 5.12) self-care**
Coid et al. (2008) (UK)	Population-based incidence survey (ELFEP)	484 FEP	2001 UK ONS census	SCAN - IGC DSM-IV	Non-affective psychoses	Incidence rates **Adj. IR = 20.9 (95% CI 16.2 – 25.6) White British** **Adj. IR = 42.4 (95% CI 28.6 – 56.2) White Other** **Adj. IR = 90.8 (95% CI 67.8 – 113.8) Black Caribbean** **Adj. IR = 73.6 (95% CI 54.4 – 92.7) Black African** **Adj. IR = 37.7 (95% CI 28.1 – 47.2) Asian** **Adj. IR = 25.1 (95% CI 13.7 – 36.4) Other** Incidence rate ratios **IRR = 4.2 (95% CI 3.0 – 5.8) Black Caribbean**

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
					Affective psychoses	**IRR = 3.4 (95% CI 2.4 – 4.7) Black African** **IRR = 1.6 (95% CI 1.1 – 2.4) 2nd generation Black Caribbean** **IRR = 3.2 (95% CI 2.3 – 4.6) 1st generation Black African** **IRR = 3.7 (95% CI 2.2 – 6.4) 2nd generation Black African** **IRR = 2.3 (95% CI 1.0 – 5.3) Asian women** **IRR = 3.1 (95% CI 2.0 – 4.7) 1st generation Black African men**
Kirkbride et al (2008) (UK)	Population-based incidence survey (ELFEP)	484 FEP	2001 UK ONS census Self-ascribed Other informants Researcher – ascribed (via case notes)	SCAN - IGC DSM-IV	Schizophrenia Affective psychoses	**IRR = 3.1 (95% CI 2.1 – 4.5) Black Caribbean** **IRR = 2.6 (95% CI 1.8 – 3.8) Black African** **IRR = 3.1 (95% CI 1.2 – 8.1) Pakistani** **IRR = 2.3 (95% CI 1.1 – 4.7) Bangladeshi (women).** **IRR = 7.7 (95% CI 3.2 – 18.8) Mixed White and Black**

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						Caribbean **IRR = 2.1 (95% CI 1.2 – 3.8) White Other**
Kirkbride et al. (2009) (UK)	Incidence study over 3 time periods	347 FEP	UK Census ONS-1981, 1991, 2001 classification Self-ascribed Other informants Researcher – ascribed (via case notes)	PSE PPHS SCAN SANS ICD-9 ICD-10	Schizophrenia Affective psychosis Substance – induced psychoses Affective psychosis	IR of all psychosis per 100,000 IR = 23.4 (95% CI 18.6 – 28.2) 1978-80 IR = 26.0 (95% CI 21.2 – 30.8) 1992-94 IR = 27.1 (95% CI 22.3 – 31.9) 1997-99 Linear change in incidence over time by diagnosis **IRR = 1.15 (95% CI 1.05 – 1.25) substance induced psychosis.** IRR = 0.98 (95% CI 0.96 – 1.00) schizophrenia IRR = 1.00 (95% CI 0.98 – 1.03) affective psychoses
Cheng et al. (2011) (UK)	Longitudinal cohort study *CAMEO study*	285 FEP	UK ONS Census 2001 and 2002 estimates Self-ascribed	ICD-10 PANSS	All psychotic disorders	IR = 50.0/100,000 overall IR = 47.0 (95% CI 41.0 – 53.9) White British IR = 49.4 (95% CI 32.8 – 71.4) non-British white IR = 94.2 (95% CI 47.0 – 168.5) Black

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						IR = 42.5 (95% CI 28.0 – 61.9) Other **Adj. IRR = 2.1 (95% CI 1.1 – 3.8)** **Black** Adj. IRR = 1.1 (95% CI 0.8 – 1.7) White non-British Adj. IRR = 0.9 (95% CI 0.6 – 1.4) Mixed and other
Veling et al. (2011) (the Netherlands)	7-yr incidence study	173 immigrant 119 second-generation citizens 226 Dutch citizens	The Municipality of the Hague Native First generation Country of birth Country of parents' birth	CASH DSM-IV IRAOS	All psychotic disorders	**IRR among non-Western Immigrants by age of migration** **IRR = 3.0 (95% CI 2.1 – 4.2)** Age 0-4 **IRR =2.3 (95% CI 1.6 – 3.3)** Age 5-9 **IRR =1.5 (95% CI 1.0 – 2.3)** Age 10-14 **IRR = 1.85 (95%CI 1.35 – 2.53)** Age 15-19 IRR = 1.40 (95% CI 0.96 – 2.03) Age 20-24 IRR = 1.14 (95% CI 0.71 – 1.83) Age 20-29 **IRR = 1.82 (95% CI 1.43 – 2.32)** **Second generation citizens**

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
Tarricone et al. (2012) (Italy)	Prospective cohort study – 8-yr	163 FEP	Municipality Registry Migrant vs. Native Country of birth	ICD-10 ICG-SCAN	Affective psychosis Non-affective psychosis Substance-induced psychosis Schizophrenia	Lower IR of FEP compared to other study centres IR = 16.4/100,000 (95% CI 13.9 – 18.9) IR higher in men, migrants and young people **IRR = 2.53 (95% CI 2.19 – 2.89) all psychosis – migrants** **IRR = 3.38 (95% CI 2.98 – 3.79) non-affective psychosis – migrants** **IRR = 4.04 (95% CI 3.55 – 4.53) SCZ – migrants**
Tortelli et al. (2014) (France)	Hospital cross-sectional study	258 patients – hospital admission	2008 French census categories (natives vs. migrants) Country of birth	ICD-10 clinical diagnosis	Non-affective psychosis Affective psychosis	Adj. IR = 28.0 (95% CI 12.5 – 62.5) Overall Adj. IR = 17.5 (95% CI 6.5 – 48.0) Natives Adj. IR = 22.0 (95% CI 9.0 – 54.0) Europe Adj. IR = 125.0 (95% CI 84.5 – 184.5) Sub-Saharan Africa Adj. IR = 25.0 (95% CI 11.0 – 59.0) North Africa IRR = 2.9 (95% CI 0.9 – 9.8)

Authors (Country)	Study Design	Sample	Measure of population denominator / Ascertainment of ethnicity	Scale for measuring psychosis	Outcome(s)	Main findings
						Migrants **IRR = 7.1 (95% CI 2.3 – 21.8) sub-Saharan African** IRR = 1.2 (95% CI 0.35 – 5.1) European IRR = 1.4 (95% CI 0.4 – 5.6) North African

IRR, incidence rate ratio. IR, incidence rate. RR, relative risks. OR, odds ratio. MRC Socio-demographic schedule (Mallett, 1997). DUP, Duration of untreated psychosis. ICC, interclass correlation coefficient. ONS, Office of National Statistics. BME, Black and minority ethnic. HSE, health survey England. CASH, comprehensive assessment of symptoms and history. IROAS, instrument for the retrospective assessment of the onset of schizophrenia. SCAN, schedule of clinical assessment in neuropsychiatry. SCAN - IGC, schedule of clinical assessment in neuropsychiatry - item group checklist SCAN. CIDI, composite international diagnostic interview. PDI, Peters et al. 1999 delusions inventory. ICD, international classification of diseases. SANS, schedule for the assessment of negative symptoms. PPHS, personal and psychiatric history schedule. PSE, present state examination. CASH-CS, comprehensive assessment of symptoms and history – cultural sensitive.

2.2.2 Ethnic density, neighbourhood and psychosis

A few years after Odegaard's findings, Faris and Dunham (1939) explored the relationship between the spatial distribution of psychosis and social organisation. They examined ethnic density (i.e. proportion and concentration of a given ethnic group in a defined area) and social class and argued that social isolation and language barriers among different communities could explain higher rates of psychosis (Faris, 1939). Their Chicago study revealed that the least socially organised inner city area had higher rates of schizophrenia. Faris and Dunham's work inspired interest in the investigation of ethnicity, ethnic density, social class and mental illness – psychosis in particular. As such, much attention has been given to exploring these areas in recent years. Table 2.2 shows studies carried out in the last ten years investigating ethnic density effects on rates of psychosis.

From the table, Kirkbride and colleagues (2007) reported a variance in the incidence of schizophrenia (23% (95% CI 9.9 – 42.2)) and non-affective psychoses (15% (95% CI 2.9 – 55.0)) at both individual and area levels. They argued that the variance could be attributed to neighbourhood-level risk factors and found that social capital (measured by voter turnout) was associated with the raised incidence (Kirkbride et al., 2007). Similar trends were observed in the Netherlands, where Veling et al. (2008) compared incidence rates for native Dutch and immigrants; they reported an IRR of 2.36 (95% CI 1.89 – 2.95) in low-ethnic density neighbourhoods whereas this was not so in high-ethnic density areas (IRR 1.25 (95% CI 0.66 – 2.37)) (Veling, Susser et al. 2008). Schofield et al. (2011) explored the ethnic density effect in explaining raised incidence among minority ethnic populations in a UK inner city area. They found that in the neighbourhoods where Black people comprised more than 25% of the population, there was no statistically significant ethnic difference, but differences were found in areas where Black people were less represented; the OR was 2.88 (95% CI 1.89 – 4.39) (Schofield et al., 2011). This is consistent with more recent findings, for example Das-Munshi (2012) and colleagues reported an overall OR of 1.07 (95% CI 1.01 – 1.14) for all minority ethnic groups in areas of lower own-group density and that residents were more likely to experience greater social adversity, which is consistent with reports of psychotic experiences. They argued that ethnic density acts as a buffer against the development of psychotic experiences (Das-Munshi et al., 2012). In a narrative review of ethnic density and impact on mental disorders, Shaw et al. (2012) reported a consistent

association between ethnic density and psychosis and even stronger associations between minority status, area-level material deprivation and low socioeconomic status. They concluded that there might be potential psychosocial benefits drawn from living among people of the same ethnic group (Shaw et al., 2012). Termorshuizen et al. (2014) echoed this phenomena when they found a decreasing rate ratio of non-affective psychotic disorder with increasing minority ethnic density (from RR = 2.36 to 1.24) in non-Western immigrants and (from RR = 1.63 to 1.01) in Western immigrants compared with native Dutch patients (Termorshuizen et al., 2014).

Several studies of ethnic density have used individual-level variables such as ethnicity, age and gender. However, more recently, Kirkbride and colleagues (2014) investigated whether incidence of psychosis varied at neighbourhood level, looking at absolute neighbourhood level factors (deprivation, social fragmentation, and social cohesion) and relative factors (inequality, ethnic density and ethnic separation). Using a Bayesian hierarchical spatial model, they reported associations with level of income inequality (RR = 1.25; 95% CI 1.04–1.49), absolute deprivation (RR = 1.28; 95% CI 1.08 – 1.51) and population density (RR= 1.18; 95% CI 1.00 – 1.41). They also found that the neighbourhood ethnic composition effects were associated with the incidence of non-affective psychosis for people of Black Caribbean and Black African ethnicities (Kirkbride et al., 2014).

Table 2.2: Studies of psychosis and ethnic density.

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis/Diagnosis	Main findings
Kirkbride et al. (2007) (UK)	Incidence and Case-control (AESOP)	218 FEP	MRC Socio-demographic schedule (Mallett 1997) 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	ICD-10 SCAN SCAN - IGC	Non-affective psychoses Schizophrenia Other non-affective psychoses	23% of variance in incidence of schizophrenia attributed to neighbourhood level risk factors **Adj. ICC = 22.5% (95% CI 9.9 – 42.2)** SCZ **Adj. ICC = 15.3% (95% CI 2.9 – 55.0)** Non-affective psychoses
Veling et al. (2008) (the Netherlands)	Prospective incidence study	226 Dutch Natives 240 immigrants FEP	The Municipality of the Hague Native First generation Country of birth Country of parents' birth	CASH DSM-IV IRAOS	Schizophrenia Major depressive with psychosis Bipolar disorder Delusional disorder	**Adj. IRR = 2.36 (95% CI 1.89 – 2.95)** Low-ethnic density neighbourhoods Adj. IRR = 1.25 (95% CI 0.66 – 2.37) High-ethnic density areas
Schofield et al. (2011) (UK)	Clinical record survey	60971 records of Black and White patients	2001 UK Census ONS classification LSOA Self-ascribed	First diagnosis of psychotic illness GP area codes	Non-organic psychosis	**OR = 2.88 (95% CI 1.89 – 4.39)** Black patients in less represented areas **OR = 5.24 (95% CI 1.95 – 14.07)** Black patients in

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis/Diagnosis	Main findings
						lowest density quintiles
Das-Munshi et al. (2012) (UK)	Cross-sectional survey Ethnic density	351 people	Self-ascribed Generational status determined by country of birth MSOA	PSQ	Psychotic symptoms: Hallucinations, Delusions, Hypomania	For 10% point reduction in own-group density **OR = 1.07 (95% CI 1.01 – 1.14) combined minority ethnic group** **Adj. OR = 0.91(95% CI0.72 – 1.14) White British** **Adj. OR = 5.44 (95% CI 0.77 – 38.3) Irish** **Adj. OR = 1.05 (95% CI 0.68 – 1.61) Black Caribbean** **Adj. OR = 1.26 (95% CI 1.00 – 1.60) Bangladeshi** **Adj. OR = 1.38 (95% CI 1.02 – 1.86) Indian** Adj. OR = 1.17 (95% CI 0.95 – 1.45) Pakistani Association of own group density and social disadvantage **Adj. OR = 2.26 (95% CI 1.62 – 3.14) interpersonal racism**

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis/Diagnosis	Main findings
						Adj. OR = 1.46 (95% CI 1.06 – 2.00) Work-related discrimination **Adj. ICC = 0.06 (95% CI 0.01 – 0.20) variation in area-level reporting psychotic experiences** **ICC = 0.03 (95% CI 0.00 – 0.30) individual-level factors accounting for variation (adjusted for discrimination, social support)**
Bhavsar et al. (2014) (UK)	Historical case register cohort study (LEO Case register)	405 First episode schizophrenia	IMD	OPCRIT	Schizophrenia	**IRR = 1.03 (95% CI 1.004 – 1.04)** Electoral ward deprivation **IRR = 1.04 (95% CI 1.02 – 1.06)** Super output deprivation
Kirkbride et al. (2014) (UK)	Population-based incidence survey ELFEP	427 FEP	2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed	DSM-IV SCAN	Non-affective psychosis Affective psychosis	**RR = 1.25 (95% CI 1.04 – 1.49)** multiple deprivation **RR = 1.28 (95% CI 1.08 – 1.15)** income inequality deprivation **RR = 1.18 (95% CI 1.00 –**

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis/Diagnosis	Main findings
			(via case notes)			**1.41)** Population density Association with own group density **RR = 1.54 (95% CI 1.12 – 2.03) lower density of own group** RR = 0.70 (95% CI 0.48 – 0.99) higher density of own group
Termorshuizen et al. (2014) (the Netherlands)	Retrospective Case register cohort	2,064 patients	Population register of Statistics Netherlands (Central Bureau voor de Statistics) Native. Migrant	DSM-IV	Non-affective psychosis	**High vs. low density** **Adj. RR = 2.36 (95% CI 2.02 – 2.76)** < 21.8% ethnic density **Adj. RR = 1.71 (95% CI 1.14 – 2.07)** 21.8% to 43.3% ethnic density Adj. RR = 1.24 (95% CI 0.96 -1.61) > 43.3% ethnic density RR decreased from 2.36 to 1.24 – non-Western immigrants RR from 1.63 to 1.01 – Western immigrants

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis/Diagnosis	Main findings

IRR, incidence rate ratio. RR, relative risks. OR, odds ratio. MRC Socio-demographic schedule (Mallett, 1997). ICC, interclass correlation coefficient. IMD, index of multiple deprivation (2004). MSOA, middle super output area (ONS 2001). LSOA, lower super output area. OPCRIT, operational criteria checklist for psychotic and affective illness (McGuffin, et al. 1991). DSM-IV, diagnostic and statistical manual of mental disorders (American Psychiatric Association and Association, 1980). GP, general practitioner.

2.2.3 Social disadvantage and psychosis

Evidence of an association between social disadvantages and increased risk of psychosis is well documented (Morgan et al., 2009, Stilo et al., 2013, Cooper et al., 2008). As such, the relationships between current or long-term social disadvantage indicators (such as unemployment, living alone or childhood adversity) and psychosis have been consistently reported over the last decade. Table 2.3 shows recent work on this topic. Different dimensions of adversity have been reported, but only a few studies looked at these specifically in relation to ethnicity. For instance, the odds of unemployment among psychosis cases compared to controls ranged between OR 3.64 (Morgan et al., 2008a) to 20.92 (Mallett et al., 2002). This was highest among Black Caribbean patients, whose OR was 20.92, compared to White British patients, whose OR was 3.13 to 7.50 (Mallett et al., 2002, Morgan et al., 2008a). Furthermore, Boydell and colleagues (2012), in an incidence study of first episode psychosis, calculated the standardised incidence rates (SIR) among unemployed patients and found a higher incidence of psychosis among the unemployed Black Caribbean (SIR = 12.05) compared to White patients (SIR = 11.75) but slightly lower among Black African patients (SIR = 6.78) (Boydell et al., 2012). Ramsay and colleagues (2012) also reported a higher proportion of unemployment among FEP patients, at 65.0% (Ramsay et al., 2012). In addition, indicators such as living alone have been reported to be higher among psychosis cases compared to controls; for example, in the last decade the reported odds ratios ranged from 0.59 (Mallett et al., 2002) to 4.55 (Stilo et al., 2013).

As can be seen in Table 2.3, nine of the sixteen studies included used cross-sectional designs which mean that direction of causality may not be established. For example, it is possible that individuals were unemployed before onset of psychosis or vice versa.

Perceived discrimination (Cooper et al., 2008) and strong identification with an ethnic minority group (Reininghaus et al., 2010a) have also been reported to be associated with increased risk of psychosis in Black and minority ethnic (BME) groups. For example, Reininghaus and colleagues found that the higher the level of ethnic identification, the higher the odds of psychosis (Reininghaus et al., 2010a). Meanwhile, Morgan and Fearon (2007) argued that psychosis is an outcome of a series of interactions (biological and social) over the life course. Negative social experiences among the migrant groups such as those

noted above may be major factors in understanding the excess of psychosis among African Caribbean patients (Morgan and Fearon, 2007). This argument was crystallised when the same authors investigated the prevalence and social correlates of psychotic-like experiences in a general population sample of Black and White British participants; they reported a 19% prevalence of unusual (psychosis-like) experiences in the sample and these were more likely to be reported among the Black participants, with an OR of 2.08 among the Black Caribbean participants and an OR of 4.59 among the Black Africans (Morgan et al., 2009).

More recently, Morgan et al. (2014) sought to investigate the associations between two putative risk factors, i.e. childhood and adult disadvantage, to further our understanding of the aetiology of psychosis. The findings were consistent with previous studies as the authors found that although complex, the combination of both predictors have a potential to set some individuals on a predominantly socio-developmental path to psychosis (Morgan et al., 2014). The contributory mediating factors they found included parental separation, education, adult disadvantage, self-esteem and parental death (Morgan et al., 2014).

Furthermore, there is growing evidence that childhood adversity is a putative risk factor for psychosis (see Table 2.3). Matheson and colleagues (2013) in a recent meta-analysis reported that increased rates of childhood adversity were more likely to be reported among patients with schizophrenia compared to controls (OR = 3.60; 95% CI 2.08 – 6.23) (Matheson et al., 2013). More specifically, Gayer-Anderson (2014) found increased risk of psychosis associated with the following experiences of abuse: severe household discord (adj. OR = 5.06;; 95% CI 2.11 – 12.09), psychological abuse (adj. OR = 6.27;; 95% CI 2.48 – 15.84) and sexual abuse (adj. OR = 2.62; 95% CI 1.06 – 6.48) (Gayer-Anderson, 2013). Similarly, Fisher et al. (2010) reported that patients with psychosis were three times more likely to report physical abuse compared to controls. Meanwhile, studies reporting odds ratios (OR) of parental separation (both or one parent) among cases and controls have found higher odds in cases, particularly in relation to ethnicity. Parental separation among Black African and Caribbean patients with psychosis has demonstrated effect sizes ranging from 2.16 (Morgan et al., 2014) to 5.0 (Mallett et al., 2002). For parental death among African and Caribbean patients the odds ratios range from 1.62 to 4.71 (Morgan et al., 2007).

Table 2.3: Studies of psychosis and social disadvantage and ethnicity.

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
Mallett et al. (2002) (UK)	Case-control study	100 cases 100 controls	UK 2001 ONS Census classifications Self-ascribed	PSE CATEGO	Schizophrenia	**Unemployment** **OR = 7.50 (95% CI 1.69 – 33.47)** **White British** **OR = 20.92 (95% CI 2.04 – 214.29)** **African- Caribbean** OR = 6.39 (95% CI 0.54 – 76. 14) Asian **OR =5.5 (95% CI 2.59 – 11.68) cases vs. controls** **Living alone** OR = 0.59 (95% CI 0.12 – 2.84) White British **OR = 2.16 (95% CI 0.13 – 15.58)** **African- Caribbean** OR = 3.35 (95% CI 0.13 – 86.72) Asian OR =1.75 (95% CI 0.86 – 3.56) cases vs. controls **Separation from both parents** **OR = 5.00 (95% CI 1.09 – 22.82)** **African-Caribbean** OR = 0.33 (95% CI 0.35 – 3.20)Asian
Fossion et al. (2004) (the	Cross-sectional survey	341 Moroccan patients	Not recorded		Schizophrenia	**Belgian v. Moroccan** **OR = 1.45 (95% CI 1.16 – 1.81) Lives with parent**

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
Netherlands)	Hospital admission data	341 Belgian patients				OR = 0.77(95% CI 0.62 – 0.96) Registered with psychiatrist OR = 0.72 (95% CI 0.52 – 0.98) Salaried employment OR = 0.70 (95% CI 0.52 – 0.94) Alcohol related problems
Morgan et al. (2007) (UK)	Case-control survey	390 FEP cases 391 controls	MRC Socio-demographic schedule (Mallett 1997) UK 2001 ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	ICD-10 SCAN SCAN-IGC	Affective psychosis Non-affective psychosis	**Separation** Adj. OR = 2.45 (95% CI 1.66 – 3.59) long-term separation overall **Adj. OR = 2.30(95% CI 1.38 – 3.86)** **White British** **Adj. OR = 2.23 (95% CI 1.20 – 4.16)** **White British Father only** **Adj. OR = 2.71 (95% CI 1.15 – 6.39)** **WB both parents** **Adj. OR = 2.92 (95% CI 1.36 – 6.28)** **Black Caribbean** **Adj. OR = 4.73 (95% CI 1.82 – 12.32)** **Black Caribbean Father only** Adj. OR = 2.37 (95% CI 0.74 – 7.64) Black Caribbean both parents Adj. OR = 1.47 (95% CI 0.27 – 7.93) Black African **Death** OR = 3.06 (95% CI 1.34 – 7.00) overall

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
						Adj. OR = 4.00 (95% CI 1.41 – 11.32) White British Adj. OR = 4.71 (95% CI 0.72 – 30.91) Black Caribbean Adj. OR = 1.62 (95% CI 0.27 – 9.85) Black African
Cooper et al. (2008) (UK)	Incidence and case-control (AESOP)	197 cases 285 controls	MRC Socio-demographic schedule (Mallett 1997) 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via case notes)	ICD-10 SCAN SCAN-IGC	Psychosis	Incidence of psychosis **OR = 4.7 (95% CI 3.1 – 7.2) Black ethnic group** **Adj. OR = 3.0 (95% CI 1.6 – 5.4) Black ethnic group** **Case status vs. Black ethnic group** **Adj. OR = 4.1 (95% CI 2.5 – 6.8) overall perception of disadvantage** **Adj. OR = 6.9 (95% CI 3.7 – 13.0) due to skin colour** **Adj. OR = 5.0 (95% CI 3.0 – 8.3) due to culture** **Adj. OR = 4.6 (95% CI 2.8 – 7.7) due to social class**
Morgan et al. (2008) (UK)	Incidence and case-control (AESOP)	390 cases 391 controls	MRC Socio-demographic schedule (Mallett 1997)	ICD-10 SCAN SCAN-IGC	Affective psychosis Non-affective psychosis	**Education – no qualification** **Adj. OR = 4.59 (95% CI 1.03 – 20.38)** Black Caribbean **Adj. OR = 2.95 (95% CI1.51 – 5.76)** white British

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
			Self-ascribed Other informants Researcher – ascribed (via case notes)			**Employment – unemployed** **Adj. OR = 3.64 (95% CI 1.81 – 9.20)** Black Caribbean **Adj .OR = 3.13 (95% CI 1.85 – 5.31)** White British **Living arrangements – lives alone** **Adj. OR = 3.27 (95% CI 1.42 – 7.52)** **Black Caribbean** **Adj. OR = 2.70 (95% CI 1.69 – 4.32)** **White British**
Morgan et al. (2009) (UK)	Cross-sectional survey (sub-sample of AESOP controls)	372 Controls – healthy volunteers	MRC Socio-demographic schedule (Mallett 1997) 2001 UK Census ONS classification Self-ascribed Other informants Researcher – ascribed (via	PSQ	Psychotic symptoms	**prevalence of psychosis =** 19% **OR = 2.08 (95% CI 1.08 – 3.89) Black Caribbean** **OR = 4.59 (95% CI 1.69- 12.46) Black African** **OR = 3.83 (95% CI 1.03 – 14.29)** **Other** **Age** **OR = 2.05 (95% CI 1.08 – 3.89) 16-15-year-olds** **Housing status** **OR = 2.26 (95% CI 1.25 – 4.07)** **Rented** **Living circumstances**

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
			case notes)			**OR = 2.11 (95% CI 1.17 – 3.79) Lives alone** **Relationship status** **OR = 1.85 (95% CI 1.02 – 2.39) Never in long-term (1+year) relationship**
Reininghaus et al. (2010) UK	Case control (AESOP)	139 Cases 243 controls	MRC Socio-demographic schedule (Mallett 1997) 2001 UK Census ONS classification	ICD-10 SCAN SCAN-IGC	Non-affective psychosis Affective psychosis	**Overall Ethnic identity** Adj. OR = 1.08 (95% CI 0.89 – 1.30) White British **Adj. OR = 1.45 (95% CI 1.08 – 1.96) BME** **Strong vs. weak ethnic identification** Adj. OR = 1.60 (95% 0.85 – 2.99) White British **Adj. OR = 2.73 (95% CI 1.22 – 6.12) BME**
Boydell et al. (2012) (UK)	Case register cohort	178 FEP	2001 UK Census classification	ICD-9 OPCRIT RDC	Schizophrenia Psychosis mania Psychotic depression	**Standardised incidence ratio for psychosis among unemployed patients** **SIR = 11.75 (95% CI 6.42 – 19.71) White British** **SIR = 12.05 (95% CI 7.87 –17.65) Black Caribbean** **SIR = 6.78 (95% CI 4.30 –10.17) Black African** SIR = (95% CI)
Morgan et al. (2014)	Case-control AESOP	390 cases 391	MRC Socio-demographic	ICD-10 SCAN	Affective psychosis	Parental separation effect by ethnicity

Authors (Country)	Study Design	Sample	Ascertainment of ethnicity	Scale for measuring psychosis	Type of Psychosis	Main findings
(UK)		controls	schedule (Mallett 1997) Self-ascribed Other informants Researcher – ascribed (via case notes)	SCAN-IGC	Non-affective psychosis	**White British** **Adj. OR = 2.98 (95% CI 1.59 – 4.45)** **Direct** **Adj. OR = 1.86 (95% CI 1.10–3.14)** **Total indirect** **Adj. OR = 5.53 (95% CI 2.83 – 10.84)** **Total** **Black Caribbean** **Adj. OR = 2.16 (95% CI 1.07 – 4.36)** **Direct** **Adj. OR = 2.79 (95% CI 1.06 – 7.35)** **Total indirect** **Adj. OR = 6.03 (95% CI 1.87 – 19.43)** **Total** **Black African** Adj. OR = 2.14 (95% CI 0.47 – 9.81) Direct Adj. OR = 0.92 (95% CI 0.03 – 27.44) Total indirect Adj. OR = 1.97 (95% CI 0.05 – 81.04) Total

RR, relative risks. OR, odds ratio. Adj. OR, Adjusted odds ratio. MRC Socio-demographic schedule (Mallett, 1997). SIR, standardised incidence ratio. PE, psychotic experience. GAF, global assessment of functioning. CIDI, composite international diagnostic interview. SAPS, scale of assessment for positive symptoms. SANS, scale of assessment for negative symptoms. SCID, structured interview for DSM-IV. SOS, symptom onset in schizophrenia. PSE, present state examination. RDC, research diagnostic criteria. NOS, Nottingham Onset Schedule (Sign et al. 2005). PSQ, psychosis screening questionnaire.

2.3 Synthesis of current evidence

Although the last decade has seen improvements in study designs measuring incidence rates of psychosis, from the dimensions of ethnicity, ethnic density and social disadvantage, there remain some methodological issues for consideration For example, twenty-two population-based studies employed case-control or cohort study designs which have many benefits in their own right such as the measure of exposure preceding the measure of psychosis (cohort design), identifying cases and controls from the same population (case-control) and being able to control for a range of possible confounders. Several of the studies included in this review have also employed semi-structured diagnostic interviews to elicit psychotic symptoms and psychotic experiences. There has also been better comparative denominator population data that enables incidence rates to be measured more accurately (e.g. UK Census data ONS 2011 and the Dutch Bureau of Statistics). However, this review has highlighted some study design and methodological issues in studies estimating the incidence of psychosis which have not been fully addressed in previous research on aetiology of psychosis and ethnicity. Three key areas that have impacted on findings from previous research include: a) definition of ethnic groups; b) sampling and design; and c) source used to collect data.

2.3.1 Definition of ethnic groups

Apart from the two large UK epidemiological studies, namely Aetiology and Ethnicity of Schizophrenia and Other Psychoses (AESOP) and the East London First Episode Psychosis (ELFEP) (Fearon et al., 2006b, Coid et al., 2008a), Black African and Black Caribbean patients are often amalgamated into one ethnic group (African-Caribbean) meaning that generalizable conclusions cannot be drawn about the true rates of psychosis among these two very different groups. It is important to treat these groups separately. The classification of ethnicity has evolved over time and it is argued to be a social construct (Mateos et al., 2009). For example, there are immigration status differences between the African and Caribbean groups in the UK. Emigration of Black Africans is more recent compared to Black Caribbeans who have mostly settled in the UK since the post– Second World War period (Mason, 1995). Other key features that differentiate Black African and Black Caribbean groups include diverse histories, culture and self-identity (Kaneshiro et al., 2011, Mason, 1995). This issue of crude classification of ethnic groups is also notable in research studies in

the United States of America, where for example 'Black' people are referred to as 'African-American'. However, this broad categorisation is not limited to research; the United States (US) Office of Management and Budget use the same classification for population data collection where only five categories of ethnicity are available for citizens to self-ascribe (Kaneshiro et al., 2011). The amalgamation of ethnic groups, e.g. under the term 'African-American', makes it difficult to disentangle differences within groups. In reality the Black population in the US have different cultures and social structures. For example, a sizeable proportion of black folks in the US have lived there for many generations whilst others may be recent migrants (Rumbaut and Portes, 2001). In addition, there is a dearth of research examining generational differences in rate of psychosis among the black populations in the US. There have also been calls for a review of the US ethnic categorisation not only for research purposes but also in recognition of social changes in this diverse population (Bhopal, 2004, Mateos et al., 2009).

Furthermore, studies from the rest of Europe have used only country of birth to define ethnicity, as opposed to self-ascription (Veling et al., 2008, Selten et al., 2001, Velthorst et al., 2012). This raises the need for cautious inference from such ethnic classifications. As highlighted by the UK Office of National Statistics and other literature, ethnicity is a multifaceted concept which requires multiple approaches to ascertain, e.g. language spoken, skin colour, geographical region, racial and religious group (ONS, 2003, Mason, 1995).

2.3.2 Study design and sampling

Despite the methodological improvements observed in recent studies, some design issues still remain. For example, thirty-six per cent (n = 17) of studies reviewed above used a cross-sectional design, a method which if not well-designed, is open to criticism about the limitations in the inferences that can be made about causal associations. One of the most key criticisms of such studies is the use of retrospective self-report data (Susser et al., 2006). For instance, among studies considered in section 2.2.3, factors such as unemployment may be difficult to disentangle since psychosis, which is linked to behavioural problems and affects relationships and executive functioning, may possibly precede unemployment, and

indeed vice versa. Another methodological consideration is the use of perceived state as a measure of social disadvantage, i.e. how someone views social interaction may be affected by their mental state e.g. 'perceived discrimination'. It is possible that people with psychosis, when making sense of the illness, may consider their social experiences e.g. discrimination, racism or lack of opportunities as possible explanation.

The design limitations in this review are noteworthy but it is also worth acknowledging that in order to disentangle the association and causal relationships between psychosis and risk factors, a prospective cohort sample needs to be recruited prior to the onset of illness. Such a design will be very expensive if not impossible in the case of psychosis, which tends to emerge in adulthood. In the absence of prospective cohort design, psychiatric epidemiology has had to rely on historical cohort study design, which has the ability to take into account the latent period and outcomes using existing clinical records to determine the number of individuals that meet study criteria and outcomes (Mortensen, 1995, Cantor-Graae and Pedersen, 2007, Susser et al., 2006)..

2.3.3 Sources used to collect data

The source used to collect data varies widely between studies. Considering the dimension of social adversity and psychosis, more than half of the studies (n = 6/8) were conducted using samples from the AESOP study. This highlights the need for new research to re-examine these indicators in relation to ethnicity, particularly those of Black African and Black Caribbean ethnicity, who have consistently shown increased risk of these adversities at first episode of psychosis.

Furthermore, overall patient samples have also varied between those including hospital inpatients for first episode psychosis and those including FEP patients presenting to both hospital and community mental health services. With several studies relying on hospital admission samples and clinical diagnosis alone, Kendell and colleagues (1993) pointed out a number of the pitfalls of using hospital first admission to measure the incidence of psychosis, including the potential for underestimation (as not everyone with psychosis gets admitted to hospital), the fact that the diagnosis of psychosis may not be made during first admission and the reality of population movements in study catchment areas (Kendell et al.,

1993). Recent hospital admission studies in this review (Tortelli et al., 2014, Selten et al., 2002, Smith et al., 2006) have also demonstrated the limitations of using such samples as there is a high likelihood of missing cases, since they have not considered those using other services such as community-based health care or outpatients. In addition, it is not possible to be sure of absence of previous psychotic episode in such samples since the capability to carry out routine administrative data may not be available.

Despite the improvements in recent studies' ability to include both hospital and community based patients, it is still possible to miss cases as not all individuals experiencing psychotic symptoms necessarily present to health services to seek help. As alluded to in section 2.3.2, the ultimate solution regarding case identification is prospective population sampling through cohort study design that has the ability to follow up a population possibly from birth and identify exposed and unexposed individuals, but given that psychosis is a rare disorder, this approach may not be feasible as it would be very expensive and time consuming (Susser et al., 2006).

2.4 Summary

The three dimensions discussed above – migration, ethnic density and social disadvantage – are evidently interconnected, and the literature reviewed so far has pointed to differences in rates of psychosis. From ethnic distribution and area level perspective the evidence suggests that ethnic density in a particular population may be a protective factor from the risk of developing of psychosis. Research on social disadvantage has demonstrated that exposure to adversities has deleterious consequences and contributes to increased risk of psychosis. And finally from migration status perspective, the rate of psychosis has been consistently higher among the migrant groups, but the few studies reporting incidence of psychosis for Black African and Black Caribbean groups have painted an inconsistent picture of incidence rates in these two groups, which suggests that the questions considered at the start of this chapter remain unresolved.

3 Chapter 3: Literature Review – Early Intervention for Psychosis, Pathways to Care and Ethnicity

3.1 Synopsis

The discussions in Chapter 2 point to the evidence that heterogeneous incidence of psychosis is a mainstay in the epidemiology of psychosis, with higher rates of incidence and prevalence reported in migrant groups in Western nations. However, understanding the pathways into and through care from the onset of illness until first help-seeking contact with mental health services is important in early recognition and intervention, to thus minimise suffering and improve outcomes (Compton et al., 2006, Birchwood, 2008, McGorry et al., 2008). Additionally, variation in aetiology of psychosis has prompted international initiatives of early intervention services (EIS) for psychosis to promote equity of care, early detection of psychosis and improved outcomes (Mann et al., 2014a). These services are now established in Europe, America and Australia (Marshall and Rathbone, 2011).

In the UK, for example, EIS is recommended in the National Institute of Clinical Excellence (NICE) guidelines on schizophrenia for England and Wales (Excellence and Health, 2002). EIS services aim to identify as soon as possible individuals who already experience psychotic symptoms but have not yet received adequate treatment (Addington, 2007, Marshall and Rathbone, 2011). As such, an early intervention service offers two components: (a) early detection and reduction in delay to first treatment and (b) phase-specific treatment. Phase-specific treatment includes psychosocial or physical treatment which has been developed or modified specifically for use with people at an early stage in the illness (Marshall and Rathbone, 2011, Joseph and Birchwood, 2005, Craig et al., 2004a, McGorry et al., 2009).

Furthermore, much research has been carried out to measure the effectiveness of such services and evidence suggests that early intervention services for psychosis reduces rates of relapse, hospital admissions, improved access to care and increased engagement with services (Garety et al., 2006, Bird et al., 2010). In spite of this encouraging evidence, it remains unclear how patients from the black and minority ethnic groups fare under the care of this specialist intervention service during first contact for episode of psychosis, because many previous studies have largely relied on symptoms and clinical predictors to explain service engagement (Birchwood et al., 2013).

One of the aims of this thesis is to investigate the pattern of engagement with services at first contact and through the treatment period. The aims of this chapter are therefore to highlight the importance of early intervention pathways into care during first episode of psychosis and touch on the concepts and processes involved. This is followed by a review of the literature on referral routes to mental health services and the pattern of engagement with such services by sociodemographic factors, especially ethnicity.

3.2 Examining the Role of Early Intervention Services in the Pathways into Care

The chapter will now outline the literature on individual (especially ethnicity) and service level factors associated with the pathways into care. The discussion will be guided by three main sub-topics: a) duration of untreated psychosis (DUP) and mode of onset (section 3.2.1-3), b) source of referral and mode of contact (section 3.3). Mode of contact in the form of compulsory admission will be reviewed and discussed extensively in section 3.4, specifically addressing the question: are there any differences in pathways to care for first episode psychosis (FEP) cases compared to 15 years ago, which was prior to the introduction of EIS; and is this associated with the introduction of EIS? Subsequently, a discussion surrounding the limitations of the current literature is provided in section 3.5, and finally section 3.6 presents a summary of the literature reviewed.

In reviewing the literature for this chapter, I have chiefly included studies published between 2002 and 2017, which were conducted using populations of first episode psychosis (FEP) patients, in order to give a picture of research efforts and evidence in the last ten years. However, studies investigating DUP are separated into two categories, UK versus international. This is due to the marked differences in the health services structure globally and particularly in Western countries. For example, the UK healthcare service is free at the point of delivery and has a very efficient primary care system, and therefore direct comparison with other healthcare systems may not be helpful. For example, in the USA access and use of healthcare incur costs at the point of use and studies have shown that this influences patients' and families' decisions to seek help for psychosis (Compton et al., 2004, Anderson et al., 2014b) . Furthermore, owing to the fact that factors such as duration of untreated psychosis and mode of contact may be influenced by how health care systems are structured, it is important to consider the evidence separately.

Searches for relevant literature were conducted using the following keywords: 'first episode', 'psychosis', 'duration of untreated', 'early intervention', 'ethnicity', 'African', 'Caribbean', 'pathway to care' and 'compulsory admission'. Bibliographic databases including Embase, Pubmed, PsychoInfo, Web of Science, Ovid and Google Scholar were used to identify relevant literature.

3.2.1 Duration of untreated psychosis, mode of onset and ethnicity – the UK evidence

Duration of untreated psychosis (DUP) (i.e. the delay between the onset of first episode psychosis and receiving an effective treatment) has been identified as a major contributor to the variation in outcomes following first episode psychosis (Birchwood et al., 2013, Marshall et al., 2005). Similarly, mode of onset of psychosis (i.e. how quickly psychotic symptoms develop) is regarded as a robust predictor of outcomes (Morgan et al., 2006b, Compton et al., 2011) While it might seem possible to regard DUP and mode of onset as two terms describing the same thing, the measurement of mode of onset is very different from that used in estimating DUP. Compton and colleagues (2011) give a clear distinction between the two and define mode of onset as 'the rapidity of development of psychotic symptoms up to the point of frank psychotic symptoms', whereas DUP is defined as 'beginning at the point of frank psychosis to the point of first contact with services' (Compton et al., 2011). In addition, some individuals may have been experiencing attenuated psychosis symptoms long before first frank symptoms appear (Fusar-Poli et al., 2009). Therefore, reducing DUP has become an international priority and much effort has been spent assessing the impact of early intervention services. As such, in the last decade a number of studies have been carried out evaluating patient-level and service-level factors associated with DUP and the effectiveness of EIS in reducing DUP.

In Table 3.1, studies carried out in the UK specifically examining the relationship between DUP and ethnicity in the last decade are presented (n = 5). From the table, an overall median DUP with interquartile range (IQR) ranged from 9 (2-40) weeks (Morgan et al., 2006b) to 3 (1-95) months (Bhui et al., 2014).

Morgan and colleagues (Morgan et al., 2006b) found no evidence that Black Caribbean patients experienced longer median DUP than White British patients (13 weeks and 10

weeks respectively). However, they reported that Black African patients experienced shorter DUP (8 weeks; log rank test X2 = 9.96, df = 1 P = 0.002) compared to their White British counterparts. This is further substantiated in their adjusted cox regression analysis where they found no evidence that Black Caribbean (adj. HR = 1.04; 95% CI 0.80 – 1.36) patients experienced longer DUP, but there was strong evidence that Black African (Adj. HR = 1.06; 95% CI 1.15 – 2.22) patients had shorter DUP than White British patients.

Similarly, (Ghali et al., 2012) in a study exploring ethnic differences in the nature and duration of pathways into early EIS, found longer delays (median (IOR)) from onset of psychosis to commencement of medication among White British = 113 (345) days compared with other ethnic groups: White Other = 72 (198) days, South Asian = 60 (164) days, Black British = 98 (182) days, Black Caribbean = 55 (236) and Black African = 57 (155) days p< 0.001. It is argued that because Black African and Black Caribbean patients tend to experience acute onset of psychosis leading to more rapid presentation to services this may explain the shorter DUP (Morgan et al., 2006b). Furthermore, Dominguez and colleagues (2013) in a study comparing DUP in adolescent-onset and adult-onset of psychosis analysed 940 FEP cases (136 adolescent vs. 804 adult). They reported greater median DUP (179 days) among the adolescent cases compared to 81 days in the adult sample (p = 0.005). They also found difference in DUP by ethnicity; the median DUP was White = 345 days; Black = 103 days; Asian and mixed = 36.5 days, p = 0.001 among the younger patients aged less than 18 years old (Dominguez et al., 2013). The higher median DUP reported among the White British patients is consistent with other studies (Birchwood et al., 2013) but one that is concerning and above the UK Department of Health target of under three months (Department of Health, 2002).

Kirkbride and colleagues (2010) investigated the role of neighbourhood on DUP and demonstrated no association of neighbourhood effect with DUP but found that Black African patients had a shorter DUP compared with other groups. Similarly, (Bhui et al., 2014) reported ethnic differences in DUP between White and Black patients (median = 4 and 3 months, p<0.001) respectively.

It can be seen from evidence emerging from the UK that there are variations in DUP across ethnic groups. An explanation may be immigration status; for example, first generation

migrants have been reported to be more likely to use emergency, acute or crisis services, which may be a reflection of their limited understanding of healthcare systems and how to utilise them (Kirmayer et al., 2007, Anderson et al., 2015). Further, plausible explanations for the prolonged DUP and treatment delay among White British patients include the tendency to seek help via GP, and living with family, which may help to reduce the burden of the illness and manage symptoms (Compton et al., 2011).

Table 3.1: UK studies of duration of untreated psychosis and ethnicity.

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
Morgan et al. (2006) (UK)	Case-control AESOP 414 FEP patients	Onset of psychotic symptoms lasting one week or more	First contact with mental health services	PPHS	16-64	Overall Median DUP (IQR) = 9 (2 – 40) weeks **Southeast London site** White British – Median (IQR) = 10 (4 – 52) weeks Black Caribbean Median (IQR) = 13 (4 – 87) weeks Black African Median (IQR) = 8 (1 – 22) weeks **Nottingham site** White British – Median (IQR) = 7 (1 – 33) weeks Black Caribbean – Median (IQR) = 5 (2 – 13) weeks Adj. HR = 1.04 (95% CI 0.80 – 1.36) – Black Caribbean **Adj. HR = 1.60 (95% CI 1.15 – 2.22) – White British vs. Black African**

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
Kirkbride et al. (2010) (UK)	Case control study 314 FEP patients	Onset of psychotic symptoms lasting one week or more	First contact with mental health services	PPHS	**16-64**	Association between DUP and ethnicity Reference = White British White other = β-0.13 (-0.93 – 0.67) Black Caribbean= β0.21 (-0.33 – 0.77) **Black African = β-0.74 (-1.4 – -0.10)*(shorter because CI excludes zero)** Asian = β-1.2 (-3.1 – 0.68) Mixed = β-0.83 (-1.8 – 0.17) Other = β-0.43 (-1.6 – 0.76)
Ghali et al. (2012) (UK)	Naturalistic cross-sectional study 775 EIS patients	Onset of psychosis	Commencement of regular antipsychotic medication	NOS	18-35	**DUP by ethnic group** White British – Median(IQR) = 113 (345) days White Other – Median = 72 (198) days South Asian – Median = 60 (164) days Black British – Median = 98 (182) days Black Caribbean –

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
						Median = 55 (236) days Black African – Median (IQR) = 57 (155) days
Dominguez et al. (2013) (UK)	Cross-sectional study 940 sample of adults (804) and adolescents (136)	Date of first psychotic symptoms	Date of commencement of regular medication with 75% adherence	NOS	14-35	**Individual DUP; Median (IQR), p = 0.005** Total sample DUP = 86 (19 – 282) days Adolescent – Median (IQR) = 179 (18 – 514) Adult – Median (IQR) =81 (19 – 244) days **Service DUP; Median (IQR), <0.001** Total sample DUP = 135 (19.3 – 372) days Adolescent = 346 (105.5 – 721.3) Adult = 120 (37 – 311.3) days **Adolescent sample by ethnic group, p = 0.03** Median (IQR) White = 345.5 (99.3 – 985.3) days Black = 103.5 (14.8 – 385.3) days Asian & Mixed = 36.5 (6.8 – 327.8) days
Bhui et al (2014)	ELFEP cohort	Onset of psychotic	Date of first taking	PPSH	**18-64**	**Median DUP (IQR) in**

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
(UK)	study – 480 FEP patients	symptoms	prescribed antipsychotic medication			**months** Overall = 3 (1 – 95) **Ethnicity p<0.001** White = 4 (2 – 10) Black = 3 (1 – 5) Indian sub-continent = 4 (2 – 12) **Gender , p = 0.05** Male = 4 (1 – 10) Female = 3 (1 – 8) **Compulsory admission, p = 0.02** Yes = 3 (1 – 6) No = 4 (1 – 12)

NOS, Nottingham onset schedule (Singh et al. 2005). FEP, first episode psychosis. ARMS, at risk mental state. PPHS, personal and psychiatric history schedule (WHO, 1996).

3.2.2 Duration of untreated psychosis, mode of onset and ethnicity – international evidence

Table 3.2 presents international studies that have specifically examined the relationship between DUP and ethnicity during this literature review window. Of the seven studies, median DUP ranged from 22.1 weeks (Archie, 2010) to 74 (1 – 1456) weeks (Addington, 2015).

As can be seen in Table 3.2, many of the international studies on ethnicity and duration of untreated psychosis have originated from Canada and the USA. The two Canadian studies consistently found ethnic differences in help-seeking behaviours among minority ethnic groups, with a higher proportion using the accident and emergency department (Archie et al., 2010, Anderson et al., 2015). However, they found no ethnic variations in the duration of untreated psychosis. Similarly, studies from the USA found no ethnic differences in DUP (Compton et al., 2006, Addington et al., 2015).

In contrast to UK evidence, international evidence points to no ethnic difference in DUP, but variations in pathways to accessing care were reported. A number of explanations have been put forward for this contrast. For example, economic factors are argued to be predictors of differences in accessing care in a privately funded healthcare system (Snowden and Yamada, 2005). In the study by Archie and colleagues (2010) for instance, patients of White ethnic groups were more likely to make initial contact with psychologist services, and psychologists are not widely available on the Canadian state-funded healthcare system (Archie et al., 2010). Further, language barriers, feelings of shame and stigmatisation may be more pronounced among ethnic minority groups, which may hinder help-seeking from healthcare system (Sterk et al., 2010).

Table 3.2: International studies of duration of untreated psychosis and ethnicity

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
Compton et al. (2004) (USA)	Hospital admission Cross-sectional 10 family members 6 patients	Initial date of onset of symptoms reported by family member	Time of help seeking	Clinician-led questionnaire	18-65	**DUP reported by family/parent** Mean (sd) 59.5 (69.65) weeks Median DUP = 40.0 (2 – 234) weeks
Compton et al. (2006) (USA)	Hospital admission Cross-sectional 25 patients	Onset of first psychotic symptoms	First hospital admission	SOS	18-39	DUI Median = 128 weeks (0.6 – 467.9) DUP Median (IQR) = 32.9 weeks (0.4 – 337.7) Median DUI (IQR) = 128 (0.6 – 476.9) **Pathways to care/source of referral** MH professional = 30% Psychiatric Emergency = 28% General emergency department = 12%

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
						Primary care = 5% Police = 21% Other = 5%
Archie et al. (2010) (Canada)	Cross-sectional 200 patients	Onset of positive symptoms	Date of initiation of treatment	CORS	16 - 50	**DUP and ethnicity,** p = 0.48 Overall median DUP = 22.1 weeks, Median DUP = 22.4 weeks – white Median DUP = 31.3 weeks – Black Median DUP = 29.4 weeks – Asian Median DUP = 19.5 weeks – Other
Sterk et al. (2010) (The Netherlands)	Cross-sectional 150 patients	Onset of positive symptoms	Start of intensive treatment	NOS	Mean age = 20.9 years (sd = 4.93)	**DUP and ethnicity** (chi-sq = 6.30, p = 0.39) **Median (IQR)** Median = 16.5 (0 – 832) weeks – overall Median = 7.0 weeks (0 – 654) – Dutch Median = 39.0 weeks (0 – 832)- non-Dutch Median = 48.0 weeks

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
						– Surinamese Median = 29.0 weeks – Ghanaian Median = 24.0 weeks Moroccan Median = 16.0 weeks – Turkish Median = 4.0 weeks – Other European
Anderson et al. (2015) (Canada)	Cross-sectional 208 EIS patients	Onset of positive symptoms	Contact with an EIS	PPHS	14+	**ED contact and ethnicity (reference = White European)** **OR = 3.78 (95% CI 1.31 – 10.92) – Black African** OR = 2.42 (95% CI 0.85 – 6.89) – Black Caribbean **OR = 0.13 (95% CI 0.05 – 0.33) GP referral** **DUP and ethnicity** Median = 9 (IQR = 3 – 28) months (expB = 1.10; 95% CI 0.6 –

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
						2.03) – **Black African** Median = 16 (IQR = 6 – 46) months (expB = 1.49; 95% CI 0.82 – 2.69) – **Black Caribbean** Median = 7 months (IQR = 2 – 34) months – **White European** **Age and DUP expB= 1.08, (95% CI 1.03 – 1.14) – Older age**
Addington et al. (2015) (USA)	Cross-sectional 404 patients	onset of psychotic symptoms	Initiation of treatment with antipsychotic medication	SCID	15-40	Overall median DUP (IQR) = 74 (1 – 1456) weeks **DUP and ethnicity, no difference** Mean DUP (sd) = 49 (6.5) weeks – **White** Mean DUP (sd) = 63 (7) weeks – **Black/African American** Mean DUP (sd) =52

Authors (Country)	Sample/design	Start of DUP	End of DUP	DUP instrument	Age range (years)	Main findings, DUP mean, median
						(1) weeks – **American Indian** Mean DUP (sd) =55 (4.5) weeks – **Asian/ Pacific Islander** **DUP and demographic factors** **Mean (sd) = 40 (7) weeks, p<0.001 –** previous hospitalisation **Mean (sd) = 74 (6.5) weeks, p<0.01 –** substance misuse

CORS, circumstances of onset of symptoms and relapse schedule (Norman et al., 2004); CORS/TOPE, circumstances of onset of symptoms and relapse schedule/topography of psychotic episode (Norman et al., 2004). NOS, Nottingham onset schedule (Singh et al., 2005). SOS, symptoms onset in schizophrenia (Perkins et al., 2000). SCID, structured clinical interview for DSM-IV axis 1 disorders.

3.3 Source of referral and mode of contact with mental health services

Before reviewing the literature on source of referral and mode of contact with mental health services, let us turn to Fig. 3.2, which maps the common route into mental health care in the UK. The map is inspired and guided by the Goldberg-Huxley pathway model, which describes five levels of care pathway routes from the community to hospital admission (Goldberg and Huxley, 2003). The model has proven very useful in understanding how far along the pathway levels an individual has reached and possibly the extent of severity of illness. As shown on the map, people can access secondary mental health services via different routes, but by and large the most common source of referral is via the general practitioner (GP) (Goldberg and Huxley, 2003), who in the UK plays a key role in gatekeeping referrals to secondary services. Once in contact with mental health care providers, patients can access services either by community-based services or hospital inpatient admission. Most hospital admissions are voluntary, but in some cases patients who are assessed as posing risks to themselves or others and do not accept voluntary admission may be admitted compulsorily without their consent, using sections of the Mental Health Act (MHA) 1983 (amended 2007) (Mentalhealthcare, 2015). Other referrals to secondary mental health care tend to operate during crisis and emergency periods, when patients require urgent treatment and intervention. These include the police, criminal justice agencies and accident and emergency departments (Morgan et al., 2004).

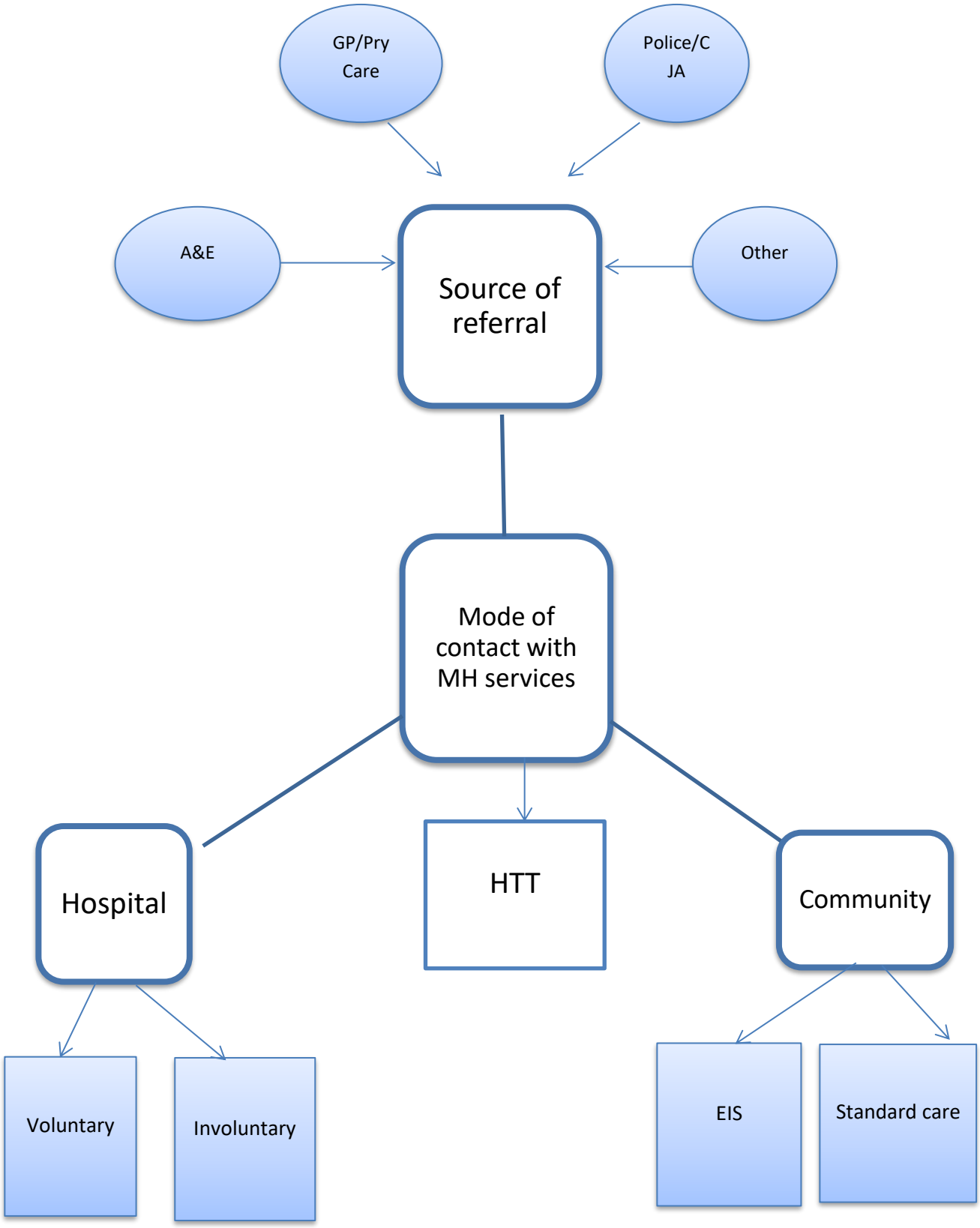


Figure 3.1: FEP pathways to care

There is well-established evidence that there are differences in referral routes and modes of contact with mental health services between ethnic groups in the Western nations. In the past two to three decades, there has been a stream of research evidence suggesting that compared to the native population, minority ethnic group patients are more likely to come into contact with mental health services via crisis routes such as emergency departments and police (Morgan et al., 2005b, Bhui and Bhugra, 2002, Anderson et al., 2010, Anderson et al., 2013b), and they are less likely to have general practitioner (GP) involvement in their referral to specialist mental healthcare (Bhui and Bhugra, 2002). For instance, Morgan and colleagues (2005) in a case-control study of 462 FEP patients, reported that compared to White British, Black Caribbean (adj. OR = 1.98; 95% CI 1.04 – 3.77) patients were more likely to be referred to mental health services via the criminal justice agency but the evidence was weaker for Black African patients (adj. OR = 1.87; 95% CI 0.86 – 4.05). However, both groups were less likely to be referred by their general practitioners: Black Caribbean (adj. OR = 0.48; 95% CI 0.25 – 0.90) and Black African (adj. OR = 0.41; 95% CI 0.18 – 0.95) (Morgan et al., 2005b). This is consistent with Ghali et al. (2012) findings that ethnic minority group patients were less likely than White British patients to make contact with a GP White Other, OR = 0.55 (95% CI 0.34 – 0.91); Black British, OR = 0.62 (95% CI0.40 – 0.96); Black Caribbean OR = 0.30 (95% CI 0.12 -0.75); Black African OR = 0.69 (95% CI 0.44 – 1.07) within their pathway to care. For contact via emergency services and the criminal justice system, the authors reported that compared to White British patients all ethnic minority groups except the South Asian patients were more likely to make contact via emergency services, whereas they found only Black ethnic groups (African, Caribbean and Black British) were more likely to make contact with services via the criminal justice system (Ghali et al., 2012).

Furthermore, Anderson et al. (2013) examined the determinants (prodromal contact, first contact, referral source and total contacts) of pathway to care using a sample of 324 FEP patients from a Canadian EIS program. They found that the likelihood of prodromal contact increased with increasing prodrome length (OR = 1.61; 95%CI 1.33 – 1.94); and that previous contact with primary care was associated with any contact during prodrome (OR = 2.70; 95%CI 1.48 – 4.96). In addition, those whose first contact was with primary care were less likely to have contacts with emergency services (OR = 0.07; 95% CI 0.04 – 0.14), but more

likely to have more than two contacts prior to reaching EIS (OR = 3.50; 95% CI 1.95 – 6.30). They reported a median number of contacts of IQR = 3 (95% CI 2 – 4) prior to contact with EIS. Asian patients were less likely to have more than two contacts (OR = 0.47; 95% CI 0.22 – 0.98). Forty-five per cent of participants came into contact with police or ambulance services and the likelihood of using such service increased as the duration of treatment delays increased (OR = 1.12; 95% CI 1.20 – 1.43) but this likelihood reduced if the initial contact was with primary care (OR = 0.47, 0.27 – 0.82). Patients in contact with primary care experienced delays in referral to EIS (expB = 2.31, 1.36 – 3.92). In terms of service engagement, Anderson and colleagues (2013) found that 28% of the sample dropped out, with median time to dropout reported as five months (IQR = 1 -11). Older age was also reported to be associated with disengagement (HR = 2.10, 1.02 – 1.19) as was Black ethnicity (HR 2.10, 1.19 – 3.70). However, individuals living alone were found to be less likely to disengage (HR = 0.46, 0.21 – 1.00) (Anderson et al., 2013b). A number of systematic reviews have been carried out exploring relationships between pathways to care, mode of contact, source of referrals and ethnicity. Anderson et al. (2014) in a meta-analysis of ethnic difference in pathways to care at FEP, reported that compared with White patients, Black patients are less likely to have GP involvement (OR = 0.70; 0.57 – 0.86) but are more likely to have police involvement (OR = 2.11; 1.67 – 2.66). Such association was not reported among other ethnic groups, e.g. Asian patients were reported to be less likely to have both police involvement (OR = 0.86; 0.57 – 1.30) and GP involvement (OR= 1.23; 0.87 – 1.75) (Anderson et al., 2014a). With only seven papers meeting the inclusion criteria for this review, Anderson and colleagues' findings also hinted at evidence of higher compulsory admission among Black patients, but pooling of such data was limited by effect modification of other sociodemographic factors. They concluded that studies on ethnic difference in pathways to care during FEP are inconsistent compared with other psychiatric disorders (Anderson et al., 2014a). Similarly, Singh et al. (2006) suggest that pathways for FEP are varied and diverse. They reported that FEP patients are more likely to have first contact with mental health professionals, while contact with non-medical or non-statutory services are less common. Methodological variations in the included studies did not allow for meta-analysis of data, but the findings confirm previous evidence that certain ethnic groups in the UK experience more adverse pathways to care; they experience delayed help-seeking which is related to the undetected prodromal and early psychosis symptoms; and family and friends play a vital

role in their help-seeking (Singh and Grange, 2006). Although not specific to FEP samples, Sass et al. (2009) conducted a systematic review of initiatives to improve pathways into mental health care for Black and minority patients. Their findings suggest that ethnically focussed care or services could potentially improve pathways to care, but the majority of the studies in their review were from outside the UK (Sass et al., 2009). However, the idea of developing culturally appropriate treatment during FEP in the UK has been previously mooted (Bhui and Bhugra, 2002, Bhugra et al., 2011a).

3.4 Pathways to Care – Compulsory Admission and Ethnicity

So far, treatment delays, source of referral and mode of contact with mental health services have been considered as key determinants of pathway to care. The association of these factors with ethnicity suggests that ethnic minority patients tend to have shorter DUP, particularly in the UK, due to urgency of symptom presentation compared with the native population. The evidence also points to a less favourable pathway to care, e.g. use of emergency services at first presentation and lesser GP involvement in the referral pathway for ethnic minority patients. Although a few of the studies reviewed above reported correlational associations, causal inference cannot be drawn.

This section now considers the negative pathways into care, i.e. compulsory admission, criminal justice involvement and emergency referral. In keeping with the evidence reviewed in sub-section 3.2.3, it is well documented that there are higher compulsory admission rates among Black and minority ethnic groups in Western nations, and this remains a major concern for patients, mental healthcare providers and policy-makers (Singh et al., 2007). So much so, in the UK for example, the government published a report on reducing the inequality in detention rates in the white paper 'Delivering Race Equality in Mental Health Care' (Department of Health, 2005). Over the past decade a number of primary research and systematic reviews have been conducted to shed light on this clinically and politically contentious issue.

Literature comparing compulsory admission rates in different ethnic groups has highlighted a paucity of evidence on the topic, especially for the Black African and Black Caribbean groups. Table 3.3 shows that 20 primary research studies have been carried out in the last ten years on this topic. However, there are concerns about the quality of studies; for

instance, Mann et al. 2014 in a systematic review found only seven eligible studies, 70% of which reported no differences in rates of compulsory admission, except Morgan et al. (2005), who reported odds ratios of compulsory admission by ethnic group, whereas others reported proportions and chi-squared test (Mann et al., 2014a). Bhui and Bhugra (2002) highlighted variations in access to services; for example, they observed an over-representation of Black patients in inpatient facilities, whereas Asian patients are less likely than White patients to use such facilities. They also reported variations in primary care assessment and GP involvement, which may hint at some of the ethnic differences in pathways to specialist services. Anderson and colleagues (2010) in their systematic review of pathways to care during FEP reported that in the majority of the studies they included, patients' first contact for help-seeking is their GP. However, they found that the greatest proportion of referral source to be via emergency services (Anderson et al., 2010). There was no consistent evidence across studies for demographic factors as predictors of pathways to care, but the authors acknowledged the need for further research to understand help-seeking behaviour during FEP (Anderson et al., 2010).

Studies reporting the odds ratios of compulsory admission compared to native populations have shown variation in the effect of the odds ratios (Table 3.3). Only two studies have examined the association between compulsory admission and specifically Black African and Black Caribbean ethnicity. For Black African patients the effect size ranges from adj. OR of 4.33 (95% CI 1.88 – 9.99) (Morgan et al., 2005a) to adj. OR of 5.4 (95% CI 2.7 – 10.7) (Mann et al., 2014b); for Black Caribbean it ranges from adj. OR of 2.0 (95% CI 0.7 – 5.5) (Mann et al., 2014b) to OR of 2.30 (95% CI 1.23 – 4.32) (Morgan et al., 2005a). Other studies have employed broad groupings of ethnicity such as Black and the effect of association for this group range from OR of 1.35 (95% CI, 1.13 – 1.62) (Singh et al., 2014a) to OR of 4.31 (95% CI 3.33 – 5.58)(Bhui et al., 2003). For Asian patients, the odds ratios for compulsory admission range from OR of 0.3 (95% CI 0.0 – 2.6) (Corrigall and Bhugra, 2013) to OR of 1.1 (95% CI 0.6 – 2.13) (Jarvis et al., 2014). These studies have mainly been conducted in the UK and were usually in large cities like London.

Evidence from the rest of Europe also suggests a similar trend. For example, compared to their Dutch counterparts, Moroccan patients have increased odds of compulsory admission ranging from adj. OR of 1.8 (95% CI 1.0 – 3.3) to adj. OR of 2.03 (95% CI 1.34 – 3.06). For the

Turkish patients, the odds of compulsory admission range from adj. OR of 1.3 (95% CI 0.5 – 3.0) to adj. OR of 3.95 (95% CI 1.52 – 10.24). Similarly, the Surinamese patients also showed a likelihood of compulsory admission, with a range of adj. OR of 2.4 (95% CI 1.5 – 3.8) to adj. OR of 1.88 (95% CI 1.19 – 2.97) (de Wit et al., 2012, van der Post et al., 2012). Furthermore, Berg and Johnsen (2004) in an investigation of whether immigrants were more likely to use emergency departments than native Norwegians, reported no difference (49 in 10,000 vs. 52 in 10,000 respectively, p = 0.72) but they found immigrants using such services were more likely to be men, younger and more likely to be compulsorily detained (Berg and Johnsen, 2004). Of note is a Dutch study by Van der Post et al. (2012); having adjusted for a number of confounders, they also replicated UK findings that sub-Saharan African patients are more likely to be detained compulsorily, with an adj. OR of 3.0 (95% CI 1.4 – 6.4) (van der Post et al., 2012).

Further, in a meta-analysis, Singh and colleagues (2007) impressively attempted to disentangle possible explanations for the excess rate of compulsory admission among minority groups. Their findings were consistent with those comparing detention rates in native patients with minority ethnic groups e.g. White vs. Black, White vs. Asian, but they went a step further and examined detention rates between ethnic minority groups, e.g. Black vs. Asian, where they found that Black patients remain more likely than Asian patients to be compulsorily detained, with an OR of 2.25 (95% CI 1.72 – 2.94). This difference between minority groups provides an opportunity to explore further the role of cultural, socioeconomic and help-seeking behaviours to improve our understanding on this topic and test the hypothesis that differences in detention rates may not all be down to ethnicity. They explored the association of detention with illness episode i.e. FEP or mixed episode and reported that the minority groups are more likely to be detained during both episodes, except the Asian patients who are less likely to be detained during FEP (Singh et al., 2007). A few years later, Singh and colleagues (2014) in an investigation of effect of ethnicity on detention following a Mental Health Act (MHA) assessment, found that Black patients (OR=1.35; 95% CI 1.37 – 1.62) and 'Other' ethnic groups (OR=1.31; 95% CI, 1.03 – 1.66) were more likely to be detained than White patients. They also found other demographic factors to be associated with MHA, for example female OR = 1.30 (95% CI 1.10 – 1.55), older age OR = 1.35 (95% CI 1.11 – 1.64) and living in supported accommodation OR = 1.80 (95% CI 1.14 –

2.85). Paradoxically, when they took the site of MHA assessment into account they observed that ethnicity was not associated with detention, which may be explained by distribution of ethnic groups since London had the highest proportion of Black patients and Birmingham had the largest number of Asians in the sample (Singh et al., 2014a). However, in a letter to the editor Sasidharan et al. (2014) highlighted key fundamental issues to bear in mind with the Singh et al. (2014) study; for example, the sampling framing they used to define compulsory detention were individuals assessed under the MHA rather than the patient population in contact with mental health services who were therefore be at risk of being detained. It is possible that the sample used in this study was an underestimate since only the patients who were seen by an approved social worker (ASW) or approved mental health professional (AMHP) would have been included. Meanwhile, clinical judgment to detain or not detain an individual would have been made prior to the patient being assessed by an ASW.

Table 3.3: Studies of psychosis compulsory admission and ethnicity

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
Law-Min et al. (2003) (UK)	5 yr Retrospective study	189 patients admitted under the MHA	White Black Asian	Proportion of schizophrenia diagnosis 63.6% Asian 47.6% Black 41.5% White Proportion of compulsory admission 61.2 White 86.7% Black 64.7% Asian
Webber & Huxley (2004) (UK)	Cross-sectional survey	300 patients admitted under section 4 of MHA	White British Non-White British	Association between compulsory admission and ethnicity (reference = White British) **OR = 2.3 (95% CI 1.40 – 3.79) non-white ethnicity** **OR = 2.23 (95% CI1.38 – 3.61) Psychosis diagnosis** **OR = 9.78 (95% CI 5.71 – 16.75) Present risk** **OR = 1.72 (95% CI 1.05 – 2.79) Insure housing** **OR = 2.01 (95% CI 1.22 – 3.31) multiple exclusion**
Cougnard et al. (2004) (France)	Cross-sectional survey	97 hospital patients	n/a	**OR = 2.9 (95% CI 1.2 – 7.4) Male** OR = 1.8 (95% CI 0.6 – 5.6) Single OR = 0.7 (95% CI 0.3 – 2.4) No children OR = 1.2 (95% CI 0.5 – 2.9) Lives alone OR = 0.7 (95% CI 0.2- 2.6) No friends OR = 1.7 (95% CI 0.7- 4.1) Educational level <12yrs OR = 0.9 (95% CI 0.4 – 2.2) Unemployed OR = 2.4 (95% CI 1.1 – 5.9) Broadly defined SCZ

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
Oluwatayo et al. (2004) (UK)	Cross-sectional survey	382 inpatients	White British African-Caribbean	**Factors associated with compulsory admission.** **White British vs. African-Caribbean** **X2 = 9.2 df = 3 p = 0.02 (GP involvement)** **X2 = 40.1 df = 12 p = 0.01 (source of referral)** **X2 = 24.2 df = 12 p = 0.05 (duration of symptoms)**
Wheeler et al. (2005) (New Zealand)	Retrospective case-note survey	932 patient admitted during 1 year period	n/a	62% compulsory admissions 38% schizophrenia – Most common diagnosis
Lay et al. (2005) (Switzerland)	Administrative record survey	23,377 referrals	Country of origin: Switzerland Southern Europe Western and Northern Europe Former Yugoslavia Turkey Eastern Europe Other countries	Compulsory admission by country of origin and gender (male) – Reference = Swiss OR = 1.09 (95% CI 0.93 – 1.26) Southern Europe OR = 0.9 (95% CI 0.73 – 1.12) Western and Northern Europe **OR = 1.62 (95% CI 1.36 – 1.93) Former Yugoslavia** **OR = 1.27 (95% CI 1.00 – 1.62) Turkey** **OR = 1.70 (95% CI 1.15 – 2.51) Eastern Europe** **OR = 2.33 (95% CI 1.99 – 2.73) Other countries** **Female** OR = 1.14 (95% CI 0.94 – 1.39) Southern Europe OR = 0.99 (95% CI 0.79 – 1.27) Western and Northern Europe **OR = 1.41 (95% CI 1.16 – 1.71) Former Yugoslavia** **OR = 1.19 (95% CI 0.86 – 1.64) Turkey** **OR = 2.78 (95% CI 1.73 – 4.45) Eastern Europe**

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
				OR = 2.63 (95% CI 2.08 – 3.33) Other countries
Morgan et al. (2005) (UK)	Incidence and Case-control (AESOP)	462 FEP	White British White other Black African Black Caribbean	Association between source of referral and ethnicity (White British as reference group) **GP referral** **OR = 0.46 (95% CI 0.29 – 0.75) African-Caribbean** **OR = 0.39 (95% CI 0.20 – 0.73) Black African** **Adj. OR = 0.48 (95% CI 0.25 – 0.90) African-Caribbean** **Adj. OR = 0.41 (95% CI 0.18 – 0.95) Black African** **Criminal Justice Agency** **OR = 2.52 (95% CI 1.49 – 4.27) African-Caribbean** **OR = 2.89 (95% CI 1.53 – 5.46) Black African** **Adj. OR = 1.98 (95% CI 1.04 – 3.77) African-Caribbean** Adj. OR = 1.87 (95% CI 0.86 – 4.05) Black African
Morgan et al. (2005) (UK)	Incidence and Case-control (AESOP)	512 FEP	White British White other Black African Black Caribbean	Association between compulsory admission and ethnicity (white British as reference group) **Adj. OR = 2.30 (95% CI 1.23 – 4.32) Black Caribbean** **Adj. OR = 4.33 (95% CI 1.88 – 9.99) Black African** **OR = 2.88 (95% CI 1.84 – 4.51) Black Caribbean** **OR = 3.26 (95% CI 1.85 – 5.77) Black African** OR = 1.18 (95% CI 0.53 – 2.61) Other White

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
Turner et al. (2006)(New Zealand)	Cross-sectional survey	200 first admission patients	Maori Non-Maori	X2 = 2.08, df = 4, p = 0.72 Diagnosis vs. types of help-seeking X2 = 1.82, df = 2, p = 0.40 rate of contact with police X2 = 2.77, df = 2, p = 0.25 outpatient X2 = 0.75, df = 2, p = 0.68 GP X2 = 1.42, df = 2, p = 0.49 rate of admission X2 = 0.49, df = 2, p = 0.78 compulsory admission
Mulder et al. (2006) (the Netherlands)	Case-register survey	720 patients	Dutch native Moroccan Turkish Surinamese Antillean Other Western Other non-Western	Risk of contact with emergency services for psychotic disorder (Dutch as reference group) **Adj. RR = 4.2 (95% CI 2.7 – 6.7) Moroccan** **Adj. RR = 2.0 (95% CI 1.2 – 3.3) Turkish** **Adj. RR = 3.5 (95% CI 2.4 – 5.1) Surinamese** **Adj. RR = 3.7 (95% CI 2.1 – 6.4) Antillean** Adj. RR = 0.9 (95% CI 0.5 – 1.6) Other Western **Adj. RR = 3.9 (95% CI 2.8 – 5.6) Other non-Western** Risk of contact followed by compulsory admission (Dutch as reference group) **Adj. RR = 2.2 (95% CI 1.0 – 5.2) Moroccan** Adj. RR = 1.4 (95% CI 0.6 – 3.2) Turks **Adj. RR = 3.0 (95% CI 1.7 – 5.2) Surinamese** **Adj. RR = 3.6 (95% CI 1.6 – 7.9) Antillean** Adj. RR = 0.7 (95% CI 0.3 – 1.6) Other Western **Adj. RR = 1.9 (95% CI 1.0 – 3.6) Other non-**

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
				Western
Archie et al. (2010) (Canada)	Cross-sectional survey	200 patients	White Black Asian Other	**X2 = 9.500, df = 3, p = 0.23 Compulsory vs. voluntary admission** X2 = 2.398, df = 3, p = 0.49 ER vs non-ER X2 = 4.349, df = 3, p = 0.22 Hospitalisation vs. no-hospitalisation X2 = 3.358, df = 3, p = 0.34 Arrested 6 months prior vs. no Arrest Odds of ER use by ethnicity Adj. OR = 1.11 (95% CI 0.37 – 3.27) Black **Adj. OR = 3.97 (95% CI 1.39 – 11.34) Asian** **Adj. OR = 3.27 (95% CI 1.16 – 9.18) Other**
Vinkers et al. (2010) (the Netherlands)	Cross-sectional survey	14,540 pre-trial reports	Dutch native Whites Black and minority ethnic group	Association between ethnicity and compulsory admission recommendation among prisoners (Dutch as reference group) **OR = 1.38 (95% CI 1.16 – 1.64) BME** **OR = 1.54 (95% CI 1.05 – 2.27) White**
Lawlor et al. (2012) (UK)	Cross-sectional survey	287 women admitted to acute inpatient wards and crisis teams	White British Other White Black African Black Caribbean Other Black	Association between compulsory admission and ethnicity (reference = White British) **Adj. OR = 3.53 (95% CI 1.57 – 7.94) Other White** **Adj. OR = 3.88 (95% CI 1.47 – 10.2) Black Caribbean** **Adj. OR = 5.80 (95% CI 2.52 – 13.4) Black African** **Adj. OR = 5.22 (95% CI 2.06 – 13.2) Black Other**

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
Van der Post et al. (2012) (the Netherlands)	Prospective cohort study	2,245 patients	Country of origin: Netherlands Morocco Turkey Surinam/Dutch Antilles Sub-Saharan Africa Other non-Western Other Western	Compulsory admission (adjusted for age, gender, living situation) (Dutch as reference group) **Adj. OR = 1.8 (95% CI 1.0 – 3.3) Morocco** Adj. OR = 1.3 (95% CI 0.5 – 3.0) Turkey **Adj. OR = 2.4 (95% CI 1.5 – 3.8) Surinam/Dutch Antilles** **Adj. OR = 3.0 (95% CI 1.4 – 6.4) Sub-Saharan Africa** **Adj. OR = 1.7 (95% CI 1.0 – 2.9) Other non-Western** Adj. OR = 1.2 (95% CI 0.7 -1.9) Other Western Compulsory admission (adjusted for age, gender, living situation, referral source, diagnosis and psychiatric history) Adj. OR = 1.6 (95% CI 0.8 – 3.4) Morocco Adj. OR = 1.0 (95% CI 0.4 – 2.4) Turkey Adj. OR = 1.4 (95% CI 0.8 – 2.5) Surinam/Dutch Antilles Adj. OR = 2.1 (95% CI 0.9 – 5.1) Sub-Saharan Africa Adj. OR = 1.5 (95% CI 0.8 – 2.8) Other non-Western **Adj. OR = 1.1 (95% CI 1.0 – 1.0) Other Western**
De Wit et al. (2012) (the	10 year Longitudinal	2,646 patients with first	Dutch Surinamese	Association between ethnicity and compulsory admission (Dutch as reference group)

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
Netherlands)	case-note cohort study	compulsory admission	Antillean Moroccan Turkish Other Western Other non-Western	**Adj. OR = 1.48 (95% CI 1.14 – 1.92) Surinamese 1st gen** **Adj. OR = 1.88 (95% CI 1.19 – 2.97) Surinamese 2nd gen** **Adj. OR = 2.02 (95% CI 1.17 – 3.49) Antillean 1st gen** Adj. OR = 2.18 (95% CI 0.75 – 6.36) Antillean 2nd gen **Adj. OR = 2.03 (95% CI 1.34 – 3.06) Moroccan 1st gen** Adj. OR = 1.32 (95% CI 0.73 – 2.40) Moroccan 2nd gen **Adj. OR = 2.03 (95% CI 1.22 – 3.38) Turkish 1st gen** **Adj. OR = 3.95 (95% CI 1.52 – 10.24) Turkish 2nd gen** Adj. OR = 0.89 (95% CI 0.65 – 1.23) Other Western 1st gen Adj. OR = 1.04(95% CI 0.76 – 1.44) Other Western 2nd gen Adj. OR = 0.97 (95% CI 0.72 – 1.32) Other non-Western 1st gen Adj. OR = 0.90 (95% CI 0.38 – 2.13) Other non-Western 2nd gen
Corrigall and Bhugra (2013) (UK)	10 yr Longitudinal case-note study	435 hospital admission adolescent	White Black Asian	Association with MHA, White British as reference group **OR = 3.0 (95% CI 1.3 – 6.7) Black**

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
		patients	Other	OR = 0.3 (95% CI 0.0 – 2.6) Asian **OR = 3.1 (95% CI 1.1 – 8.8) Other** Associations with admission for psychosis **OR = 5.7 (95% CI 3.9 – 8.3) Black** **OR = 2.6 (95% CI 1.2 – 5.3) Asian** **OR = 3.4 (95% CI 2.1 – 5.6) Other**
Singh et al. (2014) (UK)				Association between MHA and demographic factors **OR = 1.30 (95% CI 1.10 – 1.55) Female** **OR = 1.35 (95% CI 1.11 – 1.64) <30yrs** **(Living with family as reference group)** OR = 1.22 (95% CI 0.84 – 1.78) Homeless OR = 0.96 (95% CI 0.79 – 1.16) Living alone **OR = 1.80 (95% CI 1.14 – 2.85) Supported accommodation** Association between MHA and Ethnicity only (White as reference group) **OR = 1.35 (95% CI 1.137 – 1.62) Black** OR = 0.95 (95% CI 0.77 – 1.18) Asian **OR = 1.31 (95% CI 1.03 – 1.66) Other** Association between MHA and Site only (ref. = London)

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
				OR = 0.53 (95% CI 0.46 – 0.62) Oxfordshire **OR = 0.51 (95% CI 0.43 – 0.59) Birmingham** Association between MHA and Ethnicity and site (ref. = White and London) OR = 1.19 (95% CI 0.99 – 1.42) Black OR = 1.04 (95% CI 0.83 – 1.29) Asian **OR = 1.07 (95% CI 1.84 – 1.37) Other**
Mann et al. (2014) (UK)	Cross-sectional audit – with 12-month follow-up	674 EIS patients Across 4 EI services in London		Association with compulsory detention by ethnicity (White British as reference group) Adj. OR = 1.8 (95% CI 0.84 – 4.0) White other Adj. OR = 3.4 (95% CI 0.9 – 12.6) Mixed Black/White Adj. OR = 2.5 (95% CI 0.9 – 7.0) South Asian Adj. OR = 1.6 (95% CI 0.5 – 5.3) Asian other Adj. OR = 2.0 (95% CI 0.6 – 7.2) Black British Adj. OR = 2.0 (95% CI 0.7 – 5.5) Black Caribbean **Adj. OR = 5.4 (95% CI 2.7 – 10.7) Black African** Association with hospital admission by ethnicity (White British as reference group) Adj. OR = 1.8 (95% CI 0.9 – 3.7) White other Adj. OR = 1.4 (95% CI 0.4 – 5.2) Mixed Black/White Adj. OR = 1.1(95% CI 0.4 – 3.0) South Asian Adj. OR = 1.8 (95% CI 0.6 – 5.8) Asian other Adj. OR =1.7 (95% CI 0.5 – 5.7) Black British Adj. OR = 1.6 (95% CI 0.6 – 4.3) Black Caribbean

Authors (Country)	Study Design	Sample	Ethnic groups	Main findings
				Adj. OR = 4.9(95% CI 2.4 – 9.7) Black African
Jarvis et al. (2014) (Canada)	Cross-sectional survey	351 hospital patients	Euro-Canadian Afro-Canadian Asian-Canadian	Predictors of police or ambulance referral (reference = Canadian) **Exp (B) = 2.9 (95% CI 1.26 – 6.62) Afro-Canadian** Exp (B) = 1.1 (95% CI 0.6 – 2.13) Asian-Canadian

Adj. OR, adjusted odds ratio. OR, odds ratio. DUP, duration of untreated psychosis. LOS, length of stay. DUP, Duration of untreated psychosis. RR, relative risks. Adj. RR, adjusted relative risks. X2, chi-sq test. Exp (B), exponential beta coefficient. EIS, early intervention service. BME, black and minority ethnic group. EI, early intervention.

3.5 Methodological consideration and gaps in current evidence

This review has picked up upon some methodological issues in studies on DUP, mode of onset, EIS and pathways into care, which have not been adequately addressed in previous research. Firstly, the challenge of ethnic categories is posed, where for example the Black Caribbean, Black African and other Black patients are often amalgamated into one group – Black, meaning that no conclusion can be drawn about the pathway into care for Black Caribbean and Black African patients. However, it is noteworthy that three studies in this review addressed this issue (Morgan et al., 2005a, Mann et al., 2014b, Ghali et al., 2012), and they had sufficient sample power to analyse data for these two different groups separately.

Secondly, the issue of sampling and design must be addressed. In order to adjust for a range of well-known confounders and to assess the differential effect of pathways to care as well as between ethnicities, large numbers of participants are required to ensure false positive associations are not reported. However, despite a number of studies in this review having sufficient sampling power, quite a few had small sample sizes. For example, in the studies by (Compton et al., 2006), (Goulding et al., 2008), (Chien and Compton, 2008) and (Cheung et al., 2014), only 25, 34 (34 carers) and 50 participants respectively were recruited. Moreover, in the study by (Dominguez et al., 2013), differences found by ethnic groups in the adolescent sample may be subject to selection bias as the sample size was small (73 patients). In addition, age of onset was available for only 69% of the sample, so the findings may not be generalisable. Indeed some studies on compulsory admission and mode of contact have controlled for confounders such as age, gender, socioeconomic status and clinical factors(Morgan et al., 2006a, Morgan et al., 2005a, Morgan et al., 2005b, de Wit et al., 2012, Mulder et al., 2006, Mann et al., 2014b, Lawlor et al., 2012), although Webber and Huxley (2004) only adjusted for age. Some have adjusted for none and only reported unadjusted odds ratios (Corrigall and Bhugra, 2013, Lay et al., 2005), while others have only reported proportional differences and X^2 tests (Turner et al., 2006, Wheeler et al., 2005, Archie et al., 2010, Oluwatayo and Gater, 2004).

Furthermore, this review picked up some inconsistencies in measuring clinical variables in connection with pathways to care. For instance, variation in duration of untreated psychosis may be due to the way DUP have been measured across studies; some studies calculated

DUP by subtracting the date of first positive psychotic symptom from the date antipsychotic medication started (Ehmann et al., 2014, Ghali et al., 2012, Dominguez et al., 2013, Power et al., 2007, Thomas and Nandhra, 2009), others calculated to the date of first hospital admission (Compton et al., 2011, Chien and Compton, 2008) and a few used date of first contact with any mental health services (Morgan et al., 2006b, Kirkbride et al., 2010). The variation in pathways to care given the differences in healthcare systems in different countries may contribute to the lack of consensus in measuring DUP. For example, outside of the UK, the primary care system (e.g. GP) is widely available and free at point of use in Canada and parts of Europe but not in the USA, where healthcare is insurance- and payment-based.

Thirdly, we consider study design. Similar to issues picked up in the previous chapter, many of the studies included in this review have employed a cross-sectional survey design, which has the potential to limit exploration of other factors that may explain pathways to care. Sources used to draw samples vary across studies, making generalisability of findings difficult. For example, Compton et al. (2011) used hospital admission to define FEP in a cross-sectional design which has its own flaws as previously highlighted in Chapter 2. Moreover, the study sample has a majority of African-American (89.9%), a small sample of White (6.4%) and other (3.6%) subjects.

3.6 Summary

In conclusion, it appears that despite the outcome-driven nature of EIS, which is to demonstrate positive impact on early detection and treatment of psychosis, research studies in the last ten years suggest little improvement in the equality of access to care between ethnic groups.

The evidence so far indicates that only a few sociodemographic and clinical factors are predictive of DUP and pathway into care. But more importantly, evidence from the handful of studies that have examined service-level factors have demonstrated that type of contact and delays in time seeking treatment (e.g. steps taken to reach an EIS) have stronger impact on pathways to care and service engagement patterns.

Minority ethnic group patients continue to be more likely to access mental health care via negative pathways, i.e. compulsory admission and emergency departments, and have police involvement during first episode psychosis.

4 Chapter 4: Literature Review – Ethnicity, Course and Service Use Outcomes Following First Episode Psychosis

4.1 Synopsis

This chapter is anchored in the National Institute for Clinical Excellence (NICE) guidelines for schizophrenia and psychosis in adults. Specifically, it is concerned with NICE quality statement one, which states that "adults with a first episode of psychosis (FEP) start treatment in early intervention in psychosis (EIS) services within 2 weeks of referral"(NICE, 2015). The statement is based on the rationale that EIS can improve clinical and service use outcomes, such as admission rates, symptoms and relapse, for people with a first episode of psychosis. The outcomes set out in the guidelines focus on acute hospital admissions, duration of untreated psychosis and readmission rates, measured by locally collected data. In Chapter 3, I discussed early intervention services and duration of untreated psychosis (DUP) in relation to pathways to care. This chapter now goes on to review and discuss the current evidence of clinical outcomes following FEP both in the context of EIS and generic service use, specifically addressing the questions: a) are there differences by ethnic group in the length of time patients spend in hospital? and b) are there differences in rates of hospital admission and compulsory detention by ethnic groups? In section 4.2, I revisit EIS and examine its role on clinical and service use outcomes and any variations by ethnicity. I review literature on course and outcomes of FEP, examining evidence from longitudinal and follow-up studies, in section 4.3. Finally, section 4.4 includes a discussion of the implications for the findings and methodological considerations.

Although this is not a systematic review, in searching the literature to address the questions proposed above, I used the following keywords: 'early intervention', 'first episode', 'admission', 'psychosis', 'psychotic disorders', 'course', 'outcome', 'follow-up', 'longitudinal', 'cohort' and 'ethnicity', using bibliographical databases including Pubmed, Web of Science, Embase, PsychoInfo and Google Scholar. This chapter reports on the body of work carried out on the topic of course and outcome of first episode psychosis among ethnic minority populations.

4.2 Early intervention for psychosis – the promise of improved pathways to care and better clinical outcomes

As briefly mentioned in Chapter 3, we have observed the establishment of early intervention for psychosis programmes, several of which have been carefully evaluated (Craig et al., 2004a, Birchwood, 1995, Kuipers et al., 2004, McGorry et al., 2009, Bertelsen et al., 2008b). These evaluations show relatively consistent findings of improved clinical and functional outcomes (Bird et al., 2010). But perhaps surprisingly, very few of these studies have explored variation in course and outcome by ethnicity.

The Lambeth Early Onset (LEO) trial was a randomised controlled trial (RCT) comparing an EIS to standard care for people experiencing a first episode of psychosis (Craig et al., 2004b). The clinical trial took place between 2001 and 2003 towards the end of the Aetiology and Ethnicity of Schizophrenia and Other Psychosis (AESOP) study and included as one of its objectives to reduce levels of disengagement and relapse rates among young Black African and Black Caribbean patients. Attention was paid to the ethnic 'mix' of the clinical team and the service included a number of social activities provided out of hours that were expected to be of interest to local young people. There was also an informal drop in to which families were invited and encouraged to attend. The results showed that those in the intervention group were less likely to relapse (β= 0.39; 95% CI 0.10 – 0.68), and less likely to be readmitted to hospital over an 18-month period (Craig et al., 2004b). Although ethnic differences were not specifically assessed in this study, those in the EI group were also much less likely to drop out of care (β=0.28; 95% CI 0.12 – 0.73) and less likely to be readmitted (β=0.36; 95% CI 0.04 -0.66) than patients receiving standard care, with this difference being almost entirely accounted for by people of Black African and Caribbean backgrounds. Rates of hospitalisation, access to psychological therapies and medication did not differ across ethnic groups in the intervention arm.

It is worth noting that as LEO became embedded in the wider health system and the numbers of patients and hence work-pressure increased, some of the initial gains in terms of improved sensitivity to the needs of ethnic minorities may have been lost. An audit survey of four inner London EIS teams that included the LEO service about three years after

the conclusion of this clinical trial produced rather less impressive results (Mann et al., 2014b).

More recent surveys in the UK have tended to confirm this view, as for example, the findings of an observational study of 123 (45 White, 35 Black and 43 Asian) EIS patients (Singh et al., 2015a). Black patients were four times more likely than White patients to be compulsorily detained and both Black and Asian patients were more likely to have consulted faith-based institutions prior to accessing services (Singh et al., 2015a).

4.3 Examining course and outcome of psychosis and ethnicity

In the last decade, only a few longitudinal studies have been carried out addressing the course and outcome of psychotic disorder in minority ethnic groups, but the evidence so far points to a mixed picture. Available literature on course and service use outcomes in relations to ethnicity is discussed below.

In a recent systematic review, Chorlton et al. (2011) assessed differences in course and outcome following psychosis for Black Caribbean patients compared with other ethnic groups living in the UK. They included fourteen studies with varying methodology, sample size and follow-up time. In the investigation of ethnic differences in course and outcomes, Chorlton and colleagues considered a broad range of outcomes as reported in the studies included in their review. For one such outcome, service use at follow-up, the majority of studies reported no difference (Mohan et al., 2006, Goater et al., 1999) except (McGovern and Cope, 1991), who found that Black Caribbean patients were less likely to maintain contact with services. For compulsory admission, the majority of studies (Callan, 1996, McKenzie et al., 1995, Takei et al., 1995, Leff, 1988) reported that Black Caribbean patients were more likely to be compulsorily admitted to hospital compared with White British patients, but (Harrison et al., 1999) and (Goater et al., 1999) both found no difference. It is noteworthy that these two studies used crude Black and White ethnic categorisation, which may have influenced the lack of differences being observed. Next, for the frequency and duration of hospital admission, the picture is rather mixed. For example, some studies reported no difference (Callan, 1996, Harrison et al., 1999) while others found that Black Caribbean patients were more likely to experience a higher rates of admissions (McGovern and Cope, 1991) compared with White British patients, and one study (Goater et al., 1999)

reported that White British were more likely to have been admitted than other ethnicities at one-year follow-up, but the effect did not hold at five-year follow-up.

The lack of ethnic differences in Chorlton and colleagues' (2011) review may be largely due to methodological issues sample limitation as well as poorly defined ethnic groups. The limited research on course and outcome of psychotic disorder in minority ethnic groups means that important questions about development of psychotic disorder remain unanswered.

Ethnic differences by hospital admission and diagnosis have been examined in other studies with varying results. For example, Walsh and colleagues (Walsh et al., 2002) compared samples from the UK700 intervention study. They examined ethnic differences in hospitalisation using community and forensic hospital samples (n = 708 vs. 905) respectively, and found no difference between the White and African-Caribbean (adj. OR of 0.86; 95% CI 0.59 – 1.25) groups, but reported that the 'Other' ethnic group were less likely to be admitted to a forensic hospital (adj. OR = 0.23; 95% CI 0.14 – 0.38). By diagnosis they found that those with schizoaffective disorder (adj. OR = 0.46; 95% CI 0.26 – 0.83) and affective disorder (adj. OR = 0.35; 95% CI 0.19 – 0.69) were less likely to be admitted to a forensic hospital.

A few research studies have also been carried out to assess patients' prognoses following first episode psychosis and by ethnicity. Selten and colleagues (2007) conducted a 30-month follow-up of their first episode psychosis incidence cohort in the Netherlands identified in 1997–1999 and assessed the predictors of poor and good outcomes following first contact for psychosis. Using a sample of 139 patients, they reported that the majority of the sample were diagnosed as having schizophrenia (n = 125), followed by mood disorder (n = 17) and other psychotic disorder (n = 25). While they found no difference in poor (Dutch 52% vs. Non-Western 63%) or good (48% Dutch vs. 37% Non-Western, p = 0.21) outcomes by ethnicity, they reported predictors of poor outcomes among those diagnosed with schizophrenia as being male (adj. OR = 3.0; 95%; CI=1.0 – 8.9), heavy cannabis users and undergoing a long duration of dysfunctioning prior to psychosis. Age at onset, ethnicity, duration of untreated psychosis and socioeconomic status were not associated with poor outcome.

Harrison and colleagues (1999) followed up a sample of first episode patients (n = 166) who were identified in Nottingham between 1992 and 1994 for three years; they assessed the relationship between good prognosis and ethnicity (African-Caribbean and 'Other'). They found no difference between African-Caribbean and 'Other' for mean symptom score (adj. OR = 2.53; 95% CI 0.88 – 7.28). Meanwhile, when they assessed association with disability score in a crude logistic regression, there were no differences between the two ethnic groups (OR = 1.60; 95% CI 0.68 – 4.98) but associations emerged after adjusting for potential confounders e.g. age, gender, social class, DUP and diagnosis (adj. OR = 3.29; 95% CI 1.03 – 10.57), which suggests some confounding by age, social class and socioeconomic position. Although this study suffered from small sample size, the findings suggest that increased psychosis among African-Caribbean patients is not characterised by differences in symptoms either at onset or over a medium-term course of the disorder. Another UK study by Takei and colleagues (1999) followed patients up for eighteen years and compared outcomes between White and African-Caribbean groups. In this study, a sample of (n = 76) was identified between 1973–1974 using the Camberwell Case Register. They found no ethnic difference by diagnosis but reported that at follow-up, African-Caribbean patients had poor outcomes characterised by longer hospitalisation, higher readmission rates and were more likely to be involuntarily admitted compared with their White British counterparts. This is consistent with findings by (Bhugra et al., 1997), in a London study comparing incidence and outcomes for first psychosis inception in a sample of (38 White, 38 African-Caribbean and 24 Asian) which reported that poor outcomes (defined by relapse, episodic or suicidal ideation) were more common among African-Caribbean (60%) patients than for the other two groups (24% and 17%, G^2=15.33, p<0.005).

In a more recent 10-year follow-up of the AESOP sample (n = 532), Morgan and colleagues (in press) found that compared with White British, Black Caribbean patients experienced worse clinical, social and service use outcomes, and Black African patients experienced worse social and service use outcomes. At follow-up, Black Caribbean patients were around 60% less likely than White British patients to have recovered symptomatically (38.7% vs. 55.5%; adj. OR = 0.42; 95% CI 0.22 – 0.80), and were around two times more likely to have a non-episodic course (adj. OR = 2.27; 95% CI 1.09 – 4.76). Indicators of social outcomes suggest that only 1 (of 21; 5%) Black African patient, 3 (of 54; 6%) Black Caribbean patients,

and 9 (of 63; 14%) White British patients who were unemployed at baseline were employed at follow-up. In addition, the numbers and rates of admissions were greater in Black Caribbean and Black African patients than in White British, with patients in both groups admitted at a rate of around 0.36 per year (or once every three years) compared with a rate of 0.26 per year (or once every four years) for White British patients, constituting a 20% higher rate than White British patients. Further, admissions tended to be longer. Compared with a median length of 37 days for White British patients, the median inpatient stay for Black Caribbean patients was 62 days (rank sum test z -3.53, $p < 0.001$) and for Black African patients it was 54 days (rank sum test z -2.12, $p < 0.034$) (Morgan et al., in press).

4.4 Limitation of current research

While the breadth of research on this topic is limited, the varied nature of the available evidence makes drawing a definitive conclusion on course and outcomes of psychosis among black and minority ethnic groups difficult. This review has picked up some methodological issues that contribute to the variations in the research findings. For example, a number of studies were only able to include small sample size (Goater et al., 1999, Harrison et al., 1999) which may be due to attrition rates in the follow-up studies, hence making the reported estimates prone to imprecision. Furthermore, and as highlighted in the previous chapters, many studies with the exception of Morgan et al. (in press) have focussed on narrow ethnic minority categories, e.g. African-Caribbean, Asian, which may also be due to small sample size, and therefore it is difficult to disentangle differences -- if any -- between White British and Black African and Black Caribbean groups. In addition, the methodological quality of the research to date also varies in design and length of follow-up.

4.5 Summary

To summarise, evidence from evaluation of early intervention for psychosis indicates that such intervention is effective for reducing poor clinical outcomes but research is very limited into whether early intervention service improves outcomes for minority ethnic groups. It is

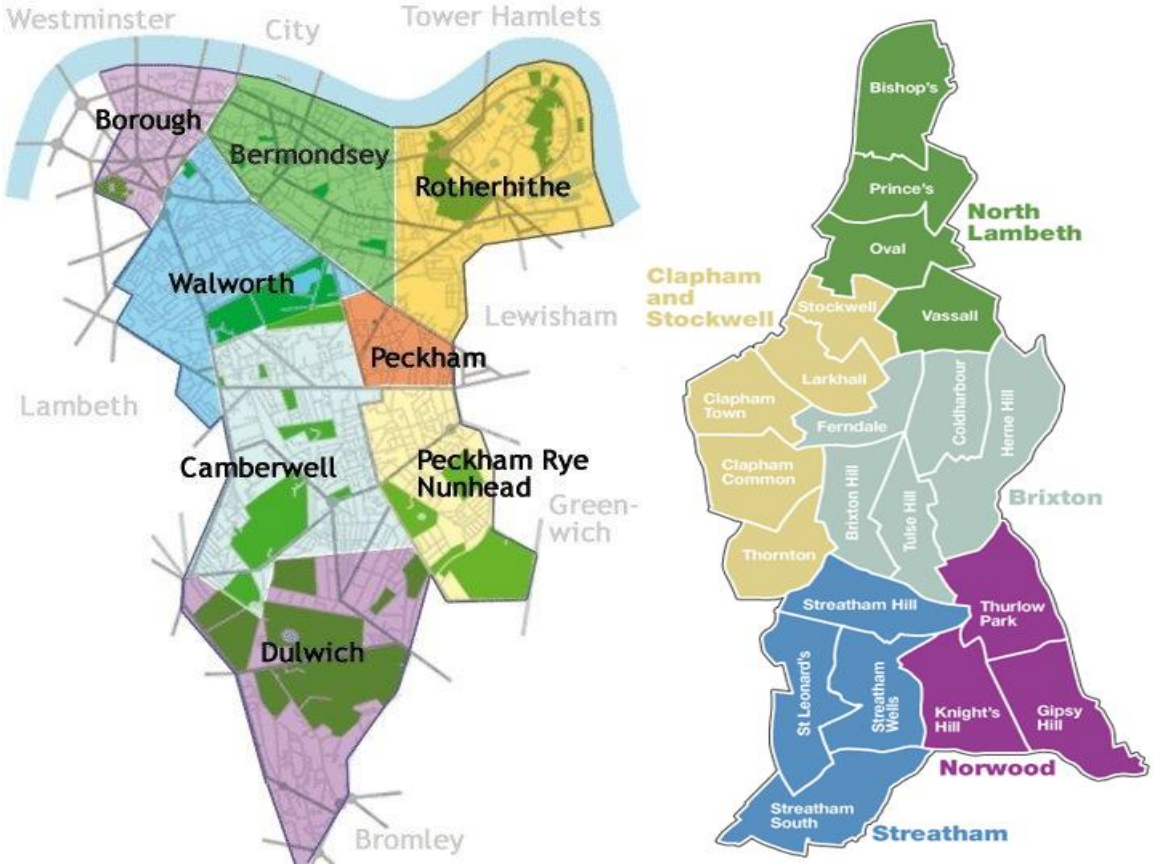
clear from the literature above, that there is a dearth of research on course and outcome of psychosis among ethnic minority groups, particularly in recent times. Studies carried out pre–early intervention service investigating the course and outcomes of psychosis among minority ethnic group patients present heterogeneous evidence. Therefore, firm conclusions cannot be drawn from the available evidence and so the question of whether ethnic differences operate in the course and outcome of psychosis remains unclear.

5 Chapter 5: At risk population and the mental health provider

5.1 Background

In this chapter, some contextual details about the population under investigation, e.g. socioeconomic factors and the set-up of the local mental health services are considered, before going into the methodology of this thesis. It is useful to consider the socioeconomic contexts of the two catchment areas included in this study through the lens of the social domains that were included in the literature review in Chapter 2. These social domains can be considered as factors that might be contributing to the incidence of psychosis in the geographical areas being investigated.

5.2 Contexts



London borough of Southwark *London borough of Lambeth*

Figure 5.1: The study catchment areas (Source: Google Wikipedia, Se16boy)

5.3 The Denominator: population of Lambeth and Southwark – Socioeconomic context

This study was conducted within two inner-city areas served by the South London and Maudsley NHS Foundation Trust (SLaM), these are the London boroughs of Lambeth (population 303,086) and Southwark (population 288,283) (ONS, 2011a). Both boroughs have risen in population since the 2001 census, 11% in Lambeth and 12% in Southwark. There is a high proportion of ethnic minority groups in both boroughs, principally African (11.6% Lambeth; 16.4% Southwark) and Caribbean (9.5% Lambeth; 6.2% Southwark). The 2011 census (ONS, 2011a) reported the overall ethnic composition of the two catchment areas as follows:

Table 5.1: Ethnic breakdown of at risk population 2011 census

Ethnicity	**% Lambeth**	**% Southwark**
White British	39	39.7
White Irish	2.5	2.2
White Gypsy	0.1	0.1
Other White	15.5	12.3
Mixed White & Black (African)	1.4	1.3
Mixed White & Black (Caribbean)	2.7	2
Mixed White and Asian	1.2	1
Mixed Other	2.3	1.9
Indian	1.6	2
Pakistani	1	0.6
Bangladeshi	0.7	1.4
Chinese	1.5	2.8
Other Asian	2	2.7
Black African	11.6	16.4

Black Caribbean	9.5	6.2
Other Black	4.8	4.2
Arab	0.6	0.8
Any Other Ethnic group	1.9	2.4

5.3.1 London Borough of Lambeth

The London borough of Lambeth is one of the most diverse local authorities in England and Wales. The borough is the third most populated borough in Inner London after Wandsworth and Newham boroughs of London (ONS, 2011a). 66.1% of the Lambeth population were UK born while 33.9% were born outside of the UK. The population has changed due to internal migration across this study period (May 2010 – April 2012), with 33,600 people (22%) moving into the borough and 35,900 (24.5%) moving out (London Borough of Lambeth, 2012).

The borough has a striking cultural and ethnic diversity, with 30% of residents describing themselves as belonging to non-white ethnic groups. Based on the 2011 census, Lambeth has a low percentage of people with an English-only identity and the proportion of White British people has decreased from 50% to 39% in the last 10 years. There are well-established Black and Irish communities with newer populations of Portuguese, South American and African residents, as well as a high and changing refugee population. Approximately 150 languages are spoken in the borough. After English the main languages spoken are: Portuguese, Yoruba, French, Spanish and Twi (London Borough of Lambeth, 2012).

A wide range of indicators highlight Lambeth as one of the most deprived areas in England. According to the 2010 indices of multiple deprivation, Lambeth ranked 14th most deprived borough in England and the 5th most deprived area in London, a worsening position since 2007, when the borough ranked 19th most deprived in England (Greater London Authority, 2011). That said, the borough also has some areas of affluence, for example 39.9% of Lambeth households are not deprived in any dimension (ONS, 2011a). Compared to national averages, the area has lower socioeconomic status, higher unemployment, higher death

rates from suicide and higher use of acute inpatient mental health services (London Borough of Lambeth, 2012).

As evidence has shown in the previous chapters, unemployment is a major risk factor for the onset of psychosis. This is an issue in Lambeth, with 7.6% of its working age population out of work according to the ONS 2012; this is marginally above the London average of 7.4%.

Educationally, 37% of Lambeth 16-year-olds did not achieve five GCSEs grade A*-C in 2011–2012, although this figure is an improvement on the previous three years, where 47% did not attain the aforementioned grades compared with the London average of 38% (Department of Education, 2012).

Nearly 6 per 1000 household were accepted as homeless in Lambeth during the periods 2010–2011, worse than the London average of 3.06 per 1000 household (New Policy Institute, 2014).

5.3.2 The London Borough of Southwark

The London borough of Southwark is the 12th most deprived area in London and 41st in England, showing a relative improvement from the 2007 ranking as 9th in London and 26th in England (Greater London Authority, 2011). It has the highest proportion of residents in the country who were born in Africa (12.9%) and over 300 languages are spoken in Southwark, making it an ethnically diverse population (London Borough of Southwark, 2011). Akin to Lambeth, unemployment is also high in Southwark, as 9.5% of its economically active population are unemployed compared to the London average of 7.4%.

Educational attainment at age 16 in Southwark is poor as 41% of 16-year-olds did not achieve five GCSEs grade A*-C in 2011–2012 compared to the London average of 38% (Department of Education, 2012). In addition, 4.04 per 1000 households were accepted as homeless in Southwark in 2010–2011 compared to the London average of 3.06 (New Policy Institute, 2014).

5.4 The Mental Health Provider

The South London and Maudsley (SLaM) NHS Foundation Trust is the largest mental health provider in Europe (Stewart et al., 2009), serving a population over 1.3 million across the London Boroughs of Lambeth, Lewisham, Croydon and Southwark and providing specialist services in Greenwich and Bromley. SLaM provides a wide range of multi-disciplinary integrated and specialist services across Child and Adolescents, Forensic, General Adult, Older Adults Addictions and Learning Disabilities clinical groups, employing approximately 4,500 members of staff. There is at least one hospital per borough providing inpatient services to acutely unwell patients; a large proportion of SLaM services are community-based. The Maudsley and Lambeth Hospitals serve the populations of the two boroughs under investigation in this study. Other hospitals within the Trust are the Bethlem Royal and Lewisham University hospitals, serving the boroughs of Croydon and Lewisham respectively. Each year, there are over 30,000 patients referred for assessment and treatment in SLaM (SLaM, 2014).

SLaM is one of the pioneering NHS Trusts to implement the use of an electronic medical record system over the last decade. By 2006 the Trust was effectively paperless, having transitioned to the electronic Patient Journey System (PJS). The PJS is a single purpose-built system that integrates all clinical notes/records used across all Trust services. PJS captures information recorded throughout patients' journeys through the clinical services including demographics, dates, contact information, detail of referrals and transfers, detailed clinical assessments, care plans, medication and clinical reviews (Stewart et al., 2009). The system is used and maintained by multi-disciplinary professionals and consists of both structured elements (e.g. checkbox, dates) and unstructured free text (including written assessments, correspondence letters and progress notes). Specific assessments and outcome measures are also available on PJS such as the Mini Mental State Examination and the Health of the Nation Outcome Scales (HONOS).

One of the questions this study sought to examine is whether the introduction of early intervention services has had significant impact on the pathways to care for patients with first episode psychosis. SLaM has well-established early intervention services across its catchment areas, i.e. one in each borough. For example, the Lambeth early onset (LEO) service has been operational since 2004 (Craig et al., 2004a), while the Southwark early

intervention team (STEP) was set up and running in 2007. The South London and Maudsley NHS Trust is a leading NHS institution that actively engages in research through working closely with its academic partner the Institute of Psychiatry, Psychology & Neuroscience (IoPPN), King's College London. The IoPPN is Europe's largest centre for research and post-graduate education in psychiatry, psychology, and neuroscience (SLaM website, 2014). In 2010, SLaM in collaboration with IoPPN launched a new research infrastructure (Clinical Record Interactive Search (CRIS) System) in the form of a case register, bringing it on the same platform as some of the well-known international case registers, such as Danish, Italian, Israeli, Japanese, Australian and American psychiatric case registers (Perera et al., 2009).

5.5 Case registers: History

Case registers have been long running in mental health research. In Europe for example, earlier national registers were created in Norway, followed by Denmark and Iceland in the 1930s. In the 1940s, registers were created in Israel, Japan, New Zealand and many in the USA (Perera et al., 2009). The 1960s saw the creation of regional registers in the UK (Aberdeen and Camberwell), Australia (Victoria) and Germany (Mannheim). The Italian and Dutch registers were introduced in the 1970s.

The Danish psychiatric central register was arguably the only ongoing case register in Europe until recently, as the Norwegian and Icelandic registers were discontinued in the 1980s (Munk-Jørgensen et al., 1993). As a national database of psychiatric records, the Danish register has served and proved its benefit for service planning, epidemiological and longitudinal studies, investigating course and predicting outcomes of illness.

In the two decades leading up to the 2000s, the popularity and use of case registers in mental health research saw a decline (Perera et al., 2009). However, the new technological advancement in computer software and opportunities for health care providers in using electronic clinical records has helped case registers become popular again as a research resource.

Stewart and colleagues (2009) developed arguably the largest regional case register in Europe, at the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (Stewart et al., 2009). The Clinical Record Interactive Search (CRIS) system was created using the electronic clinical records at SLaM.

Case registers for mental health research have been defined as 'patient-centred longitudinal records of contacts with a defined set of psychiatric services originating from a defined population' (Ten Horn et al., 1986). They contribute significantly to epidemiological research, service planning and utilisation, operational and administrative research (Perera et al., 2009). The availability of information on risk factors of rare disorders such as psychosis; demographics; and social, clinical and environmental characteristics about individuals using mental health services with any diagnosis makes it possible to interrogate case registers for conducting studies on topics such as course and outcomes (Stewart et al., 2009).

In the next chapter, the methodological approach employed in this thesis is discussed. I will give a detailed description and careful attention to detail in the use of the CRIS case register for identifying first episode psychosis cases that form the sample in this study.

6 Chapter 6: Study Methodology

6.1 Synopsis

Data for this thesis were collected as part of a larger programme of research on first episode psychosis (the Clinical Record Interactive Search - First Episode Psychosis Study: CRIS-FEP). To begin with, this chapter summarises key findings from the literature reviews from previous chapters. Subsequently, the general aims and justification for the methodology used are outlined (sections 6.2 and 6.3). The CRIS case register as research infrastructure is discussed in section 6.4. Next, the general methodology for the larger study is discussed (section 6.5), including the study design, the screening procedures employed for identifying cases and data extraction. The battery of the measures used within this thesis is described and outlined in section 6.5.5. Section 6.6 describes in more detail the automated data extraction procedures employed in the investigation of two-year follow-up outcomes in this PhD. Finally, the methods of statistical analyses are summarised (Section 6.7).

Key findings in the literature review set out in previous chapters can be summarised as below:

1. Over the last decade, studies have repeatedly reported higher incidence rates of psychosis among Black Caribbean and Black African populations in the UK compared with White British populations. The reasons for the higher rates remain unclear, partly due to methodological issues which limit causal inferences that can be drawn.

2. Most previous studies have examined pathways to care for broadly defined ethnic groups with little consideration of specific ethnic categories that mirror the base population, e.g. as defined for the UK Census 2001 and 2011. With this caveat, most studies show higher rates of compulsory hospitalisation among people from minority ethnic groups. The explanations for these higher rates remain unclear.

3. Early intervention services have shown promising signs in improving outcomes for psychosis, but there remain gaps in understanding their impact on pathways into care, especially by ethnic groups.

4. There has been less research on the course and outcome of psychotic disorder in ethnic minority groups but the available evidence points to a mixed picture, with some studies showing no difference by ethnic group while others suggest Black ethnic groups were at increased risk of hospital admissions and poor clinical outcomes.

It is on these conclusions and the limitations of previous research that the methodology of this thesis is based.

6.2 Aims and justification of study design

The overarching aim of the work presented in this thesis is to investigate patterns of the incidence of psychosis over time, pathways to care and service use among patients of Black African and Black Caribbean ethnicity with first episode psychotic illness. Individuals with first episode psychosis were drawn from both hospital and community settings of the South London and Maudsley NHS Trust (SLaM) General Adult and Forensic services. These services serve patients aged 18 to 64 years. This thesis comprises two phases – baseline and follow-up – and data were collected as follows.

Table 6.1: Study time points

Point of first contact for psychosis (case identification period)	Follow-up period (longitudinal data collection)
May 2010 – April 2012	Up to April 2014

At first contact for psychosis (baseline), cross-sectional data on sociodemographic and clinical presentation, compulsory detention and pathways to care at first contact were collected. Two questions were considered: (1) is the discrepancy in incidence rates between ethnic groups any larger (or smaller) now than it was 15 years ago? and (2) are there any differences in pathways to care for FEP cases compared to 15 years ago and is this associated with the introduction of EIS?

The aims of the first phase (baseline) were:

1. To estimate the incidence of psychosis by ethnic groups during a two-year period (May 2010 – April 2012) in a well-defined catchment area in south London.

2. To compare pathways to care, hospital admission (compulsory vs. non-compulsory) and source of referral (GP, A&E and others) at first contact for psychosis by ethnic groups.

3. To compare these pathways to care (compulsory vs. non-compulsory) and source of referral (GP, A&E and others) with those reported in the earlier AESOP sample and between those using early intervention service or not in the current study sample.

Data relating to number of hospitalisations, number of compulsory admissions and total number of days spent in hospital were collected longitudinally throughout the follow-up period. Collection of this data was intended to address two questions: a) are there differences by ethnic group in the length of time patients spend in hospital and compulsory admission during the follow-up period? and b) are there differences in rates of hospital admission and compulsory detention by ethnic groups during the follow-up period?

The follow-up phase aims were:

1. To estimate rates and rate ratios of hospital admission and compulsory detention during the two-year follow-up by ethnic group.
2. To estimate differences in length of hospital stay by ethnic group during the two-year follow-up.
3. To compare clinical and service use (hospital admission, compulsory admission) between those using early intervention services and standard community care during the two-year follow-up.
4. To determine whether there are ethnic differences in clinical and service use outcomes during the two-year follow-up in relation to early intervention service use status.

This study is not dissimilar to previous research in its methodological approach and data collection. It differs from previous research in the following respects:

I. It includes a larger number of first episode psychosis cases, especially from ethnic minority groups, than any previous first episode study in a single site.

II. It offers larger scope for collecting a wider range of variables, i.e. baseline data on incidence of psychosis, pathways to care and longitudinal follow-up data over a four-year period within the same study.

III. Using a mental health case register as the primary sampling source minimises the problem of attrition since requesting cases to consent to follow up is not required; therefore, attrition was only of those who were discharged from SLaM services before the end of the study period.

IV. Psychosis case ascertainment is more comprehensive, as a three-stage screening procedure is used.

V. It forms the basis of analysing data relating to the effect of early intervention services on pathways into and through care.

Given the dearth of research studies on course and outcomes by ethnicity, this study advances our understanding in this area, by analysing data on service engagement outcomes over a two-year follow-up period by ethnic groups.

6.3 Justification of administrative incidence with a follow up cohort study design

To assess possible causal relationships between risk factors and onset of disorders, a cohort study design is regarded as the most robust design. This design allows for the assessment of exposures prior to onset of disorder and can therefore potentially disentangle the direction of causal effects; it also allows for investigating exposures and multiple outcomes (Susser et al., 2006). However, it can be a challenging design, practically speaking, for rare disorders such as psychosis, which with a lifetime prevalence of around 1% – 3% and one year incidence of around 30 per 100,000 person years at risk (Van Os et al., 2009), requires an extremely large number of people to be followed up, possibly from birth. Since this would be an expensive endeavour, and disorders such as psychosis are also often diagnosed in adulthood, an alternative design is required.

An example of such an alternative is a case-control study design, which is more efficient for studying rare disorders like psychosis because it assesses both outcome and exposures

following occurrence of disorder (Susser et al., 2006). However, if not well-designed this type of study is subject to a number of flaws and shortcomings. For example, identifying and recruiting controls in a random manner from the same source population may be challenging (Prince et al., 2003, Susser et al., 2006). Furthermore, a case-control design is criticised for information bias of two types: (a) recall bias from the participants since they are being asked information that occurred prior to their experience of the disorder and b) observer bias which may occur when a researcher / interviewer is aware of the participant outcome status (Prince et al., 2003, Susser et al., 2006). Finally, a case-control design is able to assess only a single outcome whereas a cohort design has the ability to assess multiple outcomes (Prince et al., 2003).

With this in mind, this thesis employed an administrative incidence study design with a follow-up cohort study of outcomes of psychoses that 1) collects cross-sectional data for the period following onset of psychosis and 2) allows the investigation of the multiple outcomes of interest prospectively.

Administrative data is data collected routinely for monitoring or regulatory purposes (Ward, 2005). Hospital clinical records are an example of administrative data, which in mental health is often described as a case register. Administrative data are an attractive resource for epidemiological studies.

As such, many high-quality epidemiological studies in mental health have used cohorts constructed using case registers, including (Susser et al., 2010, Smith et al., 2006, Mortensen, 1995). An administrative incidence study design with a follow up cohort study of outcomes permits existing records to be used for determining how many individuals meet entry criteria of a study (Susser et al., 2006) and outcomes. It is useful for case ascertainment, i.e. sorting people into affected and unaffected, since all the events (exposure, latent period and outcomes) have already occurred. For these reasons, administrative incidence study design with follow-up cohort is less expensive and more time saving (Prince et al., 2003). It is also powerful in dealing with multiple outcomes, which is the main focus of the follow-up phase of this thesis and is described in detail below.

As mentioned previously, cohort studies allow us to draw inferences about associations between exposure and outcome, if they are well-designed and meet specific criteria. For

example, Susser and colleagues (2006) outline six key steps in ensuring a sound design of a cohort study: a) articulate questions; b) define source population; c) measure the exposures; d) follow the cohort; e) classify the outcome; and f) analyse the data (Susser et al., 2006). Measures taken to address these steps are described in detail in this chapter (sections 6.2, 6.4, 6.5, 6.6 and 6.7). Measures taken to address and reduce the likelihood of selection bias and confounding are outlined in sections 6.5.3 and 6.7 respectively, and these are discussed further in the Results and Discussion chapters (Chapters 7 – 12).

At this point it is important to mention that the study design employed for the work presented in this thesis, taking into consideration steps a-e above, is solely based on a regional psychiatric case register, namely the Clinical Record Interactive Search (CRIS) System. However, it is useful to put into context some background and description of the CRIS functionality as a historical case register, before discussing the study methodology in more detail.

6.4 CRIS: a case register and research platform

As discussed in the previous chapter, case registers have been pivotal to psychiatric epidemiology over many decades and as part of this tradition, this thesis utilised the CRIS system to define its sample population. CRIS is an innovative technological application built within the National Institute for Health Research (NIHR) - Biomedical Research Centre awarded to the South London & Maudsley NHS Foundation Trust. CRIS transforms clinical information in the electronic health records (locally known as electronic patient journey system, ePJS) (described in Chapter 5) so that it is anonymous. Whilst CRIS ensures that significant epidemiological data are available without compromising anonymity, some personal identifiable data are truncated, e.g. only the first half of the UK postcode and only month and year of birth are included (Stewart et al., 2009). In addition, personal information such as full name, address and NHS number are masked out and replaced with ‘zzzzzzz’ (see Figure 6.1).

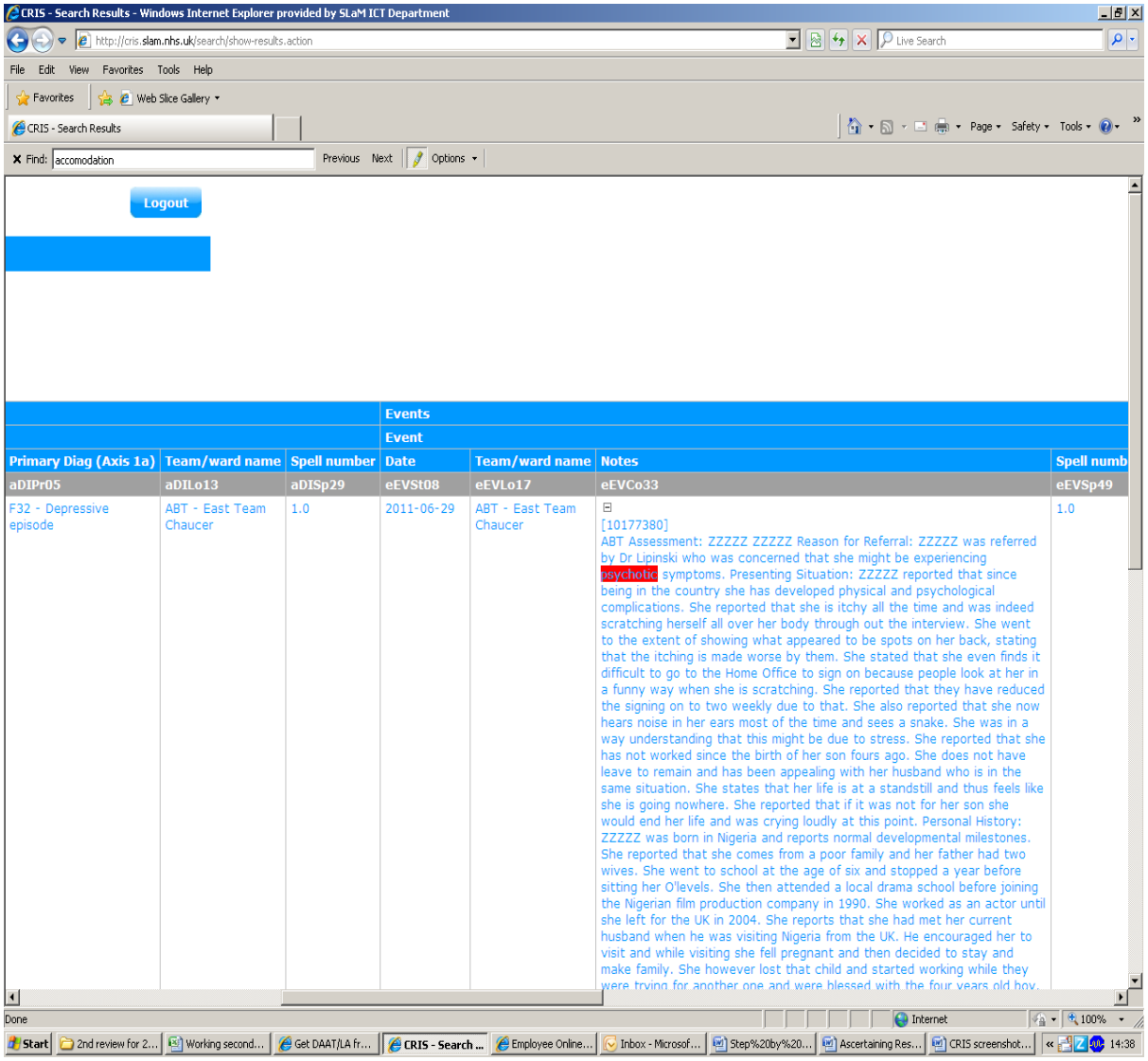


Figure 6.1: CRIS front end

One of the distinctive features of CRIS is its ability to specify populations of given disorders, and to interrogate level of service use, health state, course and outcomes of a given disorder (Stewart et al., 2009). As Stewart and colleagues put it, 'broadly speaking, a fit for purpose case register is one that is a patient-centred longitudinal record of contacts with a defined set of a psychiatric services originating from a defined population' (Stewart et al., 2009). It is this that CRIS offers, as it enables researchers to use the Trust electronic health record system for research, by conducting automated, anonymised searches on structured (date, numerical, demography etc.) and unstructured (free text) information contained in electronic case notes, where much of the clinical record is kept. The system is novel in that it accelerates and expands the scope of mental health research significantly, giving researchers answers in days rather than months. CRIS holds over 250,000 real-time mental

health records and is updated daily, making it easier to identify patterns of data, such as populations of patients per disorder and what treatment worked for some and not for others (SLaM, 2014). CRIS also enables output from record searches to be extracted into database format such as STATA, SPSS or Excel, which are commonly used by researchers.

The system exists in two forms – (a) web-based CRIS and (b) Structured Query Language CRIS (SQLCRIS). The web-based CRIS system interface has some properties of a 'flat-file' system in which every piece of data about each patient is stored together in a single row of data, as shown in Figure 2a above. CRIS is originally accessed through the web-based interface, which is also the common way of accessing the register. However, it can also be held and accessed as a relational database, i.e. SQLCRIS (Fig. 2b).

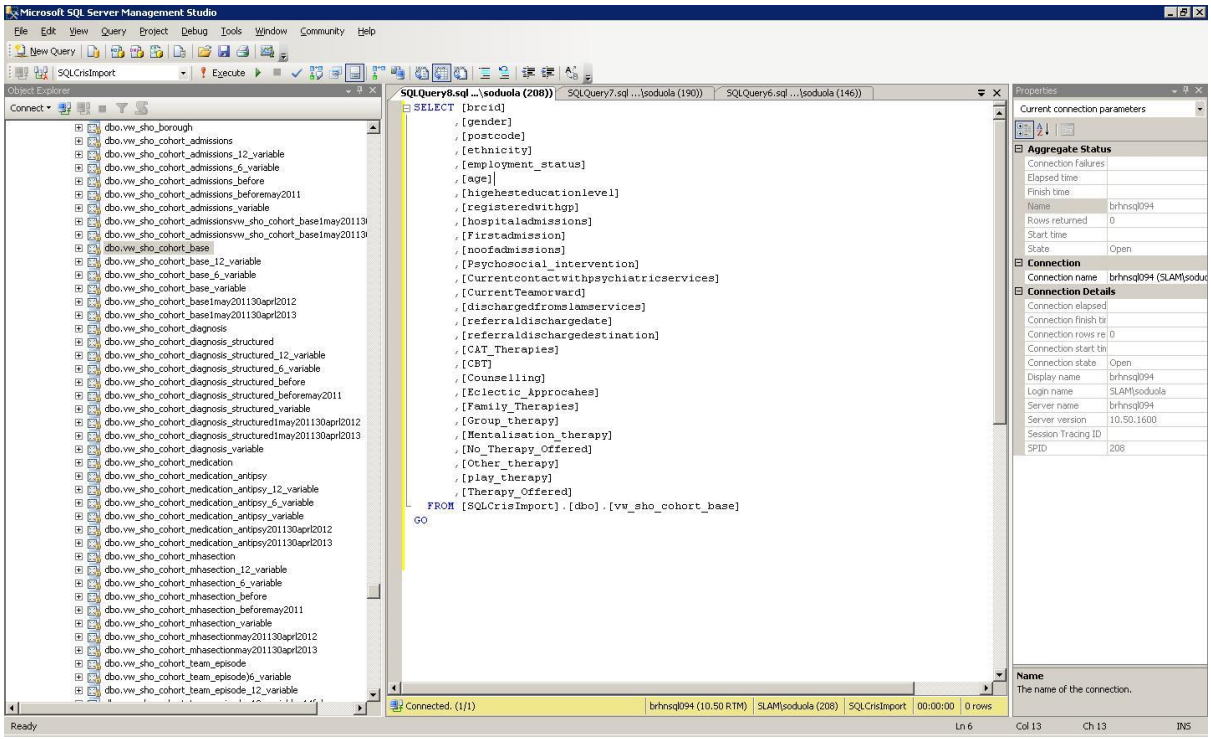


Figure 6.2: SQLCRIS front end

SQLCRIS is a relational database. A relational database is a collection of tables of data items, all which are formally described and organised according to a relational model (Codd, 1998). This makes SQLCRIS extremely flexible and powerful in combining and selecting data by using commands and codes. SQL has been widely used in large government departments, businesses and academia since the 1960s (Tulloch, 2013). The ability to generate an output dataset that contains only the data that is needed, arranged exactly as required for analysis,

makes SQLCRIS more desirable compared to the CRIS web-based interface, which is limited in its ability to select, combine and arrange data (Tulloch, 2013). SQLCRIS is particularly useful and appropriate for generating datasets for longitudinal studies such as this thesis. Details of how SQLCRIS was employed in generating follow-up data for this study are discussed extensively in section 6.6. Other advantages of SQLCRIS include: codes and commands, when correctly written, are reproducible and will produce the same results every time they are run, and codes can also be simply referred to by other codes without the need to copy and paste. SQL can also manipulate data, reducing the need for manual data cleaning and consequently minimising human error and increasing confidence in reliability of the data (Tulloch, 2013).

6.5 Methodology of the CRIS-FEP study

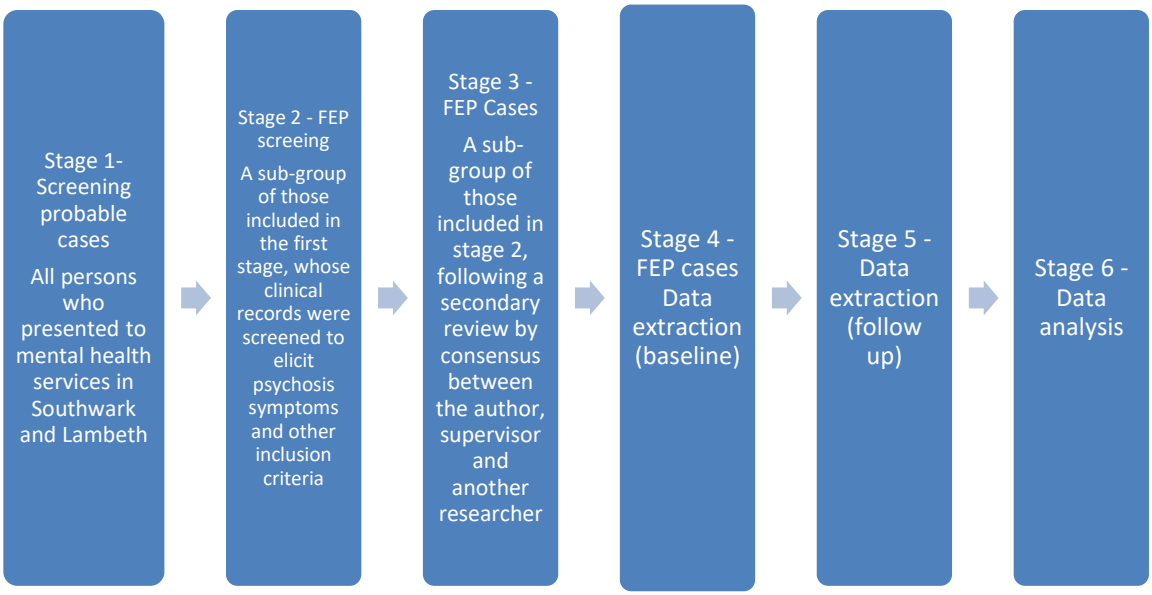


Figure 6.3: Structure of data collection

6.5.1 Background and study design

6.5.1.1 Relationship to previous study- AESOP

The CRIS-FEP study methodological approaches are based on those used in the Aetiology and Ethnicity in Schizophrenia and Other Psychosis (AESOP) study (Fearon et al., 2006a). In the last decade, the AESOP study is arguably the gold standard study in the environmental and social aetiology of psychosis and ethnicity in England to date. In summary, the AESOP study was a large prospective study of first contact psychosis cases conducted between 1997 and 1999 in three catchment areas in England, namely, southeast London, Nottingham

and Bristol. The study revealed that incidence of psychosis was higher among migrant groups compared to White British patients (Fearon et al., 2006a, Kirkbride et al., 2006). In addition, the study highlighted that crisis pathways to care (such as police involvement, coercive admission) were more common among migrant groups compared with the reference population (Morgan et al., 2005a, Morgan et al., 2005b). Therefore, AESOP provides a methodological template to re-examine the evidence on incidence, pathways to care and course and outcomes for FEP patients.

The current study employs an incidence study design with a follow-up cohort study of outcomes of psychoses using the Clinical Register Interactive Search System (CRIS) to identify all probable cases of psychosis (ICD-10 F20-29 and F30-33) presenting to General Adult and Forensic services within two catchment areas of South London and Maudsley NHS Foundation Trust (i.e. Lambeth and Southwark). Cases were identified and cross-sectional data were collected over two years between 1st May 2010 and 30th April 2012. The cohort is then followed up for a further two years as described in table 6.1 above.

6.5.2 Screening and case ascertainment of psychosis cases

Individuals were eligible for inclusion if they were:

i. Resident in the London boroughs of Lambeth or Southwark
ii. Aged 18-64 years (inclusive)
iii. Experiencing psychotic symptoms during the study periods 1st May 2010 – 30th April 2012
iv. Scored at least 2 or more for psychotic symptoms as assessed by the Psychosis Screening Schedule (Jablensky et al., 1992a)

Individuals were excluded if they met any of the following criteria:

i. Under age 18 or over 64

ii. Not currently a Lambeth or Southwark resident (according to SLaM records)

iii. Transient psychotic symptoms resulting from acute intoxication (i.e., psychotic symptoms that occur during or after psychoactive substance use and are explained on the basis of acute intoxication alone)

iv. Evidence of an organic cause of psychotic symptoms

v. Evidence of previous contact with secondary mental health services for psychotic symptoms prior to 1st May 2010

In order to define the source population for the study, SQL commands were written to interrogate the SQLCRIS to pull back the clinical records of all patients who met basic inclusion criteria and presented to any adult general psychiatric services. Researchers subsequently screened the clinical records to classify individuals who met the inclusion criteria for the presence of psychosis.

The steps for identifying and including patients as first episode psychosis involved running weekly queries in SQLCRIS in the following order:

i. Define search week and borough, e.g. '1-May-2010 to 7-May-2010, Lambeth and Southwark'.
ii. Apply search terms, e.g. postcode, age, symptoms, where the terms 'psychos*', 'psychot*', 'delusion*', 'voices' and 'hallucinat*' may appear in a medical note, correspondence letter or ward progress note.
iii. Identify all probable psychosis cases that presented to services in the search period.
iv. Steps (i-iii) return 60–70 patients per borough per week.
v. The above queries return individual patient records with unique identification numbers (BRCIDs) including ward/community progress notes, and correspondence attachment.
vi. The patient records are presented in an Excel file which is then screened and reviewed by researchers to identify first episode psychosis cases. Individuals were included if they scored 2 or more psychotic symptoms on the Psychosis Screening Schedule (PSS) (Jablensky et al., 1992a). This means that the individuals have psychotic symptoms that are persistent or severe and are of

clinical significance as assessed by clinicians. Other inclusion criteria were also verified in the notes before an individual was included as a case.

SQL commands for extracting data at this stage are presented in Appendix 1.

6.5.3 Reliability

At this stage of the case identification and data collection procedure, it is important to ensure reliability of data collection, since data were collected by more than one researcher. Table 6.2 presents the inter-rater reliability tests that were carried out among researchers. For the Psychosis Screening Schedule (PSS) (Jablensky et al., 1992a), i.e. when screening for FEP cases and the Operational Criteria (OPCRIT) checklist in generating diagnostic categories for the cases. Reliability was achieved and tested through training and a formal inter-rater reliability exercise. The CRIS-FEP researchers conducting the clinical record screening were required to undergo an OPCRIT and PSS training course to ensure that symptoms were rated in a standardised way. The successful completion of the training course was a prerequisite for researchers using the OPCRIT and PSS.

Following the identification of FEP cases from the steps above, satisfactory PSS inter-rater reliability was confirmed within the CRIS-FEP study group with me and other researchers conducting the original case register screening to identify FEP cases independently. Each rater then swapped an average of seventy cases and repeated the procedure by reviewing one another's screened and included cases. A Kappa score of 0.78 ($p<0.001$) was achieved between the raters. For the OPCRIT rating a Cronbach alpha $r = 0.95$ was also achieved between raters.

Two primary researchers including myself subsequently conducted a secondary review of all the included cases from the first stage screen to ensure cases met all inclusion criteria. An inter-rater reliability test was carried out between the two and a Cohen's Kappa coefficient of 0.77 ($p <0.01$) was achieved. In addition, there were consensus meetings among research staff and the overall project supervisor to agree consensus diagnosis following detailed discussions for all ambiguous cases after the secondary reviews.

Finally, some postcodes overlap across two or more local authorities. To address this, the patients' addresses (Lambeth or Southwark) were verified using the Public Health England postcode widget (Public Health England, 2004). The widget provides information by percentages in which local authority the postcode lies. A consensus threshold of 60% and above was reached as acceptable within our research team to include the residence area that falls within the study catchment. Furthermore, data for the middle layer super output area (MSOA) were collected and linked to individual postcode. The added advantage of this is that MSOA is a neighbourhood-level piece of information (including address) which fits within the boundaries of a local authority (ONS, 2011c). Using the MSOA information during the secondary reviews, individuals whose addresses did not match MSOA information were excluded.

Table 6.2: Inter-rater reliability for rating scales

Instrument	Outcome	Number of cases per rater	Number of raters	Reliability scores / statistics
Psychosis Screening Schedule	Psychotic symptoms	95	3	Kappa 0.78, p<0.001
OPCRIT	Diagnostic categories	10	4	Cronbach alpha r = 0.95
MRC Sociodemographic Schedule	Ethnicity	30	3 plus 1 blind rater	Kappa 0.87, p<0.001
Secondary screening reviews	Eligibility checks	40	2	Kappa 0.77, p<0.001

6.5.4 Main data collection measures

A comprehensive battery of measurement tools was used to extract data from the CRIS system, a process which took 1.5 hours per patient. Measures pertaining to the aims and hypothesis of this thesis are described below.

Psychosis Screening Schedule (PSS) (Jablensky et al., 1992a)

The Psychosis Screening Schedule is designed to screen and identify functional psychosis in first contact patients. It was developed for use as a screening instrument in the World Health Organisation Ten-Country Study (Jablensky et al., 1992a) and can be used for both face-to-face interviews and case note screenings. The PSS consists of six sections: i) demography, ii) study inclusion/exclusion criteria, iii) list of psychotic symptoms, iv) change in personality and behaviour, v) history of hospitalisation for psychosis and vi) hospital diagnosis. For the purpose of this study, we amended the PSS and restricted it to sections i to iv since diagnosis categories were rated separately using the OPCRIT and history of hospitalisation will be collected longitudinally for the cases included in this study over a four-year period. Researchers rated 'yes' or 'no' on the screening items except on the demographic information. To screen positive and be included, the patient must score at least two or more yeses on sections iii and iv. The PSS has been used widely in many previous studies for which interviews with participants were not possible, and it has been found reliable (Fearon et al., 2006a, Coid et al., 2009, Harrison et al., 1997, Bhugra et al., 1997). The schedule is appropriate for ascertaining positive psychotic symptoms from the clinical records (see Appendix 2).

Medical Research Council (MRC) Socio-demographic Schedule (Mallett, 1997)

Sociodemographic data were collected using the Medical Research Council Socio-demographic Schedule(MRC-SDS) (Mallett, 1997). MRC-SDS captures detailed information on current and past social history. An amended version of the MRC-SDS was used to collect data relating to age, gender, and ethnicity, place of birth, education qualifications, living circumstances, employment history and relationship status.

For analysis, data on education qualifications was collapsed as follows: 'School no GCSE', 'School with GCSE', 'A levels/Further education' (tertiary, vocational) and 'University' (undergraduate and postgraduate).

Data on living circumstances were collapsed as 'Alone' (alone, alone with children), 'Family/friends' (partner, partner with children, parents, other family, friends) and 'Other' (e.g. homeless refuge) or 'Not recorded'.

Similarly, data on relationship status were collapsed for analysis as follows: 'Single', 'Married/Steady relationship' (married, living with someone, in a steady relationship) and 'Divorced/separated' (including widowed) or 'Not recorded'.

Employment status data was grouped as 'Unemployed' (including economically inactive), 'Student' and 'Employed' (part-time employee, full-time employee, self-employed) or 'Not recorded' for analysis.

For housing tenure, data were collapsed as follows for analysis: 'Privately owned' (privately owned – self, privately owned –family), 'Rented' (rented –private, rented – government) and 'Other (e.g. halls of residence, homeless refuge).

Ethnicity

Central to the aims of this thesis is ethnicity. Earlier UK studies (Ghali et al., 2013, Agius and Ward, 2009) suffered methodological limitations specifically around ethnicity ascertainment in the population at risk and in identified cases, and as such many studies crudely defined ethnicity as 'Black, White or Asian'. In this study, populations at risk and case ascertainment were estimated according to the 2011 Census ethnic categories for Lambeth and Southwark as shown in Table 5.1 (section 5.3).

Since ethnicity is a multi-faceted phenomenon, the Office of National Statistics (ONS) recommends that a number of categories be employed in ascertaining ethnicity, including country of birth, nationality, language spoken at home, parents' country of birth in conjunction with country of birth, skin colour, geographical region (e.g. Saharan and sub-Saharan Africa), racial group and religious group (ONS, 2003). The ONS also suggests that a combination of these approaches is necessary to obtain the most accurate picture. In the 2011 Census survey, respondents were asked to self-ascribe to one of 18 ethnic categories, taking into account the definitions aforementioned. As this study is solely based on case register, and although the CRIS system captures ethnicity in its structured field, measures were taken to reduce biases when assigning cases' ethnicities. This involved researchers

reading clinical notes looking for information that matched the aforementioned ONS definitions and subsequently assigning patients to an ethnic group. A high inter-rater reliability was achieved (Kappa 0.87, $p<0.001$). Previous studies (Bhugra et al., 1997, Fearon et al., 2006a) have employed case note ethnicity ascription where participants were not available for interview.

All ethnicities were included in order to:

a. Compare incidence rates of psychosis across all ethnicities,

b. Compare pathways to care by ethnicity and

c. Examine whether variations in incidence and pathways to care across ethnicities can be explained by social factors alone.

For the analysis, the ethnic categories were grouped as follows: White British, Black Caribbean (Black Caribbean and Other Black), Black African, Asian (Indian, Pakistani, Bangladeshi, Chinese), Other White (White Irish, White Gypsy, White Other), Other (Arab, Any Other Ethnic group), and Mixed (all mixed groups). This created seven ethnic groups: White British, Black Caribbean, Black African, Other White, Asian, Mixed and Other.

Personal and Psychiatric History Schedule (PPHS): *Pathways to care and mode of contact*

Data relating to mode of contact were collected using an adapted form of the Personal and Psychiatric History Schedule (PPHS) for the purpose of case note data extraction (WHO, 1996). The PPHS is a structured clinical schedule designed to assess a patient's psychiatric, medical, social and developmental history using interviews and/or case notes (Jablensky et al., 1992b). It consists of sixteen parts. However, an amended version was used in this thesis, which included largely the first part of the PPHS. Those that are relevant to the aim of this study are source of referral, mode of contact, time of contact, mode of onset, duration of untreated psychosis and early intervention services use.

Clinical notes were reviewed and data relating to the source of referral at the point of first contact for psychosis were extracted. For analysis, this was collapsed into four groups: 'GP', 'A&E', 'Police/Criminal Justice system CJA' (police, court, prison) and 'Other' (nurse, social worker, other healthcare professional) or 'Not recorded'. Data on the Mental Health Act

(MHA) were grouped as (voluntary vs. compulsory). Time of contact data was collected as (office hours vs. out of hours). Data relating to mode of onset was collected by extracting the date of first contact with secondary mental health services for psychosis and the date when symptoms of psychosis first occurred. Subsequently, duration of untreated psychosis (DUP) was calculated by subtracting date of onset from date of contact with mental health services for FEP. Categorical variables for mode of onset were then grouped into four categories as follows for analysis: 'Acute' (within hours/days), 'Moderate' (within a month), 'Gradual' (within six months) and 'Insidious' (more than six months). Data on type of service engagement at first contact with services (early intervention service (EIS) vs. other community services (non-EIS)) were also collected.

Sections of the MRC-SDS and PPHS relevant to the data collected for this thesis were collated into an assessment booklet (see Appendix 3).

OPCRIT

The operational criteria (OPCRIT) checklist for psychotic and affective illness is an instrument designed to facilitate a polydiagnostic approach to mental illness (McGuffin, 1991) . It is a 90-item checklist of psychotic and affective symptoms which are rated and scored by trained researchers/raters.
In this study OPCRIT items were employed to generate diagnostic categories from the clinical records and validate clinical diagnosis of all included cases.

6.5.5 Ethical approval

The CRIS system was approved as an anonymised dataset for secondary analysis by the Oxfordshire Research Ethics Committee (reference: 08/H0606/71). A local approval for this study was obtained from the CRIS Oversight Committee at the BRC South London and Maudsley NHS Foundation Trust (reference: 09-041).

6.6 Methodology of the follow-up study

Phase two of this thesis is concerned with the service use and clinical outcomes over the two years in the study period. The follow-up data collection was guided by the WHO Life Chart Schedule (Susser et al., 2000). The WHO Life Chart Schedule (LCS) is a semi-structured instrument, designed to assess the long-term course of schizophrenia (Susser et al., 2000). It includes four main areas: symptoms, treatment, residence and work. The LCS was originally designed as an interview schedule; however, aspects of it have been used for case record retrieval in previous studies, for example in (Bertelsen et al., 2008a, Bebbington et al., 2006). The LCS has been adapted for the follow-up phase of this study, specifically to include more information on service use and clinical course.

Using the structured query language (SQL) commands, the structured clinical and administrative fields of CRIS were interrogated to retrieve information on the study cohort. Information relating to hospital admission, community service use, compulsory admission, length of stay (LOS) (dates of admission/discharge), clinical course i.e. diagnosis, and patient destination during four years post-FEP were extracted using the commands presented in Appendix 4.

To obtain detailed information on hospital admission patterns, specific commands (see Appendix 4a) were written to extract data in relation to number of inpatient admissions, admission and discharge dates and length of hospital stay during follow-up post-FEP.

Data on compulsory admission were collected in a similar manner to inpatient admission whether an individual was detained under the MHA on admission. . Commands are listed in Appendix 4b.

For community service use, data relating to type of service (EIS, CMHT, A&T, specialist, forensic and other) and discharge destination (if applicable) were extracted using commands found in Appendix 4c.

Data on clinical course were collected in relation to primary clinical diagnosis and any subsequent diagnosis using the commands listed in Appendix 4d.

All the variables collected for the follow-up phase were used in the analysis.

6.7 Statistical analysis

The following hypotheses were tested in the analyses of data presented in this thesis:

Compared with those of White British ethnicity:

Incidence

1.1 The incidence of all psychoses will be higher in those of Black Caribbean and Black African ethnicity.

1.2 The magnitude of relative risk will be smaller for the minority ethnic groups (Black African and Black Caribbean) compared with those reported in previous studies (e.g. AESOP study, Fearon et al. 2006).

Pathways to care at first contact for psychosis

2.1 Higher rates of hospital admissions will be associated with Black African and Black Caribbean ethnicity.

2.2 Increased risk of compulsory admissions will be associated with Black African and Black Caribbean ethnicity.

2.3 Higher rates of police involvement will be associated with Black African and Black Caribbean ethnicity.

2.4 Lower levels of GP referral will be associated with Black African and Black Caribbean ethnicity.

2.5 Higher rates of accident and emergency referral will be associated with Black African and Black Caribbean ethnicity.

2.6 Compared with 15 years ago (i.e. AESOP vs. CRIS-FEP samples), among patients aged 18–35 years old, ethnic differences in GP referral and crisis source of referral (criminal justice agency, accident and emergency) and compulsory admission at first contact for psychosis will be smaller for Black African and Black Caribbean patients.

Course and outcome

3.3 Over the two-year follow-up period, worse service use outcomes (characterised by increased rates of hospital admissions, compulsory admission and longer duration of hospital stay) will be observed among those of Black Caribbean and Black African ethnicity compared with White British patients.

3.4 Over the two-year follow-up period, worse service use outcomes will be associated with non-EIS use compared with EIS use and these will vary by ethnic groups.

Descriptive statistics

To begin with, an account of whole sample sociodemographic characteristics, clinical presentation, pathways to care and follow-up clinical outcomes is presented as frequencies and percentages for categorical variables, and mean and medians (including interquartile range) for continuous variables. Appropriate statistical tests were used to compare differences between ethnic groups and sociodemographic characteristics, pathways to care characteristics and four-year clinical outcome characteristics, i.e. chi-square for categorical, t-test and ANOVA for normally distributed continuous data, and Wilcoxon rank-sum and Kruskal-Wallis tests for non-normally distributed continuous data.

Incidence

Population at risk was estimated according to the 2011 Census and stratified by age (five-year age-band, i.e. 18–19; 20–24; 25–29; 30–34; 35–39; 40–44; 45–49; 50–54; 55–59; 60–64), gender and ethnicity. Age and sex-standardised incidence rates (using ONS Europe age-standardised population) of first psychosis were calculated using direct standardisation (Kirkwood and Sterne, 2003b). Crude incidence rate ratios (IRR) were calculated then adjusted for potential confounders like age and gender using Poisson regression.

Pathways to care

In assessing the risk factors associated with compulsory admission and source of referral, analysis was broken down into two parts, i.e. unadjusted and adjusted analyses using logistic regression (Kohler and Kreuter, 2005). Within the unadjusted regression model, sociodemographic and clinical presentation and pathway to care variable were assessed individually in relation to compulsory admission and source of referral. The adjusted

regression model focussed on the main exposure variable (ethnicity) in relation to compulsory admission and source of referral, and then *a priori* confounders were adjusted (age, gender, employment status, education qualification and EIS service use).

DUP was positively skewed; therefore, non-parametric Kruskal Wallis tests were employed to assess its association with sociodemographic and clinical variables.

DUP was then converted into a categorical variable for subsequent analysis e.g. logistic regression.

Course and outcomes

In this phase of the analyses, outcome data on service use variables collected during the follow-up period between May 2012 and April 2014 (i.e. hospital admission, compulsory admission and length of hospital stay) were included.

The rate of hospital admission and compulsory admission by ethnic groups were estimated per year over the follow-up period using Poisson regression (Kirkwood and Sterne, 2003b). Follow-up time/time at risk was defined as follows:

Time at risk = exit date minus entry date.

Entry date = date of contact with mental health services for FEP or date of discharge for first admission.

Exit date = study end date (30 April 2014) or date the patient left the study (i.e. discharge from SLaM services), whichever happened first.

This took into account the staggered entry into and exit from the study.

Next, for outcome variables which were count data (i.e. number of hospital admissions, number of compulsory admissions, length of hospital stay), the distribution of data were inspected using simple descriptive statistics, e.g. histogram, variance and goodness of fit test (UCLA: Statistical Consulting Group, 2016). Where the histogram distribution was skewed, i.e. the variance was greater than the mean, or where the goodness to fit test was statistically significant at p=0.05, this indicated over-dispersion; therefore, negative binomial regression was employed for adjusted and unadjusted rate ratios (Kirkwood and Sterne,

2003b, UCLA: Statistical Consulting Group, 2015). The *'exposure'* option was used to specify the length of time each patient remained in the study and *'irr'* to obtain rate ratios estimates (Kirkwood and Sterne, 2003).

For all analyses of risk factors, results are presented as follows: effect size, 95% confidence interval and p-values. For analyses of rates, results are presented as rate and 95% confidence interval per 100,000 person-years, unless otherwise stated.

All analyses were conducted using Stata version 12 (StataCorp, 2011).

7 Chapter 7: Results of Identifying First Episode Psychosis, Incidence of Psychosis and Ethnicity

7.1 Synopsis

To begin with this chapter will set the scene with a description of the Aetiology and Ethnicity of Schizophrenia and Other Psychoses (ASEOP) study and the reported findings as compared to the results from this study. Second, I will present results of the screening procedures in identifying FEP cases. Third, I will describe the overall first contact for psychosis (baseline) sample in the first of the four keys areas that data have been collected: sociodemographic characteristics, overall and by ethnic group. A detailed description of the three remaining data domains – pathways to care (at baseline), then stratified by early intervention use – will be presented and discussed in Chapters 8 and 9 respectively. Service use outcomes during the two-year follow-up period are presented and discussed in Chapters 10 and 11 respectively. The final part of this chapter (section 7.3) pertains to the analyses of incidence rates and incidence rate ratios of first episode psychosis, addressing the hypotheses that:

> Compared to White British, the incidence of all psychoses will be higher in those of Black Caribbean and Black African ethnicity but lower than that reported in previous studies (e.g. AESOP Fearon et al. 2006).
>
> The magnitude of relative risk will be attenuated for the minority ethnic groups (Black African and Black Caribbean) compared with those reported in previous studies (e.g. AESOP Fearon et al. 2006).

7.2 Background: the AESOP findings

As described in the previous chapter, the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (AESOP) study was completed over ten years ago. In that study, higher incidence rates were reported for people of Black Caribbean (Adj. IR = 140.8; 95% CI 114.4 – 167.2) and Black African (Adj. IR = 80.6; 95% CI 60.0 – 101.2) ethnicity compared to the White British population (Adj. IR = 20.2; 95% CI 17.8 – 22.7). They observed that compared to White British, Black Caribbean were almost seven times (IRR = 6.7; 95% CI 5.4 – 8.3) and

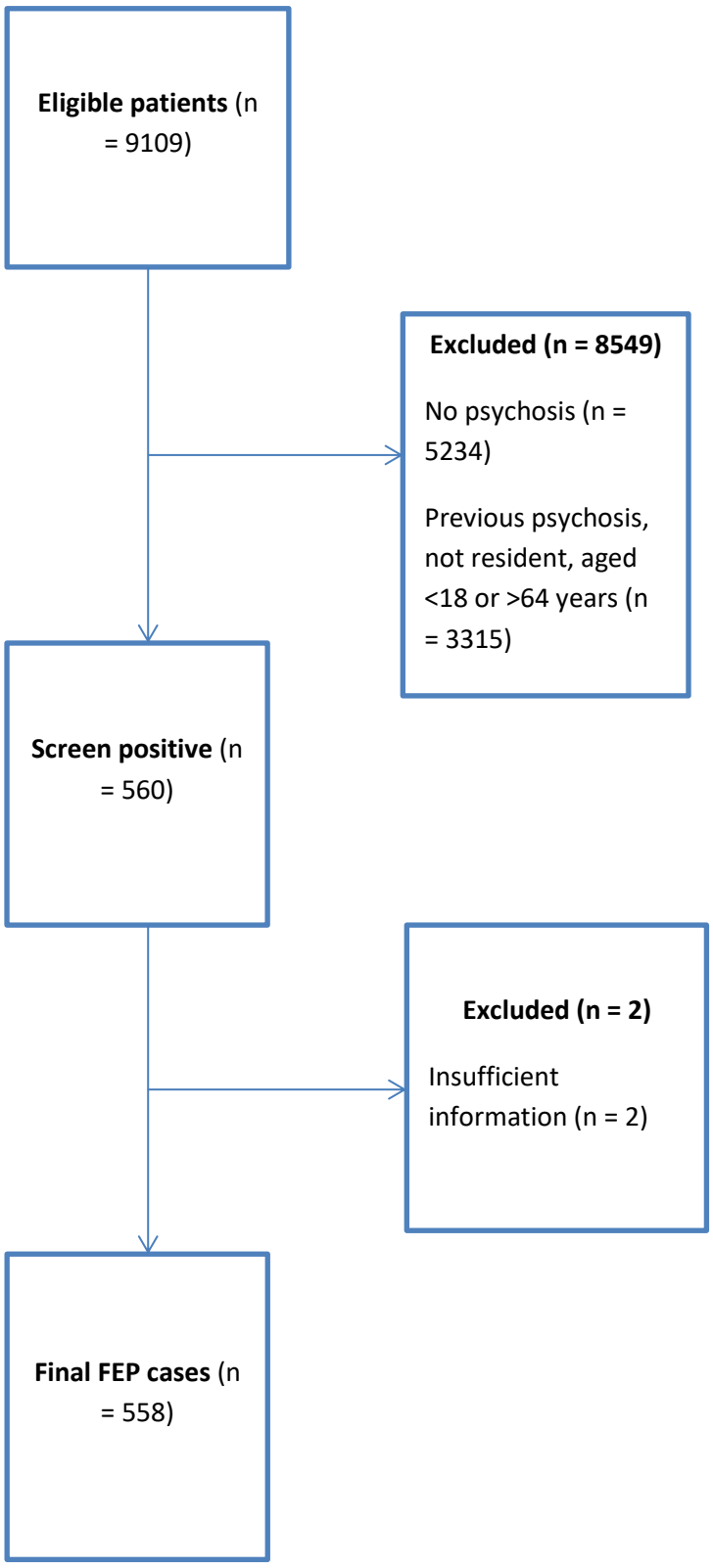
Black African were four times (IRR = 4.1; 95% CI 3.2 – 5.3) more likely to experience psychosis (Fearon et al., 2006a).

7.3 Results

7.3.1 Screening results

The search strategy described in Chapter 6 produced 9109 unique clinical records during the two-year case identification period (1 May 2010 – 30 April 2012). Figure 7.1 presents a flowchart of screening allocation. From this diagram, it can be seen that a total of 560 individuals screened positive and met the inclusion criteria. 8549 screened negative and these were excluded either for no evidence of psychosis (n = 5234) or they had signs of psychosis but did not meet the inclusion criteria (n = 3315). During the data collection phase, it came to light that two cases did not have sufficient information (missing age, ethnicity) to be included in analyses and therefore they were excluded. This left a total of 558 first episode psychosis cases over the two-year case identification period.

Figure 7.1: Screening flowchart



7.3.2 Demographic characteristics of total sample at baseline

A description of the baseline demographic characteristics for FEP cases is shown in Table 7.1. It can be seen from this table that there were more men (52.6%) and the mean age was 33.3 years. Most cases were of Black African ethnicity (26.3%) followed by White British (23.8%) and Black Caribbeans (16.3%). The majority were registered with a general practitioner (GP) (96.2%), were single (62.2%), were unemployed (68.5%), had education qualification up to A level (28.9%), lived with family or friends (60.1%), lived in rented accommodation (63.2%), were born outside the UK (53.7%) and reported to have experienced social isolation (52.6%).

Table 7.1: Overall sociodemographic variables

Characteristics	**Cases n = 558 (%)**
Mean age (sd)	33.26 (10.7)
Age-Band	
18–29	242 (43.4)
30–64	316 (56.6)
Gender	
Male	292 (52.3)
Female	266 (47.7)
Ethnicity	
White British	133 (23.8)
Black African	147 (26.3)
Black Caribbean	91 (16.3)
Other White	75 (13.4)
Asian	44 (7.9)
Mixed	27 (4.8)
Other	41 (7.3)
GP	
Yes	537 (96.2)
No	21 (3.8)
Relationship status[1]	
Single	331 (62.2)
Married/Steady relationship	127 (23.8)
Divorced/Separated	74 (13.9)
Employment[2]	
Unemployed	346 (68.5)
Student	60 (11.9)

Employed	99 (19.6)
Education[3]	
School, no GCSE	99 (25.2)
School, with GCSE	73 (18.5)
A level/ Further education	114 (28.9)
University	108 (27.4)
Lives with[4]	
Alone	161 (29.7)
Family/relatives	325 (60.1)
Other	55 (10.2)
Housing Tenure[5]	
Privately owned	68 (19.4)
Rented	222 (63.2)
Other	61 (17.4)
Country of birth[6]	
UK born	243 (46.3)
Non-UK born	282 (53.7)
Report of social isolation[7]	
Yes	248 (52.6)
No	223 (47.4)

1 *(26 missing data)*
2 *(53 missing data)*
3 *(164 missing data)*
4 *(17 missing data)*
5 *(207 missing data)*
6 *(33 missing data)*
7 *(87 missing data)*

7.3.3 Comparison between sociodemographic variables and ethnic groups

Table 7.2 shows a comparison of sociodemographic variables by ethnic groups. Patients of Black Caribbean and Asian ethnic groups were more likely to be women (57.1% female vs. 42.9% male and 56.8% female vs. 43.2% male respectively, p = 0.02) whereas those of 'Other' and 'Mixed' ethnic groups were more likely to be men (75% male vs. 24.4% female and 55.6% male vs. 44.6% female respectively, p = 0.02). Black Caribbean (9.8%) and 'Other' (8.8%) ethnic groups were least likely to be in employment compared with other ethnic groups (p = 0.06). Similarly, those with educational qualification up to university level were more likely to be White British (32.3%), Asian (34.4%) and White Other (33.9%) compared

with other ethnic groups (p = 0.06). Patients born outside the UK were more likely to be Black African (83.8%), White Other (90.7%), Asian (73.2%) and Other (91.1%) (p<0.001). There were no differences observed in other sociodemographic variables by ethnic groups.

Table 7.2: Comparison between sociodemographic variables and ethnic groups

	White British n = 133 (%)	Black African n =147 (%)	Black Caribbean n = 91 (%)	Other White n = 75 (%)	Asian n = 44 (%)	Mixed n = 27 (%)	Other n = 41 (%)	Chi-sq test	df	p
Gender										
Male	68 (51.1)	79 (53.7)	39 (42.9)	41 (54.7)	19 (43.2)	15 (55.6)	31 (75.6)	**14.12**	**6**	**0.02**
Female	65 (48.9)	68 (46.3)	52 (57.1)	34 (45.3)	25 (56.8)	12 (44.4)	10 (24.4)			
Age-band										
18–29	56 (42.1)	67 (45.6)	38 (41.8)	23 (30.7)	22 (50.0)	17 (63.0)	19 (46.3)	10.55	6	0.10
30–64	77 (57.9)	80 (54.4)	53 (58.2)	52 (69.3)	22 (50.0)	10 (37.0)	22 (53.7)			
Relationship status[1]										
Single	84 (66.1)	82 (58.2)	54 (62.8)	45 (60.8)	23 (56.1)	20 (76.9)	23 (62.2)	11.71	12	0.46
Married/Steady relationship	32 (25.2)	32 (22.7)	19 (22.1)	20 (27.0)	13 (31.7)	4 (15.4)	7 (18.9)			
Divorced/Separated	11 (8.7)	27 (19.1)	13 (12.1)	9 (12.2)	5 (12.2)	2 (7.7)	7 (18.9)			
Employment[2]										
Unemployed	78 (63.9)	84 (65.1)	66 (80.4)	47 (65.3)	24 (61.5)	18 (66.7)	29 (85.3)	20.05	12	0.06
Student	15 (12.3)	19 (14.7)	8 (9.8)	5 (6.9)	8 (20.5)	3 (11.1)	2 (5.9)			
Employed	29 (23.8)	26 (20.2)	8 (9.8)	20 (27.8)	7 (18.0)	6 (22.2)	3 (8.8)			
Education[3]										
School, no GCSE	27 (28.1)	17 (16.5)	22 (36.1)	13 (24.5)	6 (18.7)	6 (28.6)	8 (28.6)	28.04	18	0.06
School with GCSE	18 (18.7)	29 (28.2)	8 (13.1)	4 (7.6)	5 (15.6)	5 (23.8)	4 (14.3)			

A level/ Further education	20 (20.8)	29 (28.2)	22 (36.1)	18 (34.0)	10 (31.3)	5 (23.8)	10 (35.7)			
University	31 (32.3)	28 (27.1)	9 (14.7)	18 (33.9)	11 (34.4)	5 (23.8)	6 (21.4)			
Lives with[4]										
Alone	41 (32.0)	39 (27.1)	31 (35.2)	21 (28.8)	12 (27.3)	7 (26.9)	10 (26.3)	6.60	12	0.88
Family/relatives	78 (61.0)	88 (61.1)	49 (55.7)	42 (57.5)	27 (61.4)	18 (69.2)	23 (60.5)			
Other	9 (7.0)	17 (11.8)	8 (9.1)	10 (13.7)	5 (11.4)	1 (3.9)	5 (13.2)			
Housing Tenure[5]										
Privately owned	21 (25.0)	14 (16.1)	9 (18.0)	9 (16.4)	10 (32.3)	3 (13.6)	2 (9.1)	15.89	12	0.19
Rented	54 (64.3)	59 (67.8)	32 (64.0)	33 (60.0)	17 (54.8)	15 (68.2)	12 (54.6)			
Other	9 (10.7)	14 (16.1)	9 (18.0)	13 (23.6)	4 (12.9)	4 (18.2)	8 (36.4)			
Country of birth[6]										
UK born	122 (96.8)	23 (16.2)	52 (64.2)	7 (9.3)	11 (26.8)	21 (91.3)	7 (18.9)	**268**	**6**	**<0.001**
Non-UK born	4 (3.2)	119 (83.8)	29 (35.8)	68 (90.7)	30 (73.2)	2 (8.7)	30 (81.1)			
Report of social isolation[7]										
Yes	49 (44.9)	66 (53.2)	44 (59.5)	32 (47.8)	22 (55.0)	14 (60.9)	21 (61.8)	6.46	6	0.37
No	60 (55.1)	58 (46.8)	30 (40.5)	35 (52.2)	18 (45.0)	9 (39.1)	13 (38.2)			

1 – 7 (Missing values as indicated in 7.2.2)

7.4 Estimating incidence rate of first episode psychosis

In this section, I will present analyses of crude and age-gender-standardised incidence rates for the overall sample, followed by analyses of incidence rate ratios by age, gender and ethnic groups using White British as the reference ethnic group.

Table 7.3 shows the comparison between cases and the population at risk. It can be seen that there were no differences by gender, but cases were more likely to be younger, aged 20–24 years (cases 20.6% vs. population at risk 12.6%, p<0.001) and of Black African ethnicity (cases 26.3% vs. 12.6%), Black Caribbean ethnicity (cases 16.3% vs. population at risk 10.3%), 'Other' ethnicity (cases7.3% vs. population at risk 2.9%) or White British ethnicity (cases 23.8% vs. 41.2%)(p<0.001).

Table 7.3: Summary of overall study population and population at risk

	Cases N = 558 (%)	Population at risk N = 852920 (%)	Chi-sq test (df)	P-value
Gender			4.95 (3)	0.17
Male	292 (52.3)	425968 (49.9)		
Female	266 (47.7)	426952 (50.1)		
Age-band			169.0 (27)	<0.001
18–19	29 (5.2)	25706 (3.0)		
20–24	115 (20.6)	107400 (12.6)		
25–29	106 (19.0)	157722 (18.5)		
30–34	79 (14.2)	138604 (16.3)		
35–39	76 (13.6)	104994 (12.3)		
40–44	60 (10.8)	92030 (10.8)		
45–49	35 (6.3)	82040 (9.6)		
50–54	38 (6.8)	63342 (7.4)		
55–59	14 (2.5)	44914 (5.3)		
60–64	6 (1.1)	36198 (4.2)		

Ethnicity			725.3 (18)	<0.001
White British	133 (23.8)	351412 (41.2)		
Black African	147 (26.3)	107670 (12.6)		
Black Caribbean	91 (16.3)	87788 (10.3)		
Other White	75 (13.4)	160918 (18.9)		
Asian	44 (7.9)	74432 (8.7)		
Mixed	27 (4.8)	45354 (5.3)		
Other	41 (7.3)	25346 (2.9)		

In estimating the incidence rates for the overall sample, direct age-standardisation was employed using the ONS Europe standard population. Age-gender-standardisation is widely used and recommended (Kirkwood and Sterne, 2003a) to ensure that rates are standardised and comparable to the standard population age and gender. An overall age-gender standardised incidence rate for all psychoses was 59.7 (95% CI 54.4 – 65.0) per 100,000 person-years at risk (PPY).

Table 7.4 displays the crude and standardised rates by age, gender and ethnic groups. When comparing incidence rates by gender, these appear to be equal between the two groups. Compared by age-bands, incidence rates were particularly raised for those 18–19 years (113.3 per 100,000 PPY) and 20–24 years (108.0/100,000 PPY) compared with older age groups, e.g. 60–64 years (16.4 per 100,000 PPY). This would be expected since the onset of psychosis peaks during adolescence and early adulthood (McGrath et al., 2016, Drake et al., 2016, Kirkbride et al., 2012a). This is also illustrated in Figure 7.2.

With regard to ethnicity, there was evidence of elevated rates across ethnic groups compared to White British (39.4 per 100,000 PPY). But these were markedly raised for Black Africans (120.8 per 100,000 PPY), Black Caribbean (93.6 per 100,000 PPY) and 'Other' ethnic groups (126.4 per 100,000 PPY). The Mixed groups (47.5 per 100,000 PPY) had a more modest increased rate compared to White British.

Table 7.4: 4 Crude and age-standardised incidence per 100,000 person-years with 95% CI for first episode psychosis by demographic factors

	Cases N = 558 (%)	Population at risk N = 852920 (%)	Crude incidence rate	Standardised incidence rate* (95% CI)
Gender				
Male	292 (52.3)	425968 (49.9)	68.5	59.0 (51.8 – 66.3)
Female	266 (47.7)	426952 (50.1)	62.3	60.3 (52.5 – 68.1)
Age-band				
18-19	29 (5.2)	25706 (3.0)	112.8	113.3 (72.3 – 155.2)
20-24	115 (20.6)	107400 (12.6)	107.1	108.0 (88.2 – 127.7)
25-29	106 (19.0)	157722 (18.5)	67.2	67.2 (54.4 – 80.0)
30-34	79 (14.2)	138604 (16.3)	57.0	57.0 (44.4 – 69.5)
35-39	76 (13.6)	104994 (12.3)	72.4	72.4 (56.1 – 88.6)
40-44	60 (10.8)	92030 (10.8)	65.2	65.4 (48.8 – 81.9)
45-49	35 (6.3)	82040 (9.6)	42.7	42.6 (28.5 – 56.7)
50-54	38 (6.8)	63342 (7.4)	60.0	59.8 (40.8 – 78.8)
55-59	14 (2.5)	44914 (5.3)	31.2	31.1 (14.8 – 47.3)
60-64	6 (1.1)	36198 (4.2)	16.6	16.4 (3.3 – 29.5)
Ethnicity				
White British	133 (23.8)	351412 (41.2)	37.8	39.4 (32.2 – 46.6)
Black African	147 (26.3)	107670 (12.6)	136.5	120.8 (100.0 – 141.5)
Black Caribbean	91 (16.3)	87788 (10.3)	103.7	93.6 (74.0 – 113.2)
Other White	75 (13.4)	160918 (18.9)	46.6	49.1 (36.0 – 62.2)
Asian	44 (7.9)	74432 (8.7)	59.1	51.9 (33.6 – 70.2)
Mixed	27 (4.8)	45354 (5.3)	59.5	47.5 (26.2 – 68.9)
Other	41 (7.3)	25346 (2.9)	161.8	126.4 (85.5 – 167.2)

*age-gender standardised.

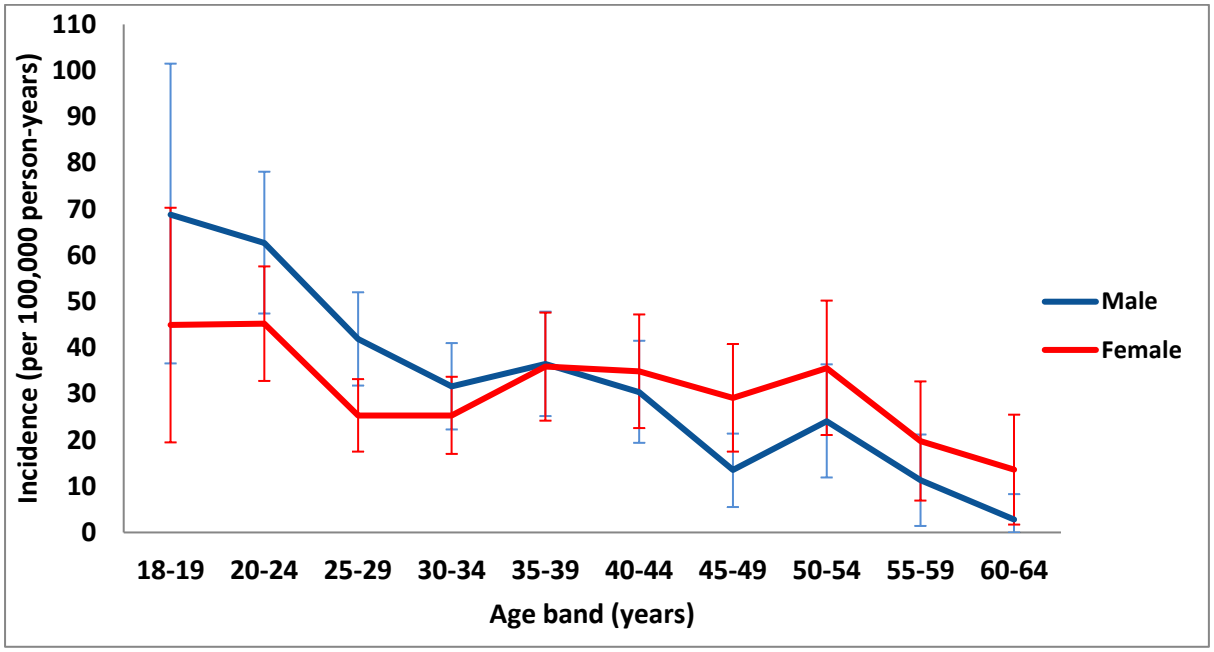


Figure 7.2: Standardised incidence rates by age and gender

7.4.1 Unadjusted and adjusted incidence rate ratios for psychosis by ethnic groups

Analysis of unadjusted and adjusted incidence rate ratios (IRR) by ethnic groups for psychosis is presented in Table 7.5 along with 95% confidence intervals (CI). Using Poisson regression, the model in this table is adjusted for age and gender. From the unadjusted model, there was evidence to suggest that compared to the White British group, Black African, Black Caribbean, Asian, Mixed and the 'Other' ethnic groups were all at increased risk of psychosis. After adjusting for age and gender, this evidence remained robust and showed that Black Africans were almost four times more likely (IRR = 3.59; 95% CI 2.8 – 4.55), Black Caribbeans were almost three times more likely (IRR = 2.81; 95% CI 2.15 – 3.68), Asians were almost one and a half times more likely (IRR = 1.43; 95% CI 1.02 – 2.02) and the 'Other' group four times more likely (IRR = 4.14; 95% CI 2.91 – 5.88) to be at risk of psychosis. However, this evidence did not hold for the 'Mixed' group after adjusting for potential confounders. There was no evidence to suggest that the Other White group were different from the White British patients.

When the risk of psychosis by ethnic groups stratified by gender was assessed (Table 7.6), the following observations were made. Increased risks were present for both men and

women, particularly among three ethnic minority groups: Black African, Black Caribbean and Other, independent of age. Men of Black African and Other ethnic groups were generally more at risk than their women counterparts. In contrast, the risk of psychosis appears to be similar in the Black Caribbean men and women. In the unadjusted model, it can be seen that increased risk among men of the 'Mixed' (IRR = 1.86; 95% CI 1.06 – 3.25) and women of Asian (IRR = 1.63; 95% CI 1.03 – 2.59) ethnic groups was evident, but the strength of evidence became weaker when age was adjusted for. This would suggest that there may be age interaction effect in these two groups, which is explored further in Table 7.6.

Table 7.5: Incidence rate ratios (IRR) with 95% CI in ethnic minority groups for first episode psychosis

	Case n = 558 (%)	Unadjusted IRR (95% CI), p-value	Adjusted IRR** (95% CI), p-value
All			
White British	133 (23.8)	1.00	1.00
Black African	147 (26.3)	**3.60 (2.85 – 4.56), <0.01**	**3.59 (2.8 – 4.55) <0.001**
Black Caribbean	91 (16.3)	**2.73 (2.09 – 3.57), <0.01**	**2.81 (2.15 – 3.68) <0.001**
Other White	75 (13.4)	1.23 (0.92 – 1.63), 0.14	1.20 (0.9 – 1.59) 0.20
Asian	44 (7.9)	**1.56 (1.11 – 2.19, 0.03**	**1.43 (1.02 – 2.02) 0.03**
Mixed	27 (4.8)	**1.57 (1.04 – 2.37), 0.03**	1.41 (0.93 – 2.14) 0.09
Other	41 (7.3)	**4.27 (3.01 – 6.06), <0.01**	**4.14 (2.91 – 5.88) <0.001**

**adjusted for age and gender

Table 7.6: Incidence rate ratios (IRR) with 95% CI in ethnic minority groups for first episode psychosis by gender

Men	N = 292 (%)	Unadjusted IRR	Adjusted IRR*
White British	68 (23.3)	1.00	1.00
Black African	79 (27.1)	**4.39 (3.17 – 6.08), <0.001**	**4.35 (3.13 – 6.02), <0.001**
Black Caribbean	39 (13.4)	**2.74 (1.84 – 4.06), <0.001**	**2.76 (1.85 – 4.10), <0.001**
Other White	41 (14.0)	1.42 (0.96 – 2.09), 0.07	1.34 (0.91 – 1.98), 0.13
Asian	19 (6.5)	1.46 (0.87 – 2.43), 0.14	1.26 (0.75 – 2.10), 0.36
Mixed	15 (5.1)	**1.86 (1.06 – 3.25), 0.03**	1.57 (0.90 – 2.76), 0.11

Other	31 (10.6)	**6.30 (4.12 – 9.64), <0.001**	**5.98 (3.90 – 9.15), <0.001**
Women	N = 266 (%)		
White British	65 (24.4)	1.00	1.00
Black African	68 (25.5)	**2.95 (2.10 – 4.14), <0.001**	**2.87 (2.04 – 4.04), <0.001**
Black Caribbean	52 (19.6)	**2.70 (1.87 – 3.89), <0.001**	**2.68 (1.86 – 3.88), <0.001**
Other White	34 (12.8)	1.05 (0.69 – 1.59), 0.81	1.05 (0.69 – 1.59), 0.81
Asian	25 (9.4)	**1.63 (1.03 -2.59), 0.03**	1.56 (0.98 – 2.48), 0.06
Mixed	12 (4.5)	1.30 (0.70 – 2.42), 0.39	1.23 (0.66 – 2.48), 0.66
Other	10 (3.8)	**2.13 (1.09 – 4.16), <0.001**	**2.09 (1.07 – 4.08), 0.02**

*adjusted for age

7.4.2 Unadjusted and adjusted age-specific incidence rate ratios by ethnic groups

Table 7.7 shows age-specific incidence rate ratios by ethnic groups using White British as reference group. The observed results suggest elevated risk in the young and middle age-bands (20–44 years) among the Black African, Black Caribbean and Other groups. Moreover, patients aged 25–29 and of Asian or Mixed ethnicities were also twice to three times more likely to experience psychosis (IRR = 2.37; 95% CI 1.10 – 5.10), (IRR = 3.36; 95% CI 1.52 – 7.44) respectively. In addition, older (55–59 years) Asian patients had four-fold increased risk of psychosis (IRR = 4.67; 95% CI 1.04 – 20.95), but no other ethnic minority group showed increased risk in this particular age group. It is noteworthy that the point estimate of risk among the Asian and 'Other' ethnic groups appears imprecise due to wide confidence intervals and this could be due to the small sample size in these groups. The observed difference in risk among Asians and the Mixed group by age-band in the adjusted IRR model may explain the gender difference shown in Table 6.5 above, meaning that it is the older women of the Asian ethnic group and men aged 22–29 of Mixed ethnicity that are most at risk. This is consistent with previously reported findings (Coid et al., 2008b, Bhugra et al., 1997).

Table 7.7: Adjusted age-specific incidence rate ratios (IRR) with 95% CI and p-value in ethnic minority groups for first episode all psychosis

Age-band (years)	Black African	Black Caribbean	Other White	Asian	Mixed	Other
18–19	0.79 (0.299 – 2.12), 0.65	0.64 (0.26 – 1.98), 0.44	0.79 (0.22 – 2.80), 0.71	0.38 (0.08 – 1.74), 0.21	0.49 (0.11 – 2.12), 0.35	No cases
20–24	**4.37 (2.61 – 7.31), >0.001**	**3.26 (1.82 – 5.84), <0.001**	1.06 (0.51 – 2.12), 0.85	1.25 (0.60 – 2.59), 0.54	1.45 (0.63 – 3.36), 0.37	**4.98 (2.33 – 10.63), <0.001**
25–29	**8.10 (4.57 – 14.34), <0.001**	**4.64 (2.33 – 9.27), <0.001**	1.09 (0.52 – 2.29), 0.81	**2.37 (1.10 – 5.10), 0.02**	**3.36 (1.52 – 7.44), <0.01**	**9.84 (4.77 – 20.27), <0.001**
30–34	**4.83 (2.59 – 9.03), <0.001**	**4.37 (2.13 – 8.93), <0.001**	1.11 (0.54 – 2.26), 0.78	1.94 (0.84 – 4.47), 0.11	0.41 (0.05 – 3.09), 0.38	**2.77 (0.93 – 8.20), 0.06**
35–39	**3.76 (1.92 – 7.37), <0.001**	**3.55 (1.66 – 7.61), <0.001**	1.59 (0.77 – 3.30), 0.20	1.18 (0.39 – 3.56), 0.76	1.53 (0.44 – 5.30), 0.49	**5.78 (2.45 – 13.64), <0.001**
40–44	**4.24 (1.90 – 9.47), <0.001**	**3.49 (1.44 – 8.45), <0.01**	2.86 (1.20 – 6.80), 0.01	**3.06 (1.02 – 9.16), 0.04**	0.86 (0.11 – 6.82), 0.83	**5.06 (1.56 – 16.45), <0.01**
45–49	1.84 (0.72 – 4.68), 0.19	1.55 (0.58 – 4.09), 0.37	1.40 (0.48 – 4.11), 0.53	0.68 (0.08 – 5.35), 0.71	1.70 (0.37 – 7.77), 0.49	2.58 (0.56 – 11.80), 0.22
50–54	0.86 (0.31 -2.36), 0.78	1.17 (0.48 – 2.86), 0.72	1.01 (0.37 – 2.78), 0.97	0.44 (0.05 – 3.33), 0.42	1.40 (0.32 – 6.12), 0.65	2.07 (0.47 – 9.03), 0.32
55–59	2.10 (0.38 – 11.51),	2.82 (0.62 – 12.65),	1.92 (0.35 – 10.54),	**4.67 (1.04 – 20.95),**	No cases	No cases

	0.38	0.17	0.44	**0.04**		
60–64	2.98 (0.54 – 16.37), 0.20	No cases	No cases	No cases	No cases	No cases

Reference = White British. Adjusted for gender.

Table 7.8: Comparison of findings from AESOP and current study by ethnicity

	Standardised IR (95% CI) AESOP	Standardised IR (95% CI) Current study	Adjusted IRR (95% CI) AESOP	Adjusted IRR (95% CI) Current study
All				
White British	20.2 (17.8 – 22.7)	39.4 (32.2 – 46.6)	1.00	1.00
Black African	80.6 (60.0 – 101.2)	120.8 (100.0 – 141.5)	**4.1 (3.2 – 5.3)**	**3.59 (2.8 – 4.55)**
Black Caribbean	140.8 (114.4 – 167.2)	93.6 (74.0 – 113.2)	**6.7 (5.4 – 8.3)**	**2.81 (2.15 – 3.68)**
Other White	33.1 (22.0 – 44.2)	49.1 (36.0 – 62.2)	**1.6 (1.1 – 2.2)**	1.20 (0.9 – 1.59)
Asian	31.6 (16.7 – 46.5)	51.9 (33.6 – 70.2)	1.5 (0.9 – 2.4)	**1.43 (1.02 – 2.02)**
Mixed	45.9 (26.4 – 65.5)	47.5 (26.2 – 68.9)	**2.7 (1.8 – 4.2)**	1.41 (0.93 – 2.14)
Other	55.0 (30.9 – 79.1)	126.4 (85.5 – 167.2)	**2.6 (1.7 – 3.9)**	**4.14 (2.91 – 5.88)**

7.5 Summary

To summarise, incidence rates of psychosis were higher among Black African, Black Caribbean and 'Other' ethnic groups than among White British. Rates were also highest among those aged 18–19 and 20–24 and least among those aged 60 and above. However, given the small number of people aged 18–19 years in the sample and the wide confidence intervals, the incidence rates for this group are likely to be less precise and therefore the interpretations for age band 18–19 years are tentative. Analyses of incidence rate ratios by age and ethnic group also confirmed higher risk of psychosis across ages 20–44 years if patients were of Black African, Black Caribbean or 'Other' ethnic groups. There were higher risks among Asian patients aged 25–29 years and 40–44 years, and this is the only ethnic group with increased risk at age 55–59 years. For patients of 'Mixed' ethnicity, the risk was only significant at 25–29 years.

In terms of incidence rates by ethnic group, these were markedly higher among Black African, Black Caribbean and 'Other' ethnic groups compared with White British. The magnitude of the risk varied across ethnic groups, but there was strong evidence that four main groups were at risk: starting with the group most at risk, there was evidence for four-fold risk among 'Other', and three-fold risk among Black African. Black Caribbean patients were almost three times at risk and Asian patients had almost one and a half increased risk compared with White British. There was tentative evidence for increased risk among those of 'Mixed' ethnicity, but this did not hold after controlling for confounders.

In relation to gender-specific rate ratios, there was evidence that men of Black African, Black Caribbean and 'Other' ethnic groups were at particularly increased risk. The increased risk for men was consistent with overall rate ratios but was stronger. For example, men of 'Other' ethnic group were around six times, Black Africans were four times and Black Caribbeans were almost three times more at risk compared with White British.

Again as before, there was tentative evidence that men of 'Mixed' ethnic groups were almost twice at risk of psychosis compared with White British, but this was no longer significant at traditional level (i.e., $p<0.05$) after adjusting for age.

For women, the picture was similar to men, particularly for the same three ethnic groups most at risk, namely Black African, Black Caribbean and 'Other'. However, the magnitude of the effect was somewhat reduced for women of Black African (almost three times increased risk) and 'Other' (twice at risk), but the effect for men and women of Black Caribbean ethnic group appears to be similar.

Asian women showed almost twice the risk of psychosis compared with White British women, but after controlling for age, the effect weakened slightly and therefore this is only a tentative interpretation.

In conclusion, the evidence in this chapter supports the hypotheses that incidence rates were higher among Black African and Black Caribbean compared with White British patients and that the magnitude of risk was attenuated. In fact magnitude of risk among Black Caribbeans appears to have halved compared to AESOP findings (Table 7.8). However, it is noteworthy that compared to the AESOP study, a higher incidence rate (almost doubled) was observed among the White British population in this study, while the rate was lower for the Black Caribbean population (Table 7.8). These two findings may explain the reduced rate ratio in the Black Caribbean ethnic group.

For the Black African group, the incidence rate remained higher and the rate ratio showed little or no difference compared to the AESOP study (Table 7.8).

7.6 Limitations

While this study has several methodological strengths which are discussed in Chapter 12, the findings in this chapter need to be interpreted with a number of key methodological limitations in mind.

Diagnostic accuracy

First, first episode psychosis cases in this study were identified using routinely collected clinical material. Although the study used standardised approach to diagnosis applied by the research team (ie. the PSS), these diagnoses are necessarily vulnerable to the accuracy and rigor with which individual symptoms are assessed. Clinicians are likely to vary in their competence at assessing and recording the key symptoms that comprise a diagnosis. Few will routinely use standardised clinical measures and some records will have been made by less experienced junior psychiatrists. However, researchers in this study have clinical expertise and where possible took into account verbatim quotes of patients that were often recorded as justification by the clinicians for the presence of symptom.

Further, it is acknowledged that excluding those with transient psychotic symptoms resulting from acute intoxication may lead to selection bias, as brief psychoses can turn out to be first signs of more enduring illness. However, given that we were able to observe the clinical records of individuals across the entire screening period (two years) and the three-stage screening process (see page 126), the risk of missing those who initially presented with transient psychotic features but later met the inclusion criteria of a case, were minimal.

Misclassification of ethnic groups

As described in Chapter one, self-ascription to an ethnic group is largely influenced by the cultural context of the individual. Participants in this study were grouped according to the ONS classifications. However, the assumption of cultural uniformity in large clusters such as African and Caribbean is crude and likely to be flawed. For example, the Caribbean people came from countries that are geographically as much as 2000 kilometres from each other and have very different cultures and 'identities'. Another example is diversity within the African group. For instance, in an African country like Nigeria there are many tribes and

ethnicities with different cultures, identities and languages. Furthermore, some second and third generation offspring whose grand- and great-grand parents migrated to the UK may be assimilated well enough to think of themselves as a culturally integrated (Singh, 1997) and consider themselves simply as British. Therefore misclassification is likely to be intrinsic in both the denominator and numerator populations. Another complication is that ethnic classifications in health records may not be taken at face value since it is difficult to be certain whether patients self-ascribe their ethnicity and where this is clinician ascribed, heterogeneity in the recording may be inevitable. This is because clinician's judgement of patient's ethnicity is inevitably subjective. While steps were taken by researchers in this study to carefully check patients' ethnicity (see Chapter 6, p 128), given the potential misclassifications in both denominator and numerator populations, these caveats will affect the findings in this study. This inevitably can only lead to imperfect findings but is an issue of population research in general, not just a concern of this thesis.

Migration status

Finally, recent migrants of refugee status may be even more at risk of mental disorder than economic migrants or those whose parents and grand-parents were the original migrants. This cannot be addressed by present study as migration status was not adjusted for due to this data not being available for the denominator population at the time of the study. Previous studies that were able to adjust for generation status and migration status had shown that higher incidence rate ratios were observed particularly in the black ethnic groups and their children (Coid et al., 2008b, Kirkbride et al., 2017). In addition, a recent study from Sweden investigated the rates of schizophrenia and non-affective psychosis in refugee and non-refugee migrants compared with native Swedish populations. They found that refugee migrants had higher rates of psychosis than non-refugee migrants, but the risk was even greater for those from sub-Saharan Africa irrespective of refugee status (Hollander et al., 2016). In addition, the increased risk of psychosis among the Asian women in this study could be due to some other social difficulties that have been highlighted as pertinent to this population. These include social isolation, quality of relationship with male partner and lack of English language proficiency (Talbani and Hasanali, 2000, Nilaweera et al., 2014).

8 Chapter 8: Results of Pathways to Care, Compulsory Admission at First Episode Psychosis and Ethnicity

8.1 Synopsis

In this chapter, I will first describe the overall sample characteristics for pathways to care at first contact for psychosis (baseline). Secondly, in section 8.3, six unadjusted logistic regression models are presented assessing the prevalence and relationships between hospital admission, compulsory admission, pathways to care/source of referral (namely: police/criminal justice referral, GP referral, A&E referral and other source of referral), sociodemographic and clinical factors. Thirdly, adjusted logistic regression models are presented assessing the association between the main predictor variable (i.e. ethnicity) and the outcome variables considered in Section 8.3, to address the following Hypotheses: compared to White British ethnicity,

1. Higher rates of hospital admissions will be associated with Black African and Black Caribbean ethnicity.
2. Increased risk of compulsory admissions will be associated with Black African and Black Caribbean ethnicity.
3. Higher rates of police involvement will be associated with Black African and Black Caribbean ethnicity.
4. Lower levels of GP referral will be associated with Black African and Black Caribbean ethnicity.
5. Higher rates of accident and emergency referral will be associated with Black African and Black Caribbean ethnicity.

On the basis of previous literature, there is no evidence that Black African and Black Caribbean ethnic groups had longer duration of untreated psychosis (DUP) compared with the White British ethnic group. Therefore, I did not formally test the hypothesis that DUP will be longer. Nonetheless for completeness, I did an analysis of the associations between DUP and ethnicity.

8.2 Pathway to care variables at first contact for psychosis (baseline)

To begin with, as noted in Chapter 6, data for this stage of the analysis were collected at the point of first contact for psychosis in seven key domains: hospital admission, compulsory admission, source of referral, time of contact, family involvement in help-seeking, mode of onset and duration of untreated psychosis. Data relating to hospital admission and compulsory admission were assessed as whether present or not (yes or no) on the day of first contact for psychosis. It is on these cross-sectional data that the analyses of outcomes in this chapter are based.

Of the total number of 558 patients, data were complete for all pathways to care variables except cannabis use (122 missing data) and early intervention service use (2 missing data), which were included in the analyses. It is worth noting that some information was not recorded in the clinical records and therefore these items were coded as missing, which then means that total frequencies vary for these items.

Table 8.1 describes the basic characteristics of pathways to care of the total sample at first contact (baseline). From this table it can be seen that a median of 93 days of duration of untreated psychosis was observed among the total sample. Onset of psychosis in the majority of the sample was insidious (n = 209, 37.5%). Around half of the sample had ever smoked cannabis (52.5%). Almost a quarter of the sample had used mental health services previously for a diagnosis other than psychosis. A majority of individuals made first contact with secondary mental health services for psychosis as in-patients (42.7%) while the remainder came in via community services (57.3%). Many were referred by the accident and emergency services (39.4%), followed by GP referral (35.1%). 77 (13.8%) people were referred by the police/criminal justice agency and the remainder, 68 (12.2%), were referred by 'Other' (i.e. healthcare professionals, nurse, doctor in non-mental health care setting). Only around 40% of the sample used an early intervention service during first contact for psychosis, while the rest used other types of mental health services. The use of the Mental Health Act was observed in (24.2%) of the sample at first contact for psychosis and around a third of the sample made contact outside of normal working hours. Most of the sample did not (64.9%) have family involvement in their help-seeking for psychosis.

Table 8.1: Basic characteristics of pathways to care variables

Characteristics	**Cases n = 558 (%)**
Median DUP *in days(IQR)*	93 (19 – 447)
Mean age at FEP *in years(sd)*	33.2 (10.7)
Mode of onset	N (%)
Acute (within a week)	116 (20.7)
Moderate (within a month)	111 (19.9)
Gradual (up to 6months)	122 (21.9)
Insidious (more than 6 months)	209 (37.5)
Pervious Service Use	
No	426 (76.3)
Yes	132 (23.7)
Hospital admission at FEP contact	
No	320 (57.3)
Yes	238 (42.7)
Source of referral	
GP/Primary care	196 (35.1)
A&E	217 (38.9)
Police/Criminal Justice agency	77 (13.8)
Other (non-mental health professionals)	68 (12.2)
MHA at FEP	
Yes	135 (24.2)
No	423 (75.8)
Time of FEP contact	
Office hours	363 (65.1)
Out of hours	195 (34.9)
Family involvement in help-seeking	
Yes	196 (32.1)
No	362 (64.9)
Ever smoked cannabis[1]	
Yes	229 (52.5)
No	207 (47.5)
Early intervention service use[2]	
Yes	222 (39.9)
No	334 (60.1)

1 *(122 missing data)*

2 *(2missing data)*

8.2.1 Comparison between ethnicity and pathways to care variables

In order to examine whether association of source of referral varied by ethnic group, each source of referral variable was dichotomised to explore each as an individual outcome variable. This resulted in four different outcomes for source of referral variables. Further, hospital admission and compulsory admission were assessed separately as outcomes in the analyses.

Table 8.2 displays comparisons between pathways to care and ethnic groups. The results show that 'Other' ethnic groups had the shortest median duration of untreated psychosis (60 days) and Black Caribbean patients the longest (126 days). In line with previous studies there was no evidence that DUP was longer in Black African and Black Caribbean ethnic groups compared with the White British group, therefore I did not proceed to do further analysis. By age, patients of 'Mixed' ethnicity were younger (mean age = 29.7, sd = 9.6) compared with other ethnic groups (X2 = 12.5 df 6, p = 0.05). Those who had used services prior to onset of psychosis were more likely to be White British (32.3%, p = 0.02) compared with other groups. Differences were also observed in those who had used cannabis and these were more likely to be White British (63.2%), Black Caribbean (65.2%) and Mixed (73.9%) ethnic groups, whist individuals of the Asian ethnic group were least likely to use cannabis (28.1%) (X2 = 29.3,df 6, p<0.001).

Black Africans were more likely to be detained under the Mental Health Act, i.e. compulsory admission, compared with White British (17.3% vs. 34.0% respectively, p = 0.01). First contact for psychosis via the community services was the most common route of access to mental health services among all patients (48.2% to 68.3%). A higher proportion of White British (41.4%) and Black African (47.6%) patients used early intervention services, but no statistical difference was detected between these groups. Although no strong statistical ethnic differences were observed for hospital admission at first contact, among those admitted, a higher proportion were of Black African (49%), Mixed (51.9%), White Other (48%) and Asian (47.7%) ethnic groups.

In terms of source of referral, most patients were referred by the Accident and Emergency department compared with GP referral. For example, 42.9% Black African, 41.3% White Other and 47.7% Asian patients were referred by A&E compared with 30.6%, 33.3% and 34.1% referred by GP respectively, but this did not reach statistical significance which may be explained by sampling error or the smaller sample size among the Asian and 'Other' groups.

Referral via police and criminal justice agency was more common among the Black African (16.3%) and 'Mixed' (22.2%) ethnic groups and the majority of the Black Caribbean group were referred by Other healthcare professionals, but no statistical differences were detected across the ethnic groups on source of referrals.

Table 8.2: Comparison between clinical, pathways to care variables and ethnic groups

	White British n = 133 (%)	**Black African n = 147 (%)**	**Black Caribbean n = 91 (%)**	**White Other n = 75 (%)**	**Asian n = 44 (%)**	**Mixed n = 27 (%)**	**Other n = 41 (%)**	**ANOVA/ Kwallis Chi-sq test**	**df**	**p**
Median DUP in days (IQR)	105 (22 – 514)	88 (17 – 447)	126 (28 – 449)	86 (14 – 408)	76.5 (8.5 – 243)	92 (23 – 361)	60 (12 – 560)	2.40	6	0.87
Mean Age at FEP *in years (SD)*	34.5 (12.5)	32.4 (9.9)	33.4 (10.6)	34.9 (9.6)	32.4 (10.3)	29.7 (9.6)	31.9 (9.1)	**12.56**	**6**	**0.05**
Median LOS (IQR) at FEP	15 (4 – 33)	29 (14 – 61)	29.5 (11 – 75)	21 (8.5 – 45.5)	14 (6 – 63)	13 (3 – 34)	28 (11 – 88)	**13.06**	**6**	**0.04**
	White British n = 133 (%)	**Black African n = 147 (%)**	**Black Caribbean n = 91 (%)**	**Other White n = 75 (%)**	**Asian n = 44 (%)**	**Mixed n = 27 (%)**	**Other n = 41 (%)**	**Chi-sq test**	**df**	**p**
Previous service use										
No	90 (67.7)	122 (83.0)	65 (71.4)	58 (77.3)	38 (86.4)	19 (70.4)	34 (82.9)	**14.36**	**6**	**0.02**
Yes	43 (32.3)	25 (17.0)	26 (28.6)	17 (26.7)	6 (13.6)	8 (29.6)	7 (17.1)			
Hospital admission at FEP										
No	83 (62.4)	75 (51.0)	59 (64.8)	39 (52.0)	23 (52.3)	13 (48.1)	28 (68.3)	10.16	6	0.11
Yes	50 (37.6)	72 (49.0)	32 (35.2)	36 (48.0)	21 (47.7)	14 (51.9)	13 (31.7)			
Mode of onset										

Acute (within a week)	25 (18.8)	33 (22.6)	18 (19.8)	15 (20.0)	11 (25.0)	4 (14.8)	10 (24.4)	11.68	18	0.86
Moderate (within a month)	26 (19.6)	29 (19.8)	16 (17.6)	18 (24.0)	7 (15.9)	6 (22.2)	9 (21.9)			
Gradual (up to 6months)	25 (18.8)	36 (24.5)	22 (24.2)	13 (17.3)	12 (27.3)	9 (33.3)	5 (12.2)			
Insidious (more than 6 months)	57 (42.8)	49 (33.3)	35 (38.4)	29 (38.7)	14 (31.8)	8 (29.6)	17 (41.5)			
Ever smoked cannabis										
Yes	72 (63.2)	44 (40.0)	45 (65.2)	28 (46.7)	9 (28.1)	17 (73.9)	14 (50.0)	**29.30**	**6**	**0.000**
No	42 (36.8)	66 (60.0)	24 (34.8)	32 (53.3)	23 (71.9)	6 (26.1)	14 (50.0)			
Compulsory admission (MHA) at FEP										
Yes	23 (17.3)	50 (34.0)	19 (20.9)	14 (18.7)	13 (29.9)	9 (33.3)	7 (17.1)	**16.02**	**6**	**0.01**
No	110 (82.7)	97 (66.0)	72 (79.1)	61(81.3)	31 (70.4)	18 (66.7)	34 (82.9)			
Time of FEP contact										
Office hours	88 (66.2)	86 (58.5)	62 (68.1)	50 (66.7)	27 (61.4)	19 (70.4)	31 (75.6)	5.92	6	0.43
Out of hours	45 (33.8)	61 (41.5)	29 (31.9)	25 (33.3)	17 (38.6)	8 (29.6)	10 (24.4)			
Early intervention service use										
No	78 (85.6)	77 (52.4)	55 (61.1)	51 (68.0)	29 (67.4)	15 (55.6)	29 (70.7)	8.88	6	0.18
Yes	55 (41.4)	70 (47.6)	35 (38.9)	24 (32.0)	14 (32.6)	12 (44.4)	12 (29.3)			
Family involvement										
Yes	44 (33.1)	48 (32.7)	39 (42.9)	29 (38.7)	17 (38.6)	8 (29.6)	11 (26.8)	5.27	6	0.50

No	89 (66.9)	99 (67.4)	52 (57.1)	46 (61.3)	27 (61.4)	19 (70.4)	30 (73.2)			
GP referral										
No	83 (62.4)	102 (69.4)	60 (65.9)	50 (66.7)	29 (65.9)	17 (63.0)	21 (51.2)	5.23	6	0.51
Yes	50 (37.6)	45 (30.6)	31 (34.1)	25 (33.3)	15 (34.1)	10 (37.0)	20 (48.8)			
A&E referral										
No	81 (60.9)	85 (57.8)	61 (67.0)	45 (60.0)	23 (52.3)	18 (66.7)	28 (68.3)	4.73	6	0.57
Yes	52 (39.1)	62 (42.2)	30 (33.0)	30 (40.0)	21 (47.7)	9 (33.3)	13 (31.7)			
Police / Criminal Justice system referral										
No	117 (88.0)	123 (83.7)	80 (87.9)	64 (85.3)	39 (88.6)	21 (77.8)	37 (90.2)	3.80	6	0.72
Yes	16 (12.0)	24 (16.3)	11 (12.1)	11 (14.7)	5 (11.4)	6 (22.2)	4 (9.8)			
Other referral										
No	118 (88.7)	131 (89.1)	72 (79.1)	66 (88.0)	41 (93.2)	25 (92.6)	37 (90.2)	8.75	6	0.27
Yes	15 (11.3)	16 (10.9)	19 (20.9)	9 (12.0)	3 (6.8)	2 (7.4)	4 (9.8)			

8.3 Associations between sociodemographic, pathways to care variables and compulsory admission

This section explores the prevalence of and relationship between hospital admission, compulsory admission and sociodemographic and pathways to care factors at first contact for psychosis, using univariable logistic regression.

8.3.1 Unadjusted odds ratios for hospital admission at first contact

Table 8.3 displays the prevalence and unadjusted odds ratios of hospital admission by sociodemographic, clinical and pathways to care variables. It can be seen in this table that four sociodemographic variables were strongly associated with hospital admission. Black African (OR = 1.59; 95% CI 0.98 – 2.56) patients were almost two times more likely to be admitted. Patients with the housing tenure (hostel/refuge) were also twice as likely to be admitted to hospital (OR = 2.16; 95% CI 1.06 – 4.38). Patients who were registered with the GP (OR = 0.22; 95% CI 0.07 – 0.61) and those divorced or separated (OR = 0.48; 95% CI 0.28 – 0.83) were less likely to be hospitalised. Meanwhile, there was weak evidence of reduced likelihood of hospital admission and the following demographic factors: age, living with relatives/friends and born outside of the UK. In terms of pathways to care variables, strong evidence of associations were observed between out of hours contact (OR = 4.89; 95% CI 3.36 – 7.12), accident and emergency referral (OR = 12.65; 95% CI 7.34 – 21.81), police/CJA referral (OR = 134; 95% CI 48.25 – 372.95), Other referral (OR = 4.45; 95% CI 2.22 – 8.92) and hospital admission. Longer (≥one year) duration of untreated psychosis and mode of onset had reduced likelihood of being hospitalised (Table 8.3).

Table 8.3: Unadjusted odds ratios of hospital admission by sociodemographic and pathways to care variables at first contact

	No-hospital admission n = (%)	**Hospital admission n = (%)**	**Unadjusted OR**	**95% confidence interval**	**P = value**
Gender					
Male	161 (55.1)	131 (44.9)	1.00		
Female	159 (59.8)	107 (40.2)	0.82	0.59 – 1.15	0.26
Age-band					
18–29	129 (53.3)	113 (46.7)	1.00		
30–64	191 (60.4)	125 (39.6)	0.74	0.53 – 1.04	0.09
Ethnicity					
White British	83 (62.4)	50 (37.6)	1.00		
Black African	75 (51.0)	72 (49.0)	**1.59**	**0.98 – 2.56**	**0.05**

Black Caribbean	59 (64.8)	32 (35.2)	0.90	0.51 – 1.56	0.71
White Other	36 (52.0)	36 (50.0)	1.53	0.86 – 2.71	0.14
Asian	23 (52.3)	21 (47.7)	1.51	0.76 – 3.01	0.23
Mixed	13 (48.2)	14 (51.8)	1.78	0.77 – 4.10	0.17
Other	28 (68.3)	13 (31.7)	0.77	0.36 – 1.62	0.49
GP Registered					
No	5 (23.8)	16 (76.2)	1.00		
Yes	315 (58.7)	222 (41.3)	**0.22**	**0.07 – 0.61**	**0.004**
Ever employed					
No	27 (64.3)	15 (35.7)			
Yes	230 (56.9)	174 (43.1)	1.36	0.70 – 2.63	0.36
Relationship status					
Single	177 (53.5)	154 (46.5)	1.00		
Married / Steady relationship	77 (60.6)	50 (39.4)	0.74	0.49 – 1.13	0.16
Divorced/Separated	52 (70.3)	22 (29.7)	**0.48**	**0.28 – 0.83**	**0.009**
Employment					
Unemployed	205 (59.2)	141 (40.8)	1.00		
Student	29 (48.3)	31 (51.7)	1.55	0.89 – 2.69	0.11
Employed	57 (57.6)	42 (42.4)	1.07	0.68 – 1.68	0.76
Education					
School, no GCSE	55 (55.6)	44 (44.4)	1.00		
School with GCSE	44 (60.3)	29 (39.7)	0.82	0.44 – 1.52	0.53
A level/ Further education	67 (58.8)	47 (41.2)	0.87	0.50 – 1.51	0.63
University	59 (54.6)	49 (45.4)	1.03	0.59 – 1.79	0.89
Lives with					
Alone	85 (52.8)	76 (47.2)	1.00		
Family/relatives	200 (61.5)	125 (38.5)	0.69	0.47 – 1.02	0.06
Other	26 (47.3)	29 (52.7)	1.24	0.67 – 2.30	0.48
Housing Tenure					
Privately owned	43 (63.2)	25 (36.8)	1.00		
Rented	127 (57.2)	95 (42.8)	1.28	0.73 – 2.25	0.37
Other (e.g. Hostel)	27 (44.3)	34 (55.7)	**2.16**	**1.06 – 4.38**	**0.03**
Place of birth					
UK born	149 (61.3)	94 (38.7)	1.00		
Non-UK born	152 (53.9)	130 (46.1)	1.35	0.96 – 1.92	0.08
Report of social isolation					
No	122 (54.7)	101 (45.3)	1.00		
Yes	147 (59.3)	101 (40.7)	0.82	0.57 – 1.19	0.31
Ever smoked					

cannabis					
No	118 (57.0)	89 (43.0)	1.00		
Yes	128 (55.9)	101 (44.1)	1.04	0.71 – 1.52	0.81
Time of FEP contact					
Office hours	256 (70.5)	107 (29.5)	1.00		
Out of hours	64 (32.8)	131 (67.2)	**4.89**	**3.36 – 7.12**	**<0.001**
DUP					
Short (< 1year)	208 (52.0)	192 (48.0)	1.00		
Long (>1 year)	112 (70.9)	46 (29.1)	**0.44**	**0.29 – 0.66**	**<0.001**
Previous service use					
No	239 (56.1)	187 (43.9)	1.00		
Yes	81 (61.4)	51 (38.6)	0.80	0.53 – 1.19	0.28
Mode of onset					
Acute (within a week)	43 (37.1)	73 (62.9)	1.00		
Moderate (within a month)	60 (54.0)	51 (46.0)	**0.50**	**0.29 – 0.85**	**0.01**
Gradual (up to 6months)	71 (58.2)	51 (41.8)	**0.42**	**0.25 – 0.71**	**0.001**
Insidious (more than 6 months)	146 (69.9)	63 (30.1)	**0.25**	**0.15 – 0.41**	**<0.001**
Source of referral					
GP	177 (90.3)	19 (9.7)	1.00		
A&E	92 (42.4)	125 (57.6)	**12.65**	**7.34 – 21.81**	**<0.001**
Police/CJA	5 (6.5)	72 (93.5)	**134.14**	**48.25 – 372.95**	**<0.001**
Other	46 (67.7)	22 (32.3)	**4.45**	**2.22 – 8.92**	**<0.001**
Family involvement					
No	214 (59.1)	148 (40.9)			
Yes	106 (54.1)	90 (45.9)	1.22	0.86 – 1.74	0.25
Early intervention service					
No	194 (58.1)	140 (41.9)	1.00		
Yes	125 (56.3)	97 (43.7)	1.07	0.76 – 1.51	0.67

8.3.2 Unadjusted odds ratios for compulsory admission at first contact

Table 8.4 presents proportions and univariable logistic regression analyses of compulsory admission by sociodemographic, clinical and pathways to care variables. From this table, the following observations were made: Black African patients were almost two and a half times more likely to be compulsorily admitted (OR = 2.46; 95% CI 1.40 – 4.33) than were the White

British, there was a weak evidence of association between compulsory admission and Mixed (OR = 2.39; 95% CI 0.95 – 5.98) and Asian (OR = 2.00; 95% CI 0.91 – 4.41) ethnic groups. There was no difference between White British and all other ethnic groups. Being married or in a steady relationship appears to be a protective factor for compulsory admission (OR = 0.60; 95% CI 0.36 – 1.00). Patients born outside the UK were almost twice as likely to be compulsorily admitted (OR = 1.72; 95% CI 1.14 – 2.60).

Furthermore, there was evidence that those detained compulsorily had the most adverse pathways to care (Table 8.3) The results also suggest that those with longer DUP were less likely to be detained (OR = 0.38; 95% CI 0.23 – 0.63), so were those with previous contact with mental health services (OR = 0.78; 95% CI 0.50 – 1.21), but this was a weak association and did not reach a statistical significance level.

In terms of mode of onset, the evidence suggests that people with longer and insidious onset of psychosis were less likely to be compulsorily detained compared with those with acute onset (Table 8.4).

There was insufficient evidence to suggest that sociodemographic and other pathways to care factors such as gender, age, employment status, educational qualification, living circumstances, report of social isolation, cannabis use, type of service use (i.e. EIS or previous service), family involvement in help-seeking or housing tenure were associated with compulsory admission.

Table 8.4: Unadjusted odds ratios of compulsory admission by socio-demographic and pathways to care variables at first contact

	Non-compulsory n=423 (%)	**Compulsory admission n= 135(%)**	**Unadjusted OR**	**95% confidence interval**	**P=value**
Gender					
Male	214 (73.3)	78 (26.7)	1.00		
Female	209 (78.6)	57 (21.4)	0.74	0.50-1.10	0.14
Age-band					
18-29	182 (75.2)	60 (24.8)	1.00		
30-64	241 (76.3)	75 (23.7)	0.94	0.63 – 1.39	0.77
Ethnicity					

White British	110 (82.7)	23 (17.3)	1.00		
Black African	97 (66.0)	50 (34.0)	**2.46**	**1.40 – 4.33**	**0.002**
Black Caribbean	72 (79.1)	19 (20.9)	1.26	0.64 – 2.48	0.50
White Other	61 (81.3)	14 (18.7)	1.09	0.52 – 2.28	0.80
Asian	31 (70.4)	13 (29.6)	2.00	0.91 – 4.41	0.08
Mixed	18 (66.7)	13 (29.3)	2.39	0.95 – 5.98	0.06
Other	34 (82.9)	7 (17.1)	0.98	0.38 – 2.49	0.97
GP Registered					
No	13 (61.9)	8 (38.1)	1.00		
Yes	410 (76.3)	127 (23.7)	0.50	0.20 – 1.24	0.13
Ever employed					
No	33 (78.6)	9 (21.4)	1.00		
Yes	305 (75.5)	99 (24.5)	1.19	0.55 – 2.57	0.65
Relationship status					
Single	242 (43.1)	89 (26.9)	1.00		
Married / Steady relationship	104 (81.9)	23 (18.1)	**0.60**	**0.36 – 1.00**	**0.05**
Divorced/Separated	60 (81.1)	14 (18.9)	0.63	0.33 – 1.19	0.15
Employment					
Unemployed	267 (77.2)	79 (22.8)	1.00		
Student	42 (70.0)	18 (30.0)	1.44	0.78 – 2.65	0.23
Employed	73 (73.7)	26 (26.3)	1.20	0.72 – 2.01	0.47
Education					
School, no GCSE	75 (75.8)	24 (24.2)	1.00		
School with GCSE	54 (74.0)	19 (26.0)	1.09	0.54 – 2.20	0.78
A level/ Further education	87 (76.3)	27 (23.7)	0.96	0.51 – 1.82	0.92
University	77 (71.3)	31 (28.7)	1.25	0.67 – 2.34	0.46
Lives with					
Alone	119 (73.9)	42 (26.1)	1.00		
Family/relatives	253 (77.8)	72 (22.2)	0.80	0.52 – 1.25	0.33
Other	38 (69.1)	17 (30.9)	1.26	0.64 – 2.48	0.49
Housing Tenure					
Privately owned	51 (75.0)	17 (25.0)	1.00		
Rented	168 (75.7)	54 (24.3)	0.96	0.51 – 1.80	0.91
Other (e.g. Hostel)	43 (70.5)	18 (29.5)	1.25	0.57 – 2.73	0.56
Place of birth					
UK born	197 (81.1)	46 (18.9)	1.00		
Non-UK born	201 (71.3)	81 (28.7)	**1.72**	**1.14 – 2.60**	**0.009**
Report of social					

isolation					
No	165 (74.0)	58 (26.0)	1.00		
Yes	194 (78.2)	54 (21.8)	0.79	0.51 – 1.21	0.28
Ever smoked cannabis					
No	158 (76.3)	49 (23.7)	1.00		
Yes	171 (74.7)	58 (25.3)	1.09	0.70 – 1.69	0.68
Time of FEP contact					
Office hours	308 (84.8)	55 (15.2)	1.00		
Out of hours	115 (59.0)	80 (41.0)	**3.89**	**2.59 – 5.83**	**<0.001**
DUP					
Short (< 1year)	286 (71.5)	114 (28.5)	1.00		
Long (>1 year)	137 (86.7)	21 (13.3)	**0.38**	**0.23 – 0.63**	**<0.001**
Previous service use					
No	318 (74.6)	108 (25.4)	1.00		
Yes	105 (79.6)	27 (20.4)	0.75	0.47 – 1.21	0.25
Mode of onset					
Acute (within a week)	68 (58.6)	48 (41.4)	1.00		
Moderate (within a month)	84 (75.7)	27 (24.3)	**0.45**	**0.25 – 0.80**	**0.007**
Gradual (up to 6months)	95 (77.9)	27 (22.1)	**0.40**	**0.22 – 0.70**	**0.002**
Insidious (more than 6 months)	176 (84.2)	33 (15.8)	**0.26**	**0.15 – 0.44**	**<0.001**
Source of referral					
GP	192 (98.0)	4 (2.0)	1.00		
A&E	156 (71.9)	61 (28.1)	**18.76**	**6.67 – 52.75**	**<0.001**
Police/CJA	17 (22.1)	60 (77.9)	**169.41**	**54.88 – 522.92**	**<0.001**
Other	58 (85.3)	10 (14.7)	**8.27**	**2.50 – 27.37**	**0.001**
Family involvement					
No	274 (75.7)	88 (24.3)	1.00		
Yes	149 (76.0)	47 (24.0)	0.98	0.65 – 1.47	0.93
Early intervention service					
No	257 (76.9)	77 (23.1)	1.00		
Yes	164 (73.9)	58 (26.1)	1.18	0.79 – 1.74	0.40

8.3.3 Unadjusted odds ratios for 'GP' referral at first contact

In Table 8.5 below, associations between GP referral and sociodemographic and pathways to care variables are presented. It can be seen from the table that there were no associations between GP referral and gender, age, ethnicity, relationship status, place of birth, cannabis use or previous contact with mental health services.

However, with regard to employment, those with student status (OR = 0.53; 95% CI 0.28 – 1.00) were less likely to be referred by GP compared with those who were unemployed. For housing, those with 'Other' tenure such as hostel or refuge (OR = 0.43; 95% CI 0.19 – 0.95) and 'Other' living arrangement (OR = 0.28;, 95% CI 0.12 – 0.64) were less likely to be referred by GP compared to those living in privately owned homes.. Among those reporting social isolation, GP referral was almost twice more likely (OR = 1.57; 95% CI 1.07 – 2.30) compared to those who did not report social isolation. There was a weak association with divorce/widowed status (OR = 1.61; 95% CI 0.96 – 2.70) compared with those who were single p = 0.06.

As would be expected, GP referral was less common during out of office hours (OR = 0.10; 95% CI 0.06 – 0.17) compared with office hours and family involvement in help-seeking (OR = 0.63; 95% CI 0.43 – 0.92) compared with those who did not have family input. Patients with longer DUP were nearly twice as likely to be referred by GP (OR = 1.79; 95% CI 1.23 – 2.62) compared to those with short DUP. In addition, GP referral was associated with moderate (OR = 4.26; 95% CI 2.16 – 8.41), gradual (OR = 5.41; 95% CI 2.78 – 10.51), and insidious (OR = 5.40; 95% CI 2.90 – 10.06) mode of onset compared with those with acute onset.

Table 8.5: Unadjusted odds ratios of GP referral by socio-demographic and pathways to care variables at first contact

	GP referral No n=362 (%)	GP referral Yes n=196 (%)	Unadjusted OR	95% confidence interval	P=value
Gender					
Male	193 (66.1)	99 (33.9)	1.00		

Female	169 (63.5)	97 (36.5)	1.11	0.79 – 1.58	0.57
Age-band					
18-29	166 (68.6)	76 (31.4)	1.00		
30-64	196 (62.0)	120 (38.0)	1.33	0.93 -1.90	0.10
Ethnicity					
White British	83 (62.4)	50 (37.6)	1.00		
Black African	102 (69.4)	45 (30.6)	0.73	0.44 – 1.20	0.21
Black Caribbean	60 (65.9)	31 (34.1)	0.85	0.49 – 1.49	0.58
White Other	50 (66.7)	25 (33.3)	0.83	0.45 – 1.50	0.53
Asian	29 (65.9)	15 (34.1)	0.85	0.41 – 1.75	0.67
Mixed	17 (63.)	10 (37.0)	0.97	0.41 – 2.29	0.95
Other	21 (51.2)	20 (48.8)	1.58	0.78 – 3.20	0.20
Relationship status					
Single	225 (68.0)	106 (32.0)	1.00		
Married / Steady relationship	78 (61.4)	49 (38.6)	1.33	0.87 – 2.04	0.18
Divorced/Separated	42 (56.8)	32 (43.2)	1.61	0.96 – 2.70	0.06
Employment					
Unemployed	220 (63.6)	126 (36.4)	1.00		
Student	46 (76.7)	14 (23.3)	**0.53**	**0.28 – 1.00**	**0.05**
Employed	63 (63.6)	36 (36.4)	0.99	0.62 – 1.58	0.99
Education					
School, no GCSE	58 (58.6)	41 (41.4)	1		
School with GCSE	47 (64.4)	26 (35.6)	0.78	0.41 – 1.46	0.44
A level/ Further education	73 (64.0)	41 (36.0)	0.79	0.45 – 1.38	0.41
University	77 (71.3)	31 (28.7)	**0.56**	**0.31 – 1.01**	**0.05**
Lives with					
Alone	101 (62.7)	60 (37.3)	1.00		
Family/relatives	202 (62.1)	123 (37.9)	1.02	0.69 – 1.51	0.90
Other (Hostel/Refuge)	47 (85.4)	8 (14.6)	**0.28**	**0.12 – 0.64**	**0.003**
Housing Tenure					
Privately owned	42 (61.8)	26 (38.2)	1.00		
Rented	141 (63.5)	81 (36.5)	0.97	0.52 – 1.62	0.79

Other	48 (78.7)	13 (21.3)	**0.43**	**0.19 – 0.95**	**0.03**
Place of birth					
Non -UK born	182 (64.5)	100 (35.5)	1.00		
UK born	157 (64.6)	86 (35.4)	0.99	0.69 – 1.42	0.98
Report of social isolation					
No	156 (70.0)	67 (30.0)	1.00		
Yes	148 (59.7)	100 (40.3)	**1.57**	**1.07 – 2.30**	**0.02**
Ever smoked cannabis					
No	138 (66.7)	69 (33.3)	1.00		
Yes	153 (66.8)	76 (33.2)	0.99	0.66 – 1.48	0.97
Time of FEP contact					
Office hours	185 (51.0)	178 (49.0)	1.00		
Out of hours	177 (90.8)	18 (9.2)	**0.10**	**0.06 – 0.17**	**<0.0001**
DUP					
Short	275 (68.7)	125 (31.3)	1.00		
Long	87 (55.1)	71 (44.9)	**1.79**	**1.23 – 2.62**	**0.002**
Previous service use					
No	284 (66.7)	142 (33.3)	1.00		
Yes	78 (59.1)	54 (40.9)	1.38	0.92 – 1.06	0.11
Mode of onset					
Acute (within a week)	102 (87.9)	14 (12.1)	1.00		
Moderate (within a month)	70 (63.1)	41 (36.9)	**4.26**	**2.16 – 8.41**	**<0.0001**
Gradual (up to 6months)	70 (57.4)	52 (42.6)	**5.41**	**2.78 – 10.51**	**<0.0001**
Insidious (more than 6 months)	120 (57.4)	89 (42.6)	**5.40**	**2.90 – 10.06**	**<0.0001**
Family involvement					
No	222 (61.3)	140 (38.7)	1.00		
Yes	140	56 (28.6)	**0.63**	**0.43 – 0.92**	**0.01**

	(71.4)				
Early intervention service use					
No	214 (64.1)	120 (35.9)	1.00		
Yes	147 (66.2)	75 (33.8)	0.90	0.63 – 1.29	0.60

8.3.3.1 Associations between ethnicity and DUP, stratified by GP referral

Table 8.5.1 shows the stratified analysis of ethnic differences in DUP by GP referral. As it can be seen from the table, there were no evidence of differences between those with short or long DUP in their referral GP status.

Table 8.5.1: Ethnic differences in DUP stratified by GP referral

	GP referral (Yes) N=196		X^2, (df), p	GP referral (No) N= 362		X^2, (df), p
Ethnicity	DUP short n=125 (%)	DUP long n=71 (%)		DUP short n=275 (%)	DUP long n=87 (%)	
White British	33 (26.4)	17 (24.0)	4.16 (6), 0.65	62 (22.5)	21 (24.1)	1.96 (6), 0.95
Black African	28 (22.4)	17 (24.0)		77 (28.0)	25 (28.7)	
Black Caribbean	20 (16.0)	11 (15.5)		45 (16.4)	15 (17.2	
White Other	18 (14.4)	7 (9.9)		36 (13.1)	14 (16.1)	
Asian	10 (8.0)	5 (7.0)		24 (8.7)	5 (5.8)	
Mixed	7 (5.6)	3 (4.2)		14 (5.1)	3 (3.5)	
Other	9 (7.2)	11 (15.4)		17 (6.2)	4 (4.6)	

DUP short: <1 year

DUP long: > 1 year

8.3.4 Unadjusted odds ratios for A&E referral at first contact

Table 8.6 displays the unadjusted logistic regression of A&E source of referral by sociodemographic and pathways to care variables. The table shows that there were no differences by ethnicity among those referred via A&E. Although a higher proportion of the older age group presented to A&E, this did not reach the traditional ($p<0.05$) statistical significance. Students and those employed were two times more likely to be come into contact via A&E (OR = 2.26; 95% CI 1.30 – 3.94 and OR = 2.10; 95% CI 1.33 – 3.31)

respectively compared to those who were unemployed. Similarly, those who were educated above GCSE (A 'level OR = 1.77; 95% CI 1.00 – 3.16 and university OR = 1.88; 95% CI 1.05 – 3.36) were almost twice likely to present to A&E compared with those without GCSE qualification.

With regard to living circumstances, those who lived with relatives and friends were almost twice more likely to present to A&E (OR = 1.70; 95% CI 1.14 – 2.55) compared with those that lived alone. Consequently, the data shows that family involvement in help-seeking was almost four times more common in A&E referral (OR = 3.74; 95% CI 2.59 – 5.40). Conversely, patients who reported social isolation were less likely to present to A&E (OR = 0.55; 95% CI 0.38 – 0.80). Unsurprisingly, those who present to A&E tend to do so out of office hours, and in fact are almost seven times more likely to do so (OR = 6.59; 95% CI 4.48 – 9.68).

In terms of mode of onset, patients with non-acute onset (moderate onset OR = 0.35; 95% CI 0.20 – 0.61; gradual onset OR = 0.27; 95% CI 0.16 – 0.47 and insidious onset OR = 0.25; 95% CI 0.15 – 0.41) were less likely to present to A&E as well as those with longer DUP (OR = 0.62; 95% CI 0.41 – 0.91). In addition, those who have used mental health services in the past were also less likely to present to A&E (OR = 0.50; 95% CI 0.33 – 0.77), compared to those who had not.

The data did not show evidence of association between A&E referral and sociodemographic factors such as gender, relationship status, registered with GP, housing tenure or cannabis use.

Table 8.6: Unadjusted odds ratios of A&E referral by socio-demographic and pathways to care variables at first contact

	A&E referral No n= 341 (%)	**A&E referral Yes n=217 (%)**	**Unadjusted OR**	**95% confidence interval**	**P=value**
Gender					
Male	180 (61.6)	112 (38.4)	1.00		
Female	161 (60.5)	105 (39.5)	1.04	0.74 – 1.47	0.78

Age-band					
18-29	138 (57.0)	104 (43.0)	1.00		
30-64	203 (64.2)	113 (35.8)	0.73	0.52 – 1.04	0.08
Ethnicity					
White British	81 (60.9)	52 (39.1)	1.00		
Black African	85 (57.8)	62 (42.2)	1.13	0.70 – 1.83	0.60
Black Caribbean	61 (67.0)	30 (33.0)	0.76	0.43 – 1.33	0.35
White Other	45 (60.0)	30 (40.0)	1.03	0.58 – 1.85	0.89
Asian	23 (52.3)	21 (47.7)	1.42	0.71 – 2.82	0.31
Mixed	18 (66.7)	9 (33.3)	0.77	0.32 – 1.86	0.57
Other	28 (68.3)	13 (31.7)	0.72	0.34 – 1.52	0.39
GP Registered					
No	11 (52.4)	10 (47.6)	1.00		
Yes	330 (61.4)	207 (38.6)	0.69	0.28 – 1.65	0.40
Relationship status					
Single	198 (59.8)	133 (40.2)	1.00		
Married / Steady relationship	73(57.5)	54 (42.5)	1.10	0.72 – 1.66	0.64
Divorced/Separated	49 (66.2)	25 (33.8)	0.75	0.44 – 1.28	0.30
Employment					
Unemployed	230 (66.5)	116 (33.5)	1.00		
Student	28 (46.7)	32 (53.3)	**2.26**	**1.30 – 3.94**	**0.004**
Employed	48 (48.5)	51 (51.5)	**2.10**	**1.33 – 3.31**	**0.001**
Education					
School, no GCSE	71 (71.7)	28 (28.3)	1.00		
School with GCSE	43 (58.9)	30 (41.1)	1.76	0.93 – 3.35	0.08
A level/ Further education	67 (58.8)	47 (41.2)	**1.77**	**1.00 – 3.16**	**0.05**
University	62 (57.4)	46 (42.6)	**1.88**	**1.05 – 3.36**	**0.03**
Lives with					
Alone	112 (69.6)	49 (30.4)	1.00		
Family/relatives	186 (57.2)	139 (42.8)	**1.70**	**1.14 – 2.55**	**0.009**
Other (Hostel/Refuge)	32 (58.4)	23 (41.8)	1.64	0.87 – 3.09	0.12
Housing Tenure					
Privately owned	40 (58.8)	28 (41.2)	1.00		
Rented	135 (60.8)	87 (39.2)	0.92	0.52 – 1.60	0.76

Other	38 (62.3)	23 (37.7)	0.86	0.42 -1.75	0.68
Place of birth					
Non-UK born	171 (60.6)	111 (39.4)	1		
UK born	151 (62.1)	92 (37.9)	0.93	0.65 – 1.33	0.72
Report of social isolation					
No	115 (51.6)	108 (48.4)	1.00		
Yes	163 (65.7)	85 (34.3)	**0.55**	**0.38 – 0.80**	**0.002**
Ever smoked cannabis					
No	118 (57.0)	89 (43.0)	1.00		
Yes	137 (59.8)	92 (40.2)	0.89	0.60 -1.30	0.55
Time of FEP contact					
Office hours	277 (76.3)	86 (23.7)	1.00		
Out of hours	64 (32.8)	131 (67.2)	**6.59**	**4.48 – 9.68**	**<0.0001**
DUP					
Short	232 (58.0)	168 (42.0)	1.00		
Long	109 (69.0)	49(31.0)	**0.62**	**0.41 – 0.91**	**0.01**
Previous service use					
No	245 (57.5)	181 (42.5)	1.00		
Yes	96 72.7()	36 (27.3)	**0.50**	**0.33 – 0.77**	**0.002**
Mode of onset					
Acute (within a week)	43 (37.1)	73 (62.9)	1.00		
Moderate (within a month)	69 (62.2)	42 (37.8)	**0.35**	**0.20 – 0.61**	**<0.0001**
Gradual (up to 6months)	83 (68.0)	39 (32.0)	**0.27**	**0.16 – 0.47**	**<0.0001**
Insidious (more than 6 months)	146 (69.9)	63 (30.1)	**0.25**	**0.15 – 0.41**	**<0.0001**
Family involvement					
No	261 (72.1)	101 (27.9)	1.00		

Yes	80 (40.8)	116 (59.2)	**3.74**	**2.59 – 5.40**	**<0.0001**
Early intervention service use					
No	207 (62.0)	127 (38.0)	1.00		
Yes	132 (59.5)	90 (40.5)	1.11	0.78 – 1.57	0.55

A&E, Accident and Emergency.

8.3.5 Unadjusted odds ratios for Police referral at first contact

Associations between police/CJA referral by sociodemographic and pathways to care are presented in Table 8.7. From this table, it can be seen that there were no differences in police referral by gender, age, education level, employment status, housing tenure, place of birth, previous service use, mode of onset, cannabis use or ethnicity.

However, four key variables were associated with police referral. Those registered with GP were less likely to be referred by police/CJA (OR = 0.29; 95% CI 0.11 – 0.76) compared to those who were not. Being married or in a steady relationship was associated with a reduced likelihood of police/CJA referral (OR = 0.41; 95% CI 0.19 – 0.87). Similarly, those living with family and friends (OR = 0.46; 95%CI 0.26 – 0.79) and those who had family involvement in their help-seeking (OR = 0.20; 95% CI 0.10 – 0.42, p<0.001) were less likely to be referred by police/CJA compared with those who lived alone. In addition, police/CJA referral was almost three times more likely to occur during out of office hours (OR = 2.57; 95% CI 1.57 – 4.19) compared to normal working hours.

Table 8.7: Unadjusted odds ratios of police/CJA referral by socio-demographic and pathways to care variables at first contact

	Police/CJA referred No n=481 (%)	**Police/CJA referred Yes n=77 (%)**	**Unadjusted OR**	**95% confidence interval**	**P=value**
Gender					
Male	248 (84.9)	44 (15.1)	1.00		
Female	233 (87.6)	33 (12.4)	0.79	0.49 – 1.29	0.36
Age-band					

18-29	208 (85.9)	34 (14.1)	1.00		
30-64	273 (86.4)	43 (13.6)	0.96	0.59 – 1.56	0.88
Ethnicity					
White British	117 (88.0)	16 (12.0)	1.00		
Black African	123 (83.7)	24 (16.3)	1.42	0.72 – 2.82	0.30
Black Caribbean	80 (87.9)	11 (12.1)	1.00	0.44 – 2.27	0.99
White Other	64 (85.3)	11 (14.7)	1.25	0.55 – 2.87	0.57
Asian	39 (88.6)	5 (11.4)	0.93	0.73 – 2,15	0.90
Mixed	21 (77.8)	6 (22.2)	2.08	0.73 – 2.51	0.16
Other	37 (90.2)	4 (9.8)	2.08	0.24 – 2.51	0.69
GP Registered					
No	14 (66.7)	7 (33.3)	1.00		
Yes	467 (87.0)	70 (13.0)	**0.29**	**0.11 – 0.76**	**0.01**
Relationship status					
Single	280 (84.6)	51 (15.4)	1.00		
Married / Steady relationship	118 (92.9)	9 (7.1)	**0.41**	**0.19 – 0.87**	**0.02**
Divorced/Separated			0.66	0.30 – 1.46	0.31
Employment					
Unemployed	298 (86.1)	48 (13.9)	1.00		
Student	51 (85.0)	9 (15.0)	1.09	0.50 – 2.36	0.81
Employed	90 (90.9)	9 (9.1)	0.62	0.29 – 1.31	0.21
Education					
School, no GCSE	82 (82.8)	17 (17.2)	1.00		
School with GCSE	67 (91.8)	6 (8.2)	0.43	0.16 – 1.15	0.09
A level/ Further education	99 (86.8)	15 (13.6)	0.73	0.34 – 1.55	0.41
University	88 (81.5)	20 (18.5)	1.09	0.53 – 2.23	0.80
Lives with					
Alone	131 (81.4)	30 (18.6)	1.00		
Family/relatives	294 (90.5)	31 (9.5)	**0.46**	**0.26 – 0.79**	**0.005**
Other (Hostel/Refuge)	42 (76.4)	13 (23.6)	1.35	0.64 – 2.82	0.42
Housing Tenure					
Privately owned	58 (85.3)	10 (14.7)	1.00		
Rented	192 (86.5)	30 (13.5)	0.90	0.41 – 1.96	0.80
Other	49 (80.3)	12.19.7()	1.42	0.56 – 3.56	0.45
Place of birth					
No-UK born	243 (86.2)	39 (13.8)	1.00		
UK born	20.7 (85.2)	36 (14.8)	1.08	0.66 – 1.76	0.78
Report of social isolation					
No	198 (88.8)	25 (11.2)	1.00		

Yes	211 (85.1)	37 (14.9)	1.38	0.80 – 2.39	0.23
Ever smoked cannabis					
Yes	179 (86.5)	28 (13.5)	1.00		
No	198 (86.5)	31 (13.5)	1.00	0.57 – 1.73	0.99
Time of FEP contact					
Office hours	328 (90.4)	35 (9.6)	1.00		
Out of hours	153 (78.5)	42 (21.5)	**2.57**	**1.57 – 4.19**	**<0.0001**
DUP					
Short	338 (84.5)	62 (15.5)	1.00		
Long	143 (90.5)	15 (9.5)	0.57	0.31 – 1.08	0.06
Previous service use					
No	364 (85.4)	62 (14.6)	1.00		
Yes	117 (88.6)	15 (11.4)	0.75	0.41 - 1.37	0.35
Mode of onset					
Acute (within a week)	97 (83.6)	19 (16.4)	1.00		
Moderate (within a month)	91 (82.0)	20 (18.0)	1.12	0.56 – 2.23	0.74
Gradual (up to 6months)	103 (84.4)	19 .15.6()	0.94	0.47 – 1.88	0.86
Insidious (more than 6 months)	190 (90.9)	19 (9.1)	**0.51**	**0.25 – 1.00**	**0.05**
Family involvement					
No	294 (81.2)	68 (18.8)	1.00		
Yes	187 (95.4)	9 (4.6)	**0.20**	**0.10 -0.42**	**<0.0001**
Early intervention service use					
No	290 (86.8)	44 (13.2)	1.00		
Yes	190 (85.6)	32 (14.4)	1.11	0.67 – 1.81	0.67

8.3.6 Unadjusted odds ratios for 'Other' referral at first contact

Table 8.8 displays associations between 'Other' source of referral (i.e. other healthcare worker, social services) and sociodemographic and pathways to care variables. The table shows that seven variables were associated with being referred via an 'Other' route. Black Caribbean patients (OR = 2.07; 95% CI 0.99 – 4.34) were twice more likely to be referred via 'Other' routes compared with White British. Compared to those unemployed, those in

employment were less likely to be referred by 'Other' sources (OR = 0.16; 95% CI 0.04 – 0.52).

In terms of housing tenure, those who lived in an 'Other' housing arrangement (e.g. hostel, refuge) were four times more likely (OR = 4.33; 95% CI 1.32 – 14.12) to be referred through an 'Other' route compared to those living in a privately owned home.

Furthermore, those contacting services via an 'Other' route were less likely to do so during out of office hours (OR = 0.09; 95%CI 0.03 – 0.27). Patients with insidious onset (OR = 2.35; 95% CI 1.12 – 4.92) were twice more likely to be referred via an 'Other' route and they were two times more likely to have used mental health services previously (OR = 2.41; 95% CI 1.41 – 4.10). Family involvement (OR = 0.48; 95% CI 0.26 – 0.88) was less common among patients referred through 'Other' routes.

There were no significant associations with the remaining variables in the table.

Table 8.8: Unadjusted odds ratios of 'Other' source of referral by socio-demographic and pathways to care variables at first contact

	'Other' source referred Yes n=490 (%)	**'Other source' referred No n=68 (%)**	**Unadjusted OR**	**95% confidence interval**	**P=value**
Gender					
Male	255 (87.3)	37 (12.7)	1		
Female	235 (88.4)	31 (11.6)	0.90	0.54 – 1.51	0.71
Age-band					
18-29	214 (88.4)	28 (11.6)	1.00		
30-64	276 (87.3)	40 (12.7)	1.10	0.66 – 1.85	0.69
Ethnicity	()	()			
White British	118 (88.7)	15 (11.3)	1.00		
Black African	131	16 (10.9)	0.96	0.45 – 2.02	0.91

	(89.1)				
Black Caribbean	72 (79.1)	19 (20.9)	**2.07**	**0.99 – 4.34**	**0.05**
White Other	66 (88.0)	9 (12.0)	1.07	0.44 – 2.58	0.87
Asian	41 (93.2)	3 (6.8)	0.57	0.15 – 2.09	0.40
Mixed	25 (92.6)	2 (7.4)	0.62	0.13 – 2.92	0.55
Other	37 (90.2)	4 (9.8)	0.85	0.26 – 2.72	0.78
GP Registered					
No	18 (85.7)	3 (14.3)	1.00		
Yes	472 (87.9)	65 (12.1)	0.82	0.23 – 2.88	0.76
Relationship status					
Single	290 (87.6)	41 (12.4)	1.00		
Married / Steady relationship	112 (88.2)	15 (11.8)	0.94	0.50 – 1.77	0.86
Divorced/Separated	65 (87.8)	9 (12.2)	0.97	0.45 – 2.11	0.95
Employment					
Unemployed	290 (83.8)	56 (16.2)	1		
Student	55 (91.5)	5 (8.3)	0.47	0.18 – 1.22	0.12
Employed	96 (97.0)	3 (3.0)	**0.16**	**0.04 – 0.52**	**0.003**
Education					
School, no GCSE	86 (86.9)	13 (13.1)	1.00		
School with GCSE	62 (84.9)	11 (15.1)	1.17	0.49 – 2.79	0.71
A level/ Further education	103 (90.3)	11 (9.7)	0.70	0.30 – 1.65	0.42
University	97 (89.8)	11 (10.2)	0.75	0.32 – 1.76	0.50
Lives with					
Alone	139 (86.3)	22 (13.7)	1.00		
Family/relatives	293 (90.2)	32 (9.8)	0.69	0.38 – 1.23	0.20
Other (Hostel/Refuge)	44 (80.)	11 (20.0)	1.57	0.71 – 3.51	0.26
Housing Tenure					
Privately owned	64 (94.1)	4 (5.9)	1.00		
Rented	198 (89.2)	24 (10.8)	1.93	0.64 – 5.79	0.23
Other	48 (78.7)	13 (21.3)	**4.33**	**1.32 – 14.12**	**0.01**
Place of birth					
Non- UK born	250 (88.7)	32 (11.3)	1.00		
UK born	214	29 (11.9)	1.05	0.62 – 1.80	0.83

	(88.1)				
Report of social isolation					
No	200 (89.7)	23 (10.3)	1.00		
Yes	222 (89.5)	26 (10.5)	1.01	0.56 – 1.84	0.95
Ever smoked cannabis					
No	186 (89.9)	21 (10.4)	1.00		
Yes	199 (86.9)	30 (13.1)	1.33	0.73 – 2.41	0.33
Time of FEP contact					
Office hours	299 (82.4)	64 (17.6)	1.00		
Out of hours	191 (97.9)	4 (2.1)	**0.09**	**0.03 – 0.27**	**<0.001**
DUP					
Short	355 (88.7)	45 (11.3)	1.00		
Long	135 (85.4)	23 (14.6)	1.34	0.78 – 2.30	0.28
Previous service use					
No	385 (90.4)	41 (9.6)	1.00		
Yes	105 (79.6)	27 (20.5)	**2.41**	**1.41 – 4.10**	**0.001**
Mode of onset					
Acute (within a week)	106 (91.4)	10 (8.6)	1.00		
Moderate (within a month)	103 (92.8)	8 (7.2)	0.82	0.31 – 2.16	0.69
Gradual (up to 6months)	110 (90.2)	12 (9.8)	1.15	0.47 – 2.78	0.74
Insidious (more than 6 months)	171 (81.8)	38 (18.2)	**2.35**	**1.12 – 4.92**	**0.02**
Family involvement					
No	309 (85.4)	53 (14.6)	1.00		
Yes	181	15 (7.6)	**0.48**	**0.26 – 0.88**	**0.01**

	(92.4)				
Early intervention service use					
No	291 (87.1)	43 (12.9)	1.00		
Yes	197 (88.7)	25 (11.3)	0.85	0.50 – 1.45	0.57

8.4 Adjusted Odds of admission (hospital and compulsory) and source of referral by ethnicity at first contact

Results from the unadjusted regression models above revealed that only three of the outcomes variables were associated with ethnicity, namely hospital admission, compulsory admission and 'Other' referral source. It is still important, however, to assess association of ethnicity with all pathways to care outcomes and therefore, all five outcomes and ethnicity were assessed further and entered into fully adjusted logistic regression analyses.

Adjusted logistic regression models were fitted for each of the outcome variables with ethnicity as predictor variable. Three logistic regression models were fitted, unadjusted and then adjusted for *a priori* confounders as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender

Model 3 – all variables in model 2, plus education level and employment status

Two further independent variables were adjusted for in the final model, namely duration of untreated psychosis and family involvement as they showed associations with the outcome variables under consideration. Therefore, a fourth logistic regression model was fitted as follows:

Model 4 – all variables in model 3, plus duration of untreated psychosis and family involvement

All analyses henceforth were carried out using complete case sample n = 367 (66% of whole sample) for whom data were complete for the main exposure variable, and each of the confounding variables (e.g. information on education level and employment status was not

available for 191 patients) were included in the regression model. This will allow comparison of associations across the models (i.e. unadjusted and adjusted).

8.4.1 Adjusted odds ratios for hospital admission by ethnicity at first contact

Table 8.9 shows the associations between ethnicity and hospital admission at first contact for psychosis. The results in this table show that three main ethnic groups (Black African, White Other and Mixed) showed consistent and strong associations with hospital admission throughout all the regression models. Interestingly, for the three groups, the effect sizes of association attenuated from the univariable analysis when age and gender were controlled for in model 2. Black African (OR = 2.31; 95% CI 1.27 – 4.21 to adj. OR = 2.24; 95% CI 1.23 – 4.11) White Other (OR = 2.03; 95% CI 1.01 – 4.08 to adj. OR = 1.96; 95% CI 0.97 – 3.97) and Mixed (OR = 2.71; 95% CI 1.02 – 7.41 to adj. OR = 2.64; 95% CI 0.99 – 7.00). However, these became stronger after adjusting for socioeconomic and pathways to care variables in models 3 and 4 (Table 8.9).

Table 8.9: Adjusted odds ratios of associations between hospital admission and ethnicity at first contact (n=367)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**2.31**	**1.27 -4.21 (<0.01)**	**2.24**	**1.23 -4.11 (<0.01)**	**2.27**	**1.23 -4.18 (<0.01)**	**2.38**	**1.27 -4.42 (<0.01)**
Black Caribbean	1.12	0.56 -2.27 (0.73)	1.14	0.56 -2.31 (0.71)	1.18	0.57 -2.42 (0.64)	1.20	0.57 -2.49 (0.62)
White Other	**2.03**	**1.01 -4.08 (0.04)**	**1.96**	**0.97 -3.97 (0.05)**	**2.02**	**0.99 -4.11 (0.05)**	**2.08**	**1.01 -4.27 (0.04)**
Asian	1.89	0.81 -4.43 (0.13)	1.97	0.83 -4.64 (0.12)	1.94	0.81 -4.61 (0.13)	2.10	0.86 -5.11 (0.10)
Mixed	**2.71**	**1.02 – 7.14 (0.04)**	**2.64**	**0.99 -7.00 (0.05)**	**2.71**	**1.02 -7.22 (0.04)**	**2.65**	**0.99 -7.09 (0.05)**
Other	0.61	0.31 -0.76 (<0.01)	0.54	0.19 -1.51 (0.24)	0.56	0.20 -1.59 (0.28)	0.58	0.20 -1.65 (0.31)

Model 1 – unadjusted; Model 2 – adjusted for age and gender; Model 3 – adjusted for age, gender, level of education, employment status; Model 4 – all variables in model 3 plus duration of untreated psychosis and family involvement

8.4.2 Adjusted odds ratios for compulsory admission by ethnicity at first contact

To begin with, a Mantel Haenzel test of homogeneity was carried out to test for effect modification for gender and the following results were observed: X^2= 4.29, df=1, p=0.03. With the Mantel Haenzel significant test result showing that association for men and women differs, stratified analyses by gender were necessary to further investigate differences in associations for compulsory admission and ethnicity by gender, whilst adjusting for the remaining *a priori* confounders.

8.4.3 Adjusted odds ratios for compulsory admission by ethnicity and gender at first contact

Table 8.10 shows the results for men and reveals that, in all four logistic regression models, only Black African men had strong association with compulsory admission. It is worth highlighting the change in effect sizes between models 2 (adj. OR = 2.54; 95% CI 1.02 – 6.29, p = 0.04) and 3 (adj. OR = 2.68; 95% CI 1.06 – 6.74, p = 0.03), which also held in model 4 (adj. OR = 3.25; 95% CI 1.24 – 8.52, p = 0.01). There were no further ethnic differences observed for compulsory admission compared with White British patients.

For women, the results were somewhat different. In Table 8.11, models 1–4 showed that women of 'Mixed', Asian and Black African ethnic groups were more likely to be compulsorily admitted at first contact for psychosis and these were independent of potential confounders. The wide confidence intervals in the adjusted and unadjusted models are noteworthy due to the smaller sample size for women.

Table 8.10: Adjusted odds ratios of associations between compulsory admission and ethnicity for men at first contact (n=191)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**2.55**	**1.03 -6.29 (0.04)**	**2.54**	**1.02 -6.29 (0.04)**	**2.68**	**1.06 -6.74 (0.03)**	**3.25**	**1.24 -8.52 (0.01)**
Black Caribbean	1.32	0.43 -4.06 (0.62)	1.32	0.42 -4.05 (0.62)	1.49	0.46 -4.79 (0.49)	1.65	0.50 -5.44 (0.40)
White Other	0.48	0.13 -1.71 (0.26)	0.48	0.13 -1.72 (0.26)	0.51	0.14 -1.85 (0.31)	0.54	0.15 -1.98 (0.35)
Asian	1.48	0.31 -6.69 (0.62)	1.45	0.31 -6.70 (0.62)	1.51	0.31 -7.25 (0.60)	1.44	0.30 -6.98 (0.64)
Mixed	1.27	0.28 -5.72 (0.75)	1.27	0.28 -5.72 (0.75)	1.28	0.28 -5.87 (0.75)	1.42	0.30 -6.55 (0.65)
Other	0.60	0.14 -2.47 (0.49)	0.60	0.14 -2.47 (0.48)	0.64	0.15 -2.71 (0.55)	0.70	0.16 -3.02 (0.63)

Model 1 – unadjusted; Model 2 – adjusted for age; Model 3 – adjusted for age, gender, level of education, employment status; Model 4 – all variables in model 3 plus duration of untreated psychosis and family involvement

Table 8.11: Adjusted odds ratios of associations between compulsory admission and ethnicity for women at first contact (n=176)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**

Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**4.05**	**1.31 -12.49 (0.01)**	**4.26**	**1.37 -13.29 (0.01)**	**3.84**	**1.21 -12.17 (0.02)**	**3.88**	**1.19 -12.57 (0.02)**
Black Caribbean	2.01	0.55 -7.29 (0.25)	2.03	0.56 -7.40 (0.27)	2.21	0.59 -8.25 (0.23)	2.43	0.62 -9.45 (0.20)
White Other	2.80	0.70 -11.04 (0.14)	2.82	0.71 -11.16 (0.14)	2.71	0.65 -11.20 (0.16)	2.72	0.64 -11.55 (0.17)
Asian	**3.87**	**1.01 -14.80 (0.04)**	**4.14**	**1.07 -16.05 (0.03)**	**3.96**	**1.00-15.56 (0.04)**	**4.18**	**1.02 -17.15 (0.04)**
Mixed	**8.40**	**1.71 -39.49 (<0.01)**	**8.76**	**1.84 -41.59 (<0.01)**	**10.01**	**2.02 -49.66 (<0.01)**	**8.36**	**1.67 – 41.85 0.01)**
Other	1.68	0.16 -17.41 (0.66)	1.81	0.17 -18.96 (0.61)	2.23	0.20 -24.92 (0.51)	2.10	0.18 -23-34 (0.54)

Model 1- unadjusted ; Model 2 – adjusted for age; Model 3- adjusted for age, gender, level of education, employment status; Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement

The relationships between compulsory admission and ethnicity for the overall sample are shown in Table 8.12, along with 95% confidence intervals (CI) for association with being compulsorily admitted.

The results from models 1 and 2 (Table 8.12) show that Black African and 'Mixed' ethnic group patients were more likely to be detained compared with White British. Meanwhile, a weak association was observed in the Asian group (adj. OR = 2.39; 95% CI 0.90 – 6.30). There were no associations between compulsory admission and Black Caribbean or any other ethnic groups.

After adjusting for socioeconomic factors in model 3, (Table 8.12), strong associations remained for Black African and 'Mixed' patients (adj. OR = 3.11; 95% CI 1.53 – 6.33 and adj. OR = 3.29; 95% CI 1.14 – 9.43 respectively). A weak association between compulsory admission and Asian ethnic group also remained (adj. OR = 2.35; 95% CI 0.88 – 6.28, p = 0.08). No associations were observed among the Black Caribbean or any other ethnic groups compared with White British patients.

In the final model where duration of untreated psychosis and family involvement in help-seeking were taken into account (Table 8.12), the strength of association with Black African, 'Mixed' and Asian ethnic groups remained relatively the same for compulsory admission.

Table 8.12: Adjusted odds ratios of associations between ethnicity and compulsory admission at first contact

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**3.11**	**1.55-6.23 (<0.01)**	**3.13**	**1.56 -6.37 (<0.01)**	**3.11**	**1.53 -6.33 (<0.01)**	**3.23**	**1.57 -6.63 (<0.01)**
Black Caribbean	1.53	0.66 -3.51 (0.31)	1.55	0.67 -3.57 (0.30)	1.72	0.73 -4.04 (0.20)	1.78	0.75 -4.24 (0.18)
White Other	1.06	0.42 -2.62 (0.89)	1.02	0.41 -2.55 (0.95)	1.06	0.42- 2.67 (0.88)	1.08	0.43 -2.73 (0.86)
Asian	2.28	0.87 -5.96 (0.09)	2.39	0.90 -6.30 (0.07)	2.35	0.88 -6.28 (0.08)	2.53	0.93 -6.87 (0.06)
Mixed	**3.11**	**1.10 -8.82 (0.03)**	**3.15**	**1.11 -8.96 (0.03)**	**3.29**	**1.14 -9.43 (0.02)**	**3.20**	**1.10 -9.26 (0.03)**
Other	0.92	0.27 -3.06 (0.89)	0.87	0.48 -1.30 (0.82)	0.94	0.27 -3.20 (0.92)	0.94	0.27 -3.25 (0.93)

Model 1- unadjusted ; Model 2 – adjusted for age; Model 3- adjusted for age, gender, level of education, employment status; Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement

8.4.4 Adjusted odds ratios for 'Other' referral by ethnicity at first contact

To begin with, there were no Asian patients referred by 'Other' source of referral, and therefore the number of patients included in this analysis was 338. In assessing the association of 'Other' source of referral and ethnicity, results from models 1–4 (Table 8.13) suggest that there were no ethnic differences in being referred to mental health services via 'Other' (i.e. healthcare professionals, nurse, doctor in non-mental health care setting).

Table 8.13: Adjusted odds ratios of associations between ethnicity and 'Other' referral at first contact (n=338)

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	0.78	0.31 -2.00 (0.61)	0.82	0.32 -2.10 (0.68)	0.76	0.29 -2.00 (0.58)	0.73	0.27 -1.92 (0.52)
Black Caribbean	1.98	0.80 -4.86 (0.13)	2.06	0.83 -5.10 (0.11)	1.85	0.73 -4.72 (0.19)	1.96	0.75 -5.07 (0.16)
White Other	0.94	0.32 -2.73 (0.92)	0.90	0.31 -2.64 (0.86)	0.90	0,30-2.69 (0.82)	0.89	0.29 -2.70 (0.84)
Asian	No cases	-	No cases	-	No cases	-	No cases	-
Mixed	0.75	0.15 -3.74 (0.74)	0.80	0.16 -3.96 (0.78)	0.78	0.15 -3.94 (0.76)	0.78	0.15 -3.96 (0.76)
Other	0.94	0.24 -3.68 (0.93)	0.88	0.22 -3.52 (0.30)	0.77	0.19 -3.15 (0.72)	0.73	0.17 -3.01 (0.67)

Model 1- unadjusted ; Model 2 – adjusted for age and gender; Model 3- adjusted for age, gender, level of education, employment status;

Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement

8.4.5 Adjusted odds ratios for GP referral by ethnicity at first contact

There were no differences in GP referral by ethnicity regardless of all potential confounders (see Table 8.14).

8.4.6 Adjusted odds ratios for A&E referral by ethnicity at first contact

There were no associations observed between A&E referral and ethnicity both in the unadjusted and adjusted regression models (see Table 8.15).

8.4.7 Adjusted odds ratios for Police/CJA referral by ethnicity at first contact

In investigating association of police/criminal justice agency referral and ethnicity, the results shown in Table 8.16 reveal that there was no association noted in the univariable or fully adjusted models.

Table 8.14: Adjusted odds ratios of associations between ethnicity and GP referral at first contact

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	0.60	0.32 -1.11 (0.11)	0.62	0.33 -1.16 (0.13)	0.66	0.35 -1.25 (0.21)	0.63	0.33 -1.19 (0.15)
Black Caribbean	0.58	0.28 -1.19 (0.14)	0.58	0.28 – 1.19 (0.13)	0.54	0.26 -1.14 (0.10)	0.54	0.35 -1.15 (0.11)
White Other	0.64	0.31 -1.33 (0.24)	0.65	0.31 -1.36 (0.25)	0.65	0.31 -1.36 (0.25)	0.63	0.29 -1.34 (0.23)
Asian	1.03	0.44 -2.40 (0.94)	1.03	0.43 -2.42 (0.94)	1.13	0.47 -2.73 (0.77)	1.06	0.43 -2.62 (0.89)
Mixed	0.72	0.26 -1.98 (0.53)	0.75	0.27 -2.06 (0.58)	0.72	0.26 -1.99 (0.53)	0.73	0.26 -2.03 (0.55)
Other	1.70	0.70 -4.09 (0.23)	1.82	0.74 -4.43 (0.18)	1.81	0.72 -4.50 (0.20)	1.74	0.68 -4.40 (0.24)

Model 1- unadjusted ; Model 2 – adjusted for age and gender; Model 3- adjusted for age, gender, level of education, employment status;

Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement

Table 8.15: Adjusted odds ratios of associations between ethnicity and A&E referral at first contact

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	1.62	0.89 -2.95 (0.11)	1.56	085 -2.85 (0.14)	1.50	0.81 -2.78 (0.19)	1.70	0.89 -3.26 (0.10)
Black Caribbean	1.16	0.58 -2.32 (0.62)	1.15	0.57 -2.33 (0.68)	1.29	0.62 -2.65 (0.48)	1.07	0.50 -2.30 (0.85)
White Other	1.31	0.64 -2.64 (0.45)	1.34	0.66 -2.74 (0.41)	1.41	0.68 -2.92 (0.35)	1.39	0.65 -2.99 (0.39)
Asian	2.07	0.88 -4.84 (0.09)	2.01	0.85 -4.73 (0.11)	1.97	0.82 -4.71 (0.34)	2.13	0.85 -5.33 (0.10)
Mixed	0.77	0.27 -2.19 (0.63)	0.73	0.25 -2.09 (0.56)	0.75	0.25 -2.09 (0.55)	0.75	0.24 -2.31 (0.62)
Other	0.71	0.27 -1.87 (0.49)	0.69	0.26 -1.86 (0.47)	0.77	0.28 -2.09 (0.61)	0.85	0.29 -2.46 (0.77)

Model 1- unadjusted ; Model 2 – adjusted for age and gender; Model 3- adjusted for age, gender, level of education, employment status;

Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement.

Table 8.16: Adjusted odds ratios of associations between police/CJA referral and ethnicity at first contact

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	1.18	0.51 -2.71 (0.69)	1.18	0.51 -2.71 (0.69)	1.19	0.50 -2.79 (0.68)	1.05	0.43 -2.57 (0.90)
Black Caribbean	0.94	0.34 -2.55 (0.90)	094	0.34 -2.55 (0.90)	0.94	0.34 -2.64 (0.92)	1.28	0.43 -3.77 (0.64)
White Other	1.37	0.53 -3.52 (0.50)	1.36	0.53 -3.50 (0.51)	1.28	0.49 -3.34 (0.32)	1.48	0.53 -3.99 (0.45)
Asian	0.48	0.10 -2.31 (0.36)	0.49	0.10 -2.35 (0.37)	0.45	0.94 -9.33 (0.06)	0.38	0.07 -1.99 (0.25)
Mixed	2.63	0.85 -8.10 (0.09)	2.63	0.85 -8.12 (0.09)	2.97	0.10 -2.51 (0.40)	2.45	0.73 -8.14 (0.14)
Other	0.54	0.11 -2.62 (0.45)	0.53	0.11 -2.60 (0.44)	0.51	0.51 -1.77 (0.88)	0.42	0.08 -2.20 (0.31)

Model 1- unadjusted ; Model 2 – adjusted for age and gender; Model 3- adjusted for age, gender, level of education, employment status;

Model 4- all variables in model 3 plus duration of untreated psychosis and family involvement

8.5 Summary

In relation to odds of compulsory admission, there was strong evidence that Black African and 'Mixed' ethnic groups were associated with increased risk of compulsory admission, independent of potential confounders. Stratification by gender revealed that only Black African men had increased risk of compulsory admission. However, the stratified analysis showed strong and independent associations between women of Black African, Asian and 'Mixed' ethnicity and the risk of being detained compulsorily. The evidence of the excess rate of compulsory admissions among the Black African ethnic group suggest that the risk is present in both men and women, which is in contrast to evidence for the other minority ethnic groups.

The odds ratios for hospital admission also indicated that compared with White British patients, Black African, White Other and 'Mixed' ethnic group patients were more likely to be admitted to hospital at first contact for psychosis. These findings were independent of all the potential confounders.

With regard to associations between source of referral and ethnicity, the key findings were that Black Caribbean individuals were more likely to follow alternative routes to care, but this evidence did not hold in the adjusted analyses.

There was no evidence of associations between any other source of referral (i.e. criminal justice agency, A&E or GP) and ethnicity.

In conclusion, the results in this chapter partly support the hypotheses that pathways to care are problematic for the Black African patients in the domains of hospital admission and compulsory admission at first contact for psychosis. However, the results here did not support the same hypothesis for the Black Caribbean ethnic group, with the evidence suggesting that there were no differences in pathways to care compared with the White British ethnic group. Overall, the evidence showed that there were no differences in source of referrals (GP, criminal justice agency or A&E) between Black African, Black Caribbean and White British patients. Detailed discussion of possible explanations for these findings will be discussed in Chapter 12.

8.6 Limitations

This phase of the study used cross-sectional sociodemographic and pathways to care data and the design does not allow causality conclusion of the relationships between ethnicity, compulsory admission and source of referrals. In addition to the limitations highlighted in Chapter 7, two important methodological shortcomings are also noteworthy in interpreting the results in this chapter.

Classification of variables

First, epidemiological studies often use crude dichotomies e.g. employed versus unemployed to explore relationships between exposure and outcome. This means that "the precise meaning of observed associations is unclear, and the social experiences that these variables may index remain unknown" (Morgan et al., 2008). This is true in this chapter with dichotomies such as police/CJA referral, which involved collapsing down referrals via the police and criminal justice systems into a single variable. This could potentially result in the inability to discern which of the variables are salient to the findings. However, given the small number of patients that were referred via these routes, separating them may produce a less meaningful result. Therefore, based on previous studies (Morgan et al., 2005, Ghali et al., 2012) referrals via police and CJA were collapsed into one as they are considered to involve some element of coercion (Morgan et al., 2005).

Missing data

Second, the issue of missing values. While this thesis is reasonably well-powered, the lack of complete data on some of the covariates is an important limitation to be acknowledged. As highlighted in Chapter 3, (section 3.5) it is important to adjust for the known confounders in order to assess differential effect of pathways to care and between ethnic groups. This study attempted to achieve this by controlling for a range of confounders such as socioeconomic status, demographic and clinical characteristics. However, the socioeconomic variables suffered significant missing values, particularly 'educational qualification', which meant a loss of statistical power. To this end, a two-stage regression analysis was employed to estimate crude odds ratios, (a) on the whole sample (n=558) and (b) on the people for whom complete data was available (n=367). This helped in assessing the impact missing data may or may not have on the observed associations. There were no notable differences

in the odds ratio estimates between analysis (a) and (b), particularly for associations between compulsory admission and ethnicity.

9 Chapter 9: Results of the Impact of Early Intervention Services on Pathways to Care for Minority Ethnic Groups during First Episode Psychosis: comparing data from the AESOP and present (CRIS-FEP) studies

9.1 Synopsis

In Chapter 8, relationships between ethnicity and hospital admission, compulsory admission and source of referrals were presented and discussed using full samples from the study for this thesis. The findings suggest that there were ethnic differences in relation to hospital admissions and compulsory admission but somewhat weaker associations with source of referral. This chapter builds on the work in Chapter 8 and examines the question: Are there any differences in pathways to care for FEP cases compared to 15 years ago and did the introduction of early intervention service (EIS) explain the difference?? The chapter addresses the following aim and hypothesis:

> 1. To estimate and compare pathways to care (compulsory vs. non-compulsory) and source of referral (general practitioner (GP), accident and emergency (A&E) and criminal justice agency (CJA)) at first contact for psychosis by ethnic groups in the AESOP sample and those using early intervention services or not in the current study sample.

Hypothesis

> Compared with 15 years ago (i.e. AESOP vs. CRIS-FEP samples), among patients aged 18–35 years old ethnic differences in GP referral and crisis source of referral (criminal justice agency, accident and emergency) and compulsory admission at first contact for psychosis will be smaller for Black African and Black Caribbean patients.

To begin with, a sample from the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ASEOP) study was used as baseline for comparison with the current study. As

mentioned in Chapter 7, the AESOP study was completed over a decade ago, before the introduction of early intervention services in SLaM, and so it provides a good template against which to test differences and changes in compulsory admission, pathways to care and help-seeking behaviours among people with FEP since the introduction of EIS.

At the time of the study for this thesis (CRIS-FEP), the eligibility criteria for early intervention services (EIS) in SLaM were that the patient be 18–35 years old. Therefore, data from the CRIS-FEP and the AESOP studies for this chapter were restricted to patients aged 18–35 years. In addition, ethnic groups White British, Black African, Black Caribbean and White Other have been reported to experience more problematic pathways to care. To that end, for the purpose of analysis, data from both CRIS-FEP and AESOP studies were restricted to the aforementioned ethnic groups. This enabled direct comparisons between the two study samples.

9.2 Analysis

A secondary analysis on the AESOP (London site) data was performed to compare results with the CRIS-FEP study stratified by EIS use status. First, unadjusted logistic regression analyses are presented assessing the crude associations between sociodemographic and pathways to care variables and each source of referral outcome variables (i.e. GP, police or criminal justice agency and emergency referrals) and compulsory admission. Second, multivariable logistic regression models are presented assessing associations between the main exposure variable (ethnicity) and each outcome variable, using White British as the reference ethnic group. In the multivariable regression model, I began by adjusting for *a priori* potential confounders (age, gender, education level and employment status) to control for demographic and socioeconomic status. Subsequently, other variables (covariates) that were crudely associated with the outcome variables from the unadjusted analyses were added to the model; covariates were included if the p-value was ≤0.05. Complete data were used in the multivariable analyses, i.e. only patients who had complete data for all the covariates were included (i.e. 201 for CRIS-FEP sample and 183 for the AESOP sample).

9.3 Results

9.3.1 Sample characteristics

A total of 278 first episode psychosis patients at the London site were included in the AESOP study, of whom 193 were aged 18–35 years and so were included for the current analysis. From the CRIS-FEP study, a total of 558 first episode patients were identified, of whom 265 were 18–35 years and thus would have been eligible for EIS services. Of these, 184 received EIS and 81 patients were eligible for EIS care but did not receive it (non-EIS).

Table 9.1 shows the demographic and pathways to care variables for AESOP and CRIS-FEP, with the latter reflecting whether or not the patient received care from a specialist EIS team. Compared to AESOP, the Black Caribbean ethnic group comprises a smaller, and the Black African group a larger fraction of the total sample, and there was a somewhat greater proportion of people with higher or university level education. The proportion of patients accessing services via police and criminal justice agencies was also substantially lower than observed in AESOP. Further, the prevalence of compulsory admission was lower in the CRIS-FEP sample compared with the AESOP sample. More differences emerge when the CRIS-FEP sample was broken down by whether or not they received EIS services. It is apparent that the patients who were seen by EIS were somewhat younger, more likely to be male, educated to university level, live with family and to have family involvement in their pathway to care than either patients in AESOP or those who were eligible for EIS but did not receive it (non-EIS). Interestingly, a greater proportion of those compulsorily detained in the CRIS-FEP were in the EIS group.

Table 9.1: Demographic and pathways to care characteristics of AESOP and CRIS –FEP samples

	AESOP	CRIS-FEP		
	AESOP N=193 (%)	Whole sample N =265 (%)	Non-EIS N=81 (%)	EIS N= 184 (%)
DEMOGRAPIC VARIABLES				
Mean age (sd)years	26.7 (4.9)	26.2 (5.1)	27.5 (5.0)	25.5 (5.1)
Gender				
Men	110 (57.0)	154 (58.1)	38 (46.9)	116 (63.0)
Women	83 (43.0)	111 (41.9)	43 (53.1)	68 (37.0)
Ethnicity				
White British	60 (31.1)	78 (29.4)	23 (28.4)	55 (29.9)
Black African	50 (25.9)	95 (35.9)	25 (30.9)	70 (38.1)
Black Caribbean	65 (33.7)	52 (19.6)	17 (21.0)	35 (19.0)
White Other	18 (9.3)	40 (15.1)	16 (19.7)	24 (13.0)
Education[1]				
School, no GCSE	51 (27.6)	50 (24.0)	23 (35.4)	27 (18.9)
School, GCSE	46 (24.8)	39 (18.7)	11 (16.9)	28 (19.6)
Further	57 (30.8)	60 (28.9)	15 (23.1)	45 (31.4)
Higher / University	31 (16.8)	59 (28.4)	16 (24.6)	43 (30.1)
Employment[2]				
Unemployed	112 (59.0)	157 (63.0)	56 (73.7)	101 (58.4)
Student/Other	24 (12.6)	46 (18.5)	7 (9.2)	39 (22.5)
Employed	54 (28.4)	46 (18.5)	13 (17.1)	33 (19.1)
Relationship status[3]				
Single	124 (70.1)	178 (69.8)	55 (71.4)	123 (69.1)
Married/in steady relationship	42 (23.7)	58 (22.7)	17 (22.1)	41 (23.0)
Divorced/ widowed	11 (6.2)	19 (7.5)	5 (6.5)	14 (7.9)
Living arrangements[4]				

Alone	86 (45.0)	59 (22.7)	25 (31.6)	34 (18.8)
Family/ relatives	90 (47.1)	168 (64.6)	42 (53.2)	126 (69.6)
Other	15 (7.9)	33 (12.7)	12 (15.2)	21 (11.6)
PATHWAYS TO CARE VARIABLES				
DUP[5]				
Short (≤ 1year)	157 (81.4)	190 (71.7)	61 (75.3)	129 (70.1)
Long (> 1year)	36 (18.6)	75 (28.3)	20 (24.7)	55 (29.9)
Family involvement in help-seeking[6]				
Yes	65 (35.5)	154 (58.1)	25 (30.9)	86 (46.7)
No	118 (64.5)	111 (41.9)	56 (69.1)	93 (53.3)
GP referral [7]				
No	129 (67.2)	184 (69.4)	59 (72.8)	125 (67.9)
Yes	63 (32.8)	81 (30.6)	22 (27.2)	59 (32.1)
Emergency referral[8]				
No	127 (66.1)	154 (58.1)	46 (56.8)	108 (58.7)
Yes	65 (33.9)	111 (41.9)	35 (43.2)	76 (41.3)
Police/CJA referral[9]				
No	141 (73.4)	227 (85.7.1)	71 (87.7)	156 (84.8)
Yes	51 (26.6)	38 (14.3)	10 (12.3)	28 (15.2)
Compulsory admission				
No	110 (57.0)	197 (74.3)	63 (77.8)	134 (72.8)
Yes	83 (43.0)	68 (25.7)	18 (22.2)	50 (27.2)

Missing data

1 AESOP, 8; CRIS –FEP, 57 (EIS= 41; non-EIS= 16)

2 AESOP, 3; CRIS –FEP, 16 (EIS= 11; non-EIS= 5)

3 AESOP, 16; CRIS –FEP, 10 (EIS= 6; non-EIS= 4)

4 AESOP, 2; CRIS –FEP, 5 (EIS= 3; non-EIS= 2)

6 AESOP, 10; CRIS –FEP, none

7-9 AESOP, 1; CRIS –FEP, none

In the next stage of the analyses, first the prevalence of each outcome variable (compulsory admission, GP, emergency and criminal justice referral) by sociodemographic and pathways to care characteristics was estimated. Second, univariable logistic regression was used to assess crude associations between sociodemographic and pathways to care characteristics and each outcome variable on the AESOP and CRIS-FEP samples; the latter was stratified by EIS status.

9.3.2 Unadjusted associations between sociodemographic/pathways to care variables and GP referral by use of EIS

Table 9.2 shows relationships between sociodemographic and pathways to care characteristics and GP referral. It can be seen from this table that there was notable evidence in the AESOP sample that Black African (OR = 0.29; 95% CI 0.12 – 0.70) and Black Caribbean (OR = 0.45; 95% CI 0.21 – 0.95) patients were less likely to be referred to mental health services by their GP. There was weak evidence that those employed and students in the AESOP sample were more likely to be referred by their GP. In the non-EIS group of the CRIS-FEP sample, there was weak evidence that patients of Black African (OR = 0.32; 95% CI 0.09 – 1.16) ethnic group were less likely to be referred by GP but the evidence was stronger for the Black Caribbean group (OR = 0.17; 95% CI 0.03 – 0.93). There was no evidence of association between sociodemographic variables and GP referral in the EIS group, although those with longer duration of untreated psychosis were twice more likely to be referred by GP.

Table 9.2: Unadjusted odds ratios of associations between sociodemographic/pathways to care variables and GP referral by use of EIS

	AESOP N=193			CRIS-FEP STUDY: Non- EIS group N= 81			CRIS-FEP STUDY: EIS group N= 184		
DEMOGRAPIC VARIABLES	GP referral (No) n=129 (%)	GP referral (Yes) n=53 (%)	OR (95% CI)	GP referral (No) n=59 (%)	GP referral (Yes) n=22 (%)	OR (95% CI)	GP referral (No) n=125 (%)	GP referral (Yes) n=59 (%)	OR (95% CI)
Age (sd) years	27.1 (4.8)	26.0 (4.9)	0.95 (0.89-1.01)	28.0 (5.1)	25.9 (4.5)	*0.91 (0.82-1.00)*~	25.5 (5.0)	25.8 (5.0)	1.01 (0.95 – 1.07)
Gender									
Men	74 (67.9)	35 (32.1)	1	28 (73.7)	10 (26.3)	1	80 (69.0)	36 (31.0)	1
Women	55 (66.3)	28 (33.7)	1.07 (0.58 – 1.97)	31 (72.1)	12 (27.9)	1.08 (0.40-2.89)	45 (66.2)	23 (33.8)	1.13 (0.60-2.14)
Ethnicity									
White British	32 (54.2)	27 (45.8)	1	13 (56.5)	10 (43.5)	1	35 (63.6)	20 (36.4)	1
Black African	40 (80.0)	10 (20.0)	**0.29 (0.12-0.70) †**	20 (80.0)	5 (20.0)	*0.32 (0.09-1.16)*~	53 (75.7)	17 (24.3)	0.56 (0.25-1.21)
Black Caribbean	47 (72.3)	18 (27.7)	**0.45 (0.21-0.95)***	15 (88.2)	2 (11.8)	**0.17 (0.03-0.93)***	24 (68.6)	11 (31.4)	0.80 (0.32-1.97)
White Other	10 (55.6)	8 (44.4)	0.94 (0.32-2.74)	11 (68.7)	5 (31.3)	0.59 (0.15-2.25)	13 (54.2)	11 (45.8)	1.48 (0.55-3.91)
Education[1]									
School, no GCSE	33 (66.0)	17 (34.0)	1	16 (69.6)	7 (30.4)	1	15 (55.6)	12 (44.4)	1
School, GCSE	32 (69.6)	14 (30.4)	0.84 (0.35-2.00)	8 (72.7)	3 (27.3)	0.85 (0.17-4.23)	19 (67.9)	9 (32.1)	0.59 (0.19-1.77)
Further	40 (70.2)	17 (29.8)	0.85 (0.36-1.86)	10 (66.7)	5 (33.3)	1.14 (0.28-4.60)	32 (71.1)	13 (28.9)	0.50 (0.18-1.37)
Higher / University	19 (61.3)	12 (38.7)	1.22 (0.48-3.10)	12 (75.0)	4 (25.0)	0.76 (0.18-3.21)	32 (74.4)	11 (25.6)	0.42 (0.15-1.19)

Employment[2]									
Unemployed	81 (73.0)	30 (27.0)	1	39 (69.6)	17 (30.4)	1	66 (65.3)	35 (34.7)	1
Student/Other	13 (54.2)	11 (45.8)	*1.85 (0.93-3.68)~*	6 (85.7)	1 (14.3)	0.38 (0.04-3.42)	30 (76.9)	9 (23.1)	0.56 (0.24-1.32)
Employed	32 (59.3)	22 (40.7)	*2.28 (0.92-5.65)~*	10 (76.9)	3 (23.1)	0.68 (0.16-2.81)	21 (63.6)	12 (36.4)	1.07 (0.47-2.44)
Relationship status[3]									
Single	83 (67.5)	40 (32.5)	1	38 (69.1)	17 (30.9)	1	87 (70.7)	36 (29.3)	1
In steady relationship	28 (66.7)	14 (33.3)	1.03 (0.49-2.18)	14 (82.3)	3 (17.7)	0.47 (0.12-1.88)	25 (61.0)	16 (39.0)	1.54 (0.73-3.23)
Divorced/ widowed	9 (81.8)	2 (18.2)	0.46 (0.09-2.23)	4 (80.0)	1 (20.0)	0.55 (0.05-5.38)	8 (57.1)	6 (42.9)	1.81 (0.58-5.59)
Living arrangements[4]									
Alone	63 (73.3)	23 (26.7)	1	18 (72.0)	7 (28.0)	1	23 (67.7)	11 (32.3)	1
Family/ relatives	50 (56.2)	39 (43.8)	2.13 (1.13-4.03)	29 (69.0)	13 (31.0)	1.15 (0.38-3.43)	82 (65.1)	44 (34.9)	1.12 (0.50-2.51)
Other	14 (93.3)	1 (6.7)	0.19 (0.02-1.57)	10 (83.3)	2 (16.7)	0.51 (0.08-2.96)	18 (85.7)	3 (14.3)	0.34 (0.08-1.43)
PATHWAYS TO CARE VARIABLES									
DUP									
Short (≤ 1year)	105 (67.3)	51 (32.7)	1	42 (68.8)	19 (31.2)	1	96 (74.4)	33 (25.6)	1
Long (> 1year)	24 (66.7)	12 (33.3)	1.02 (0.47-2.22)	17 (85.0)	3 (15.0)	0.39 (0.10-1.49)	29 (52.7)	26 (47.3)	**2.60 (1.34-5.05) †**
Family involvement in help-seeking[5]									

No	87 (73.7)	31 (26.3)	1	38 (67.9)	18 (32.1)	1	64 (65.3)	34 (34.7)	1
Yes	42 (65.6)	22 (34.4)	1.47 (0.76 -2.84)	21 (84.0)	4 (16.0)	0.40 (0.12 -1.34)	61 (70.9)	25 (29.1)	0.77 (0.41 -1.44)

~P=0.1; *p≤0.05; †p≤0.01

9.3.3 Unadjusted associations between sociodemographic/pathways to care variables and accident and emergency referral by use of EIS

Table 9.3 shows associations between sociodemographic, pathways to care variables and accident and emergency referral. There was strong evidence that those who had family involvement in their pathways to care were more likely to seek help via the A&E department; this was notable in both the AESOP (25.4%, OR = 3.64; 95% CI 1.91 – 6.91, p<0.01) and CRIS-FEP (non-EIS 32.1%, OR = 4.48; 95% CI 1.63 – 12.32, p<0.04 and EIS 23.5%, OR = 5.23; 95% CI 2.72 – 9.91, p<0.01) samples. This suggests that family play a crucial role in help-seeking, particularly during an acute onset of psychosis when help may be required urgently. There was no evidence of associations between other independent variables and A&E referral in the AESOP sample. In the non-EIS group, Black Caribbean patients were four times more likely to come into contact with mental health services via emergency route (58.8%, OR = 4.04; 95% CI 1.05 – 15.47, p = 0.04). In the EIS group, compared with those educated to university level, patients without school qualifications were less likely to access services via the accident and emergency route (OR = 0.29; 95% CI 0.10 – 0.88, p = 0.03).

Table 9.3: Unadjusted odds ratios of associations between sociodemographic/pathways to care variables and A&E referral by use of EIS

	AESOP N=193			CRIS-FEP STUDY: Non- EIS group N= 81			CRIS-FEP STUDY: EIS group N= 184		
DEMOGRAPIC VARIABLES	A&E referral (No) n=127 (%)	A&E referral (Yes) n=65 (%)	OR (95% CI)	A&E referral (No) n=46 (%)	A&E referral (Yes) n= 35 (%)	OR (95% CI)	A&E referral (No) n=108 (%)	A&E referral (Yes) n=76 (%)	OR (95% CI)
Age (sd)	27.0 (4.9)	26.1 (4.8)	0.96 (0.90-1.02)	28.1 (4.8)	26.8 (5.6)	0.95 (0.87-1.04)	25.6 (4.9)	25.4 (5.2)	0.99 (0.93-1.05)
Gender									
Men	73 (67.0)	36 (33.0)	1	25 (65.8)	13 (34.2)	1	68 (58.6)	48 (41.4)	1
Women	54 (65.1)	29 (34.9)	1.08 (0.59-1.98)	21 (48.8)	22 (51.2)	2.01 (0.82-4.94)	40 (58.8)	28 (41.2)	0.99 (0.53-1.82)
Ethnicity									
White British	37 (62.7)	22 (37.3)	1	17 (73.9)	6 (26.1)	1	35 (63.6)	20 (36.4)	1
Black African	31 (62.0)	19 (38.0)	1.03 (0.47-2.24)	14 (56.0)	11 (44.0)	2.22 (0.65-7.54)	37 (52.9)	33 (47.1)	1.56 (0.75-3.21)
Black Caribbean	47 (72.3)	18 (27.7)	0.64 (0.30-1.37)	7 (41.2)	10 (58.8)	**4.04 (1.05-15.47)***	22 (62.9)	13 (37.1)	1.03 (0.42-2.48)
White Other	12 (66.7)	6 (33.3)	0.84 (0.27-2.55)	8 (50.0)	8 (50.0)	2.83 (0.76-10.94)	14 (58.3)	10 (41.7)	1.25 (0.46-3.30)
Education[1]									
School, no GCSE	36 (72.0)	14 (28.0)	1	12 (52.2)	11 (47.8)	1	21 (77.8)	6 (22.2)	1
School, GCSE	28 (60.9)	18 (39.1)	1.65 (0.70-3.88)	6 (54.6)	4 (45.4)	0.90 (0.21-3.84)	17 (60.7)	11 (39.3)	2.26 (0.69-7.38)
Further	36 (63.2)	21 (36.8)	1.50 (0.66-3.40)	10 (66.7)	5 (33.3)	0.54 (0.14-2.10)	23 (51.1)	22 (48.9)	**3.34 (1.13-9.85)***

Higher / University	24 (77.4)	7 (22.6)	0.75 (0.26-2.13)	9 (56.2)	7 (43.8)	0.84 (0.23-3.05)	22 (51.2)	21 (48.8)	**3.34 (1.12-9.90)***
Employment[2]									
Unemployed	75 (67.6)	36 (32.4)	1	34 (60.7)	22 (39.3)	1	66 (65.4)	35 (34.6)	1
Student/Other	17 (70.8)	7 (29.2)	0.85 (0.32-2.25)	2 (28.6)	5 (71.4)	3.86 (0.68-21.69)	19 (48.7)	20 (51.3)	*1.98 (0.94-4.20)~*
Employed	33 (61.1)	21 (38.9)	1.32 (0.67-2.60)	6 (46.1)	7 (53.9)	1.80 (0.53-6.07)	16 (48.5)	17 (51.5)	*2.00 (0.90-4.44)~*
Relationship status[3]									
Single	85 (69.1)	38 (30.9)	1	30 (54.6)	25 (45.4)	1	70 (56.9)	53 (43.1)	1
In steady relationship	26 (61.9)	16 (38.1)	1.37 (0.66-2.85)	9 (52.9)	8 (47.1)	1.06 (0.35-3.17)	23 (56.1)	18 (43.9)	1.03 (0.50-2.10)
Divorced/ widowed	6 (54.6)	5 (45.4)	1.86 (0.53-6.48)	4 (80.0)	1 (20.0)	0.30 (0.03-2.85)	10 (71.4)	4 (28.6)	0.52 (0.15-1.77)
Living arrangements[4]									
Alone	60 (69.8)	26 (30.2)	1	17 (68.0)	8 (32.0)	1	24 (70.6)	10 (29.4)	1
Family/ relatives	58 (60.2)	31 (34.8)	1.23 (0.65-2.32)	21 (50.0)	21 (50.0)	2.15 (0.75-5.98)	70 (55.6)	56 (44.4)	1.92 (0.84-4.34)
Other	8 (53.3)	7 (46.7)	2.01 (0.66-6.15)	7 (58.3)	5 (41.7)	1.51 (0.36-6.29)	13 (61.9)	8 (38.1)	1.47 (0.46-4.65)
PATHWAYS TO CARE VARIABLES									
DUP[5]									
Short (≤ 1year)	101 (64.7)	55 (35.3)	1	36 (59.0)	25 (41.0)	1	71 (55.0)	58 (45.0)	1
Long (> 1year)	26 (72.2)	10 (27.8)	0.70 (0.31-1.57)	10 (50.0)	10 (50.0)	1.44 (0.55-3.97)	37 (67.3)	18 (32.7)	0.59 (0.30-1.15)
Family									

involvement in help-seeking[6]									
No	88 (74.6)	30 (25.4)	**1**	38 (67.9)	18 (32.1)	**1**	75 (76.5)	23 (23.5)	**1**
Yes	29 (45.3)	35 (54.7)	**3.64 (1.91 -6.91) †**	8 (32.0)	17 (68.0)	**4.48 (1.63 -12.32) †**	33 (38.4)	53 (61.6)	**5.23 (2.76 -9.91) †**

~P=0.1; *p≤0.05; †p≤0.01

A&E, accident and emergency

9.3.4 Unadjusted associations between sociodemographic/pathways to care variables and CJA referral by use of EIS

Table 9.4 displays the relationship between sociodemographic and pathways to care variables and criminal justice agency referral. In the AESOP sample, three independent variables, namely mean age (28 years old, OR = 1.11; 95% CI 1.03 – 1.19, p<0.01), ethnicity (Black African: 34%, OR = 4.55; 95% CI 1.62 – 12.71 and Black Caribbean: 38.5%, OR = 5.52; 95% CI 2.06 – 14.72, p<0.01) were strongly associated with CJA referral. As would be expected, those who had family involvement in their help-seeking were less likely to be referred by the criminal justice agency (35.5%, OR = 0.20; 95% CI 0.08 – 0.49, p<0.01). This was echoed in the EIS group showing that having family involvement was associated with reduced likelihood of criminal justice agency referral (58.1%, OR = 0.15; 95% CI 0.04 – 0.45, p<0.01). There was weak evidence suggestive of some associations between relationships status, DUP, family involvement and CJA referral in the EIS sample. By contrast, only age was weakly associated with CJA referral in the non-EIS group.

Table 9.4: Unadjusted odds ratios of associations between sociodemographic/pathways to care variables and CJA referral by use of EIS

	AESOP N=193			CRIS-FEP STUDY: Non- EIS group N= 81			CRIS-FEP STUDY: EIS group N= 184		
DEMOGRAPIC VARIABLES	CJA referral (No) n=131 (%)	CJA referral (Yes) n=51 (%)	OR (95% CI)	CJA referral (No) n=71 (%)	CJA referral (Yes) n= 10 (%)	OR (95% CI)	CJA referral (No) n=156 (%)	CJA referral (Yes) n=28 (%)	OR (95% CI)
Age (sd) years	26.08 (4.9)	28 (4.3)	**1.11 (1.03-1.19) †**	27.2 (5.0)	30.2 (4.4)	*1.14 (0.9-1.35)~*	25.5 (5.1)	25.6 (4.8)	1.00 (0.92-1.08)
Gender									
Men	77 (70.6)	32 (29.4)	1	32 (84.2)	6 (15.8)	1	98 (84.5)	18 (15.5)	1
Women	64 (77.1)	19 (22.9)	0.71 (0.37-1.37)	39 (90.7)	4 (9.3)	0.54 (0.14-2.10)	58 (85.3)	10 (14.7)	0.93 (0.40-2.17)
Ethnicity									
White British	53 (89.8)	6 (10.2)	1	19 (82.6)	4 (17.4)	1	47 (85.5)	8 (14.5)	1
Black African	33 (66.0)	17 (34.0)	**4.55 (1.62-12.71) †**	22 (88.0)	3 (12.0)	0.64 (0.12-3.26)	57 (81.4)	13 (18.6)	1.33 (0.51-3.50)
Black Caribbean	40 (61.5)	25 (38.5)	**5.52 (2.06-14.72) †**	15 (88.2)	2 (11.8)	0.63 (0.10-3.93)	30 (85.7)	5 (14.3)	0.97 (0.29-3.27)
White Other	15 (83.3)	3 (16.7)	1.76 (0.39-7.91)	15 (93.8)	1 (6.2)	0.31 (0.03-3.13)	22 (91.7)	2 (8.3)	0.53 (0.10-2.72)
Education[1]									
School, no GCSE	36 (72.0)	14 (28.0)	1	20 (87.0)	3 (13.0)	1	21 (77.8)	6 (22.2)	1
School, GCSE	34 (73.9)	12 (26.1)	0.90 (0.36-2.23)	10 (90.9)	1 (9.1)	0.66 (0.06-7.25)	24 (85.7)	4 (14.3)	0.58 (0.14-2.35)
Further	42 (73.9)	15 (26.3)	0.91 (0.39-2.15)	14 (93.3)	1 (6.7)	047 (0.04-5.06)	40 (88.9)	5 (11.1)	0.43 (0.11-1.60)

Higher / University	21 (67.7)	10 (32.3)	1.22 (0.46-3.24)	14 (87.5)	2 (12.5)	0.95 (0.14-6.46)	35 (81.4)	8 (18.6)	0.79 (0.24-2.62)
Employment[2]									
Unemployed	76 (68.5)	35 (31.5)	1	50 (89.3)	6 (10.7)	1	85 (84.2)	16 (15.8)	1
Student/Other	20 (83.3)	4 (16.7)	0.55 (0.25-1.20)	7 (100)	0	No cases	32 (82.0)	7 (18.0)	1.16 (0.43-3.06)
Employed	43 (79.6)	11 (20.4)	0.43 (0.13-1.36)	12 (92.3)	1 (7.7)	0.69 (0.07-6.32)	30 (90.9)	3 (9.1)	0.53 (0.14-1.95)
Relationship status[3]									
Single	87 (70.7)	36 (29.3)	1	48 (87.3)	7 (12.7)	1	102 (82.9)	21 (17.1)	1
In steady relationship	33 (78.6)	9 (21.4)	0.65 (0.28-1.51)	15 (88.2)	2 (11.8)	0.91 (0.17-4.88)	39 (95.1)	2 (4.9)	*0.24 (0.05-1.11)*~
Divorced/ widowed	7 (63.6)	4 (36.4)	1.38 (0.38-5.00)	5 (100)	0	No cases	11 (78.6)	3 (21.4)	1.32 (0.33-5.16)
Living arrangements[4]									
Alone	59 (68.6)	27 (31.4)	1	20 (80.0)	5 (20.0)	1	27 (79.4)	7 (20.6)	1
Family/ relatives	72 (80.9)	17 (19.1)	*0.51 (0.25-1.03)*~	39 (92.9)	3 (7.1)	0.30 (0.06-1.42)	113 (89.7)	13 (10.3)	0.44 (0.16-121)
Other	9 (60.0)	6 (40.0)	1.43 (0.47-4.50)	10 (83.3)	2 (16.7)	0.80 (0.13-4.87)	13 (61.9)	8 (38.1)	2.37 (0.70-7.96)
PATHWAYS TO CARE VARIABLES									
DUP[5]									
Short (≤ 1year)	115 (73.7)	41 (26.3)	1	53 (86.9)	8 (13.1)	1	105 (81.4)	24 (18.6)	1
Long (> 1year)	26 (72.2)	10 (27.8)	1.07 (0.74-2.42)	18 (90.0)	2 (10.0)	0.73 (0.14-3.79)	51 (92.7)	4 (7.3)	*0.34 (0.11-1.04)*~
Family									

involvement in help-seeking[6]									
No	74 (62.7)	44 (37.3)	**1**	47 (83.9)	9 (16.1)	1	74 (75.5)	24 (24.5)	1
Yes	57 (89.1)	7 (10.9)	**0.20 (0.08 -0.49) †**	24 (96.0)	1 (4.0)	0.21 (0.02 -1.81)	82 (95.3)	4 (4.7)	**0.15 (0.49 -0.45) †**

~P=0.1; *p≤0.05; †p≤0.01

9.3.5 Unadjusted associations between sociodemographic/pathways to care variables and compulsory admission by use of EIS

Finally, the crude associations between sociodemographic and pathways to care variables and compulsory admission at first contact for psychosis are presented in Table 9.5. The AESOP sample shows that there were strong associations between compulsory admission and Black African and Black Caribbean ethnic groups. The evidence suggests that both groups were five and four times (respectively) more likely to be compulsorily detained. Being older was also associated with increased odds of compulsory admission in both the AESOP and non-EIS samples. By contrast, among those who received EIS, Black African patients were twice more likely to be detained, whereas longer DUP was associated with less likelihood of compulsory admission. This suggests perhaps an acute onset of psychosis increases the odds of compulsory detention.

Table 9.5: Unadjusted odds ratios of associations between sociodemographic/pathways to care variables and compulsory admission by use of EIS

	AESOP N=193			CRIS-FEP STUDY: Non- EIS group N= 81			CRIS-FEP STUDY: EIS group N= 184		
DEMOGRAPIC VARIABLES	Non-Compulsory admission n= (%)	Compulsory admission n= (%)	OR (95% CI)	Non-Compulsory admission n= (%)	Compulsory admission n= (%)	OR (95% CI)	Non-Compulsory admission n= (%)	Compulsory admission n= (%)	OR (95% CI)
Age (sd) years	26.1 (4.9)	27.5 (4.8)	**1.06 (1.00 -1.12)***	26.9 (5.0)	29.8 (4.5)	**1.13 (1.00 - 1.28)***	25.5 (2.5)	25.8 (5.5)	1.01 (0.94 -1.07)
Gender									
Men	67 (60.9)	43 (39.1)	1	28 (73.7)	10 (26.3)	1	81(69.8)	35 (30.2)	1
Women	43 (51.8)	40 (48.2)	1.44 (0.81 -2.57)	35 (81.4)	8 (18.6)	0.64 (0.22 -1.83)	53 (77.9)	15 (22.1)	0.65 (0.32 -1.31)
Ethnicity									
White British	47 (78.3)	13 (21.7)	1	19 (82.6)	4 (17.4)	1	43 (78.2)	12 (21.8)	1
Black African	21 (42.0)	29 (58.0)	**4.99 (2.17-11.47) †**	17 (68.0)	8 (32.0)	2.23 (0.56 -8.77)	43 (61.4)	27 (38.6)	**2.25 (1.01 -5.01)***
Black Caribbean	30 (46.1)	35 (53.9)	**4.21 (1.92 -9.24) †**	14 (82.3)	3 (17.7)	1.01 (0.19 -5.29)	25 (71.4)	10 (28.6)	1.43 (0.54 -3.79)
White Other	12 (66.7)	6 (33.3)	1.84 (0.56 -5.74)	13 (81.2)	3 (18.8)	1.09 (0.20 -5.73)	23 (95.8)	1 (4.2)	0.15 (0.01 -1.27)
Education[1]									
School, no GCSE	27 (52.9)	24 (47.1)	1	17 (73.9)	6 (26.1)	1	20 (74.1)	7 (25.9)	1
School, GCSE	25 (54.3)	21 (45.7)	0.94 (0.42 -2.10)	9 (81.8)	2 (18.2)	0.62 (0.10 -378)	18 (64.3)	10 (35.7)	1.58 (0.49-5.04)
Further	34 (59.7)	23 (40.3)	0.76	12 (80.0)	3 (20.0)	0.70	36 (80.0)	9 (20.0)	0.71

			(0.35 -1.63)			(0.14 -3.40)			(0.23 -2.20)
Higher / University	17 (54.8)	14 (45.2)	0.92 (0.37 -2.26)	13 (81.2)	3 (18.8)	0.65 (0.13 -3.12)	29 (67.4)	14 (32.6)	1.37 (0.47 -4.02)
Employment[2]									
Unemployed	55 (49.1)	57 (50.9)	1	44 (78.6)	12 (21.4)	1	74 (73.3)	27 (26.7)	1
Student/Other	16 (66.7)	8 (33.3)	0.48 (0.19 -1.21)	6 (85.7)	1 (14.3)	0.61 (0.06 -5.57)	27 (69.2)	12 (30.8)	1.21 (0.54 -2.73)
Employed	38 (70.4)	16 (29.6)	**0.40 (0.20-0.81) †**	10 (76.9)	3 (23.1)	1.10 (0.26 -4.64)	25 (75.8)	8 (24.2)	0.87 (0.35 -2.17)
Relationship status[3]									
Single	74 (59.7)	50 (40.3)	1	41 (74.6)	14 (25.4)	1	86 (69.9)	37 (30.1)	1
In steady relationship	21 (50.0)	21 (50.0)	1.48 (0.73 -2.99)	14 (82.3)	3 (17.7)	0.62 (0.15 -2.51)	33 (80.5)	8 (19.5)	0.56 (0.23 -1.33)
Divorced/ widowed	5 (45.4)	6 (54.6)	1.77 (0.51 -6.13)	5 (100)	0	No cases	10 (71.4)	4 (28.6)	0.92 (0.27 -3.15)
Living arrangements[4]									
Alone	59 (68.6)	27 (31.4)	1	19 (76.0)	6 (24.0)	1	25 (73.5)	9 (26.5)	1
Family/ relatives	72 (80.9)	17 (19.1)	**0.43 (0.23 -0.79) †**	35 (83.3)	7 (16.7)	0.63 (0.18 -2.15)	93 (73.8)	33 (26.2)	0.98 (0.41 -2.23)
Other	9 (60.0)	6 (40.0)	0.79 (0.26 -2.39)	8 (66.7)	4 (33.3)	1.58 (0.34 -7.17)	14 (66.7)	7 (33.3)	1.38 (0.42 -4.54)
PATHWAYS TO CARE VARIABLES									
DUP[5]									
Short (≤ 1year)	87 (55.4)	70 (44.6)	1	45 (73.8)	16 (26.2)	1	85 (65.9)	44 (34.1)	1
Long (> 1year)	23 (63.9)	13 (36.1)	0.70 (0.33 -1.48)	18 (90.0)	2 (10.0)	0.31 (0.06 -1.49)	49 (89.1)	6 (10.9)	**0.23 (0.09 -0.59) †**

Family involvement in help-seeking[6]									
No	67 (56.8)	51 (43.2)	1	42 (75.0)	14 (25.0)	1	68 (69.4)	30 (30.6)	1
Yes	39 (60.0)	26 (40.0)	0.87 (0.47 -1.62)	21 (84.0)	4 (16.0)	0.57 (0.16 -1.95)	66 (76.7)	20 (23.3)	0.68 (0.35 -1.32)

~P=0.1; *p≤0.05; †p≤0.01

9.4 Multivariable logistic regression models

In the next stage of the analyses, multivariable logistic regressions are presented assessing the relationships between ethnicity and each outcome variable (compulsory admission, GP referral, A&E referral and CJA referral) in both the AESOP and CRIS-FEP samples. For these set of analyses, patients who had complete data for all the covariates were included (i.e. 201 (EIS = 137, non-EIS = 64) for the CRIS-FEP sample and 183 for the AESOP sample). From this, four logistic regression models were fitted as follows:

Model 1: unadjusted (reported in the text)

Model 2: age and gender

Model 3: age, gender, employment status and education level

Model 4: age, gender, employment status, education level, family involvement and duration of untreated psychosis

9.4.1 Associations between ethnicity and GP referral by use of EIS

Unadjusted odds ratios for associations between ethnicity and GP referral in the AESOP sample showed that Black Caribbean (OR = 0.44; 95% CI 0.21 – 0.95, p = 0.03) and Black African (OR = 0.28; 95% CI 0.12 – 0.68, p<0.01) were less likely to be referred by GP. There was no difference between White Other (OR = 1.02; 95% CI 0.34 – 3.01, p = 0.97) and White British. Unadjusted OR in the EIS group suggest that there were no differences between White British patients and Black African (OR = 0.59; 95% CI 0.24 – 1.45, p = 0.25), Black Caribbean (OR = 0.91; 95% CI 0.32 – 2.56, p = 0.87) and White Other (OR = 1.01; 95% CI 0.32 – 2.12, p = 0.95) patients for GP referral. Meanwhile, the univariable analysis in the non-EIS group showed a weak association of reduced likelihood of GP referral among Black Caribbean patients (OR = 0.12; 95% CI 0.01 – 1.14, p = 0.06). But no difference was observed in Black African (OR = 0.32; 95% CI 0.07 – 1.33, p = 0.12) or White Other (OR = 0.67; 95% CI 0.16 – 2.76, p = 0.58) compared with White British patients.

In the adjusted regression analyses, Table 9.6 results from the AESOP analysis remained consistent, showing strong evidence that Black African and Black Caribbean patients were less likely to be referred by GP, and this was independent of all potential confounders. For the non-EIS group, there was evidence that Black Caribbean patients were less likely to be

referred by GP and this was independent of demographic and socioeconomic status (Model 2). However, the strength of association became attenuated after adjusting for DUP and family involvement in the pathways to care. There were no ethnic differences in GP referral in the EIS group.

Table 9.6: Adjusted odds ratios of associations between ethnicity and GP referral by use of EIS

	AESOP Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: Non- EIS group Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: EIS group Adjusted odds ratios (95% CI)		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Ethnicity									
White British	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black African	**0.29 (0.12 -0.69)***	**0.24 (0.09-0.64) †**	**0.25 (0.08-0.70)***	0.36 (0.08 -1.55)	0.27 (0.05 -1.33)	0.37 (0.07 -2.00)	0.59 (0.24 -1.46)	0.64 (0.24 -1.68)	0.57 (0.20 -1.62)
Black Caribbean	**0.42 (0.19-0.92) †**	**0.45 (0.19 -1.04)***	**0.37 (0.15-0.92) †**	0.13 (0.01 -1.32)	**0.08 (0.01 -0.93)***	0.18 (0.01 -2.47)	0.90 (0.32 -2.53)	0.96 (0.32 -2.87)	1.20 (0.37 -3.87)
White Other	1.18 (0.39 -3.57)	1.31 (0.42-4.09)	1.12 (0.32 -3.90)	0.83 (0.19 -3.69)	0.70 (0.12 -4.16)	0.97 (0.14-6.62)	1.06 (0.34-3.33)	1.10 (0.34 -3.54)	1.14 (0.32 -4.04)

Model 1: age, gender; Model 2: age, gender, employment status, education level; Model 3: age, gender, employment status, education level, family involvement and duration of untreated psychosis

~P=0.1; *p≤0.05; †p≤0.01

9.4.2 Associations between ethnicity and A&E referral by use of EIS

The following observations were made in the unadjusted regression model for associations between ethnicity and A&E referral. In the AESOP sample, Black Caribbean (OR = 0.64; 95% CI 0.29 – 1.36, p = 0.25), Black African (OR = 1.00; 95% CI 0.46 – 2.18, p = 0.99), White Other (OR = 0.68; 95% CI 0.21 – 2.19, p = 0.52). For unadjusted OR in the EIS group, Black African (OR = 0.59; 95% CI 0.24 – 2.45, p = 0.25), Black Caribbean (OR = 0.91; 95% CI 0.32 – 2.56, p = 0.87), White Other (OR = 1.01; 95% CI 0.32 – 3.12, p = 0.95). For unadjusted in the non-EIS group, Black African (OR = 0.32; 95% CI 0.07 – 1.33, p = 0.12), Black Caribbean (OR = 0.12; 95% CI 0.01 – 1.14, p = 0.06), White Other (OR = 0.67; 95% CI 0.16 – 2.76, p = 0.58).

Table 9.7 displays results from the adjusted regression model assessing the relationships between ethnicity and A&E referral. It can be seen from the table that there were no associations between ethnicity and A&E referral in the AESOP and EIS samples. However, there was strong evidence in the non-EIS group that Black African and Black Caribbean patients were seven and forty-eight times respectively more likely to be referred to mental health services via the accident and emergency department, and this was consistent across the regression models, hence the evidence was independent of all potential confounders. There was also some weak evidence suggestive of association with the White Other group being seven times more likely to be referred by GP after controlling for potential confounders.

Table 9.7: Adjusted odds ratios of associations between ethnicity and A&E referral by use of EIS

	AESOP Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: Non- EIS group Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: EIS group Adjusted odds ratios (95% CI)		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Ethnicity									
White British	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black African	1.03 (0.47 -2.26)	1.00 (0.44 -2.50)	1.21 (0.47 -3.10)	**4.74 (1.00 - 22.29)***	**7.87 (1.34 - 46.16)***	**7.34 (1.15 -46.74)***	1.42 (0.61 -3.31)	1.36 (0.54 -3.30)	1.98 (0.71 -5.48)
Black Caribbean	0.61 (0.23 -1.33)	0.50 (0.21 -1.19)	0.56 (0.22 -1.38)	**15.73 (2.20 - 109.56) †**	**45.28 (4.05 - 505.86) †**	**48.89 (3.49 -684.71) †**	1.09 (0.34 -3.03)	1.09 (0.36 -3.26)	0.75 (0.22 -2.55)
White Other	0.76 (0.23 -2.51)	0.82 (0.23 -2.83)	0.90 (0.23-3.49)	4.04 (0.76 -21.50)	7.11 (0.93 -54.41) ~	7.03 (0.78 -62.76) ~	1.95 (0.63 -5.95)	2.01 (0.63 -6.40)	1.74 (0.48 -6.32)

Model 1: age, gender; Model 2: age, gender, employment status, education level; Model 3: age, gender, employment status, education level, family involvement and duration of untreated psychosis

~P=0.1; *p≤0.05; †p≤0.01

9.4.3 Associations between ethnicity and criminal justice agency referral by use of EIS

In AESOP, unadjusted analyses showed that Black Caribbeans (OR = 5.20; 95% CI 1.94 – 13.92, P<0.01) and Black Africans (OR = 4.46; 95% CI 1.59 – 12.59, p<0.01) were more likely to be referred by a criminal justice agency. White Other (OR = 1.85; 95% CI 0.41 – 8.37, p = 0.42) were less likely. Unadjusted OR in the EIS group showed that Black Africans (OR = 1.42; 95% CI 0.46 – 4.30, p = 0.53), Black Caribbeans (OR = 0.76; 95% CI 0.17 – 3.35, p = 0.71), White Other (OR = 0.68; 95% CI 0.12 – 3.74, p = 0.65) were not associated with criminal justice agency referral. Meanwhile, unadjusted OR in the non-EIS group showed no ethnic differences in criminal justice agency referral: Black African (OR = 0.66; 95% CI 0.09 – 4.50, p = 0.67), Black Caribbean (OR = no cases), White Other (OR = 0.43; 95% CI 0.04 – 4.68, p = 0.49).

Table 9.8 shows the associations between criminal justice agency referral and ethnicity. Consistent with the univariable odds ratios, Black African and Black Caribbean ethnic groups in the AESOP sample were up to four and eight times respectively more likely to be referred by a criminal justice agency, and this evidence was independent of all potential confounders. In the CRIS-FEP sample, there was no evidence of ethnic differences for criminal justice agency referral in both the EIS and non-EIS groups.

Table 9.8: Adjusted odds ratios of associations between ethnicity and CJA referral by use of EIS

	AESOP Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: Non- EIS group Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: EIS group Adjusted odds ratios (95% CI)		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Ethnicity									
White British	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black African	**4.45 (1.55-12.48) †**	**5.30 (1.67-16.84) †**	**4.13 (1.24-13.75)***	0.41 (0.05-3.34)	0.20 (0.15 -2.84)	0.26 (0.01 -4.09)	1.45 (0.47 -4.42)	1.47 (0.45 -4.75)	1.35 (0.35 -5.20)
Black Caribbean	**6.29 (2.23 -17.67) †**	**7.66 (2.50-23.44) †**	**8.29 (2.59-26.54) †**	No cases	No cases	No cases	0.77 (0.17 -3.44)	0.91 (0.19 -4.34)	1.06 (0.16 -7.01)
White Other	1.42 (0.30 -6.63)	1.27 (0.64 -6.12)	1.31 (0.25 -6.84)	0.22 (0.01-2.94)	0.05 (0.01 -2.82)	0.62 (0.01 -3.82)	0.65 (0.11 -3.65)	0.74 (0.13 -4.24)	1.14 (0.14 -8.73)

Model 1: age, gender; Model 2: age, gender, employment status, education level; Model 3: age, gender, employment status, education level, family involvement and duration of untreated psychosis

~P=0.1; *p≤0.05; †p≤0.01

9.4.4 Associations between ethnicity and compulsory admissions by use of EIS

Unadjusted odds ratios for compulsory admission in the AESOP sample showed the Black Caribbean (OR = 4.01; 95% CI 1.82 – 8.81, P<0.01) and Black African (OR = 4.88; 95% CI 2.12 – 11.24, p<0.01) ethnic groups were at increased odds compared with the White British group. But White Other ethnic group (OR = 1.47; 95% CI 0.43 – 4.95, p = 0.53) did not differ from the White British. Unadjusted odds ratios in the EIS group showed that Black African (OR = 2.69; 95% CI 1.07 – 6.79, p = 0.03) patients were more likely to be detained compulsorily. However, no differences were observed between Black Caribbean (OR = 1.30; 95% CI 0.42 – 4.09, p = 0.64), and White British. Unadjusted odds ratios in the non-EIS group showed no ethnic difference for compulsory admission: Black African (OR = 1.84; 95% CI 0.41 – 7.96, p = 0.41), Black Caribbean (OR = 0.40; 95% CI 0.03 – 4.10, p = 0.44), White Other (OR = 0.66; 95% CI 0.10 – 4.26, p = 0.66).

Table 9.9 presents associations between compulsory admission and ethnicity; it can be seen from this table that Black African and Black Caribbean patients consistently showed increased odds of compulsory admission in the AESOP sample regardless of potential confounders. The evidence was similar for Black African patients in the EIS sample, showing that they were up to three and a half times more likely to be detained compulsorily independent of potential confounders. Meanwhile, no differences were observed among patients in the non-EIS group.

Table 9.9: Adjusted odds ratios of associations between ethnicity and compulsory admission by use of EIS

	AESOP Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: Non- EIS group Adjusted odds ratios (95% CI)			CRIS-FEP STUDY: EIS group Adjusted odds ratios (95% CI)		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Ethnicity									
White British	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Black African	**4.84 (2.08-11.25) †**	**5.80 (2.27-14.80) †**	**6.15 (2.29-16.54) †**	1.35 (0.28 -6.43)	1.14 (0.20 -6.22)	1.29 (0.22 -7.57)	**2.81 (1.09-7.21)***	**2.78 (1.02-7.57)***	**3.49 (1.12 -10.86)***
Black Caribbean	**3.85 (1.72 -8.63) †**	**4.15 (1.72-10.03) †**	**4.79 (1.89-12.15) †**	0.25 (0.02 -2.90)	0.16 (0.01-2.63)	0.24 (0.01 -5.00)	1.36 (0.43 -4.34)	2.04 (0.57 -7.20)	1.95 (0.49 -7.75)
White Other	1.25 (0.36 -4.32)	1.03 (0.28 -3.73)	0.95 (0.23 -3.92)	0.40 (0.06 -3.00)	0.32 (0.03 -3.01)	0.37 (0.03 -3.73)	No cases	No cases	No cases

Model 1: age, gender; Model 2: age, gender, employment status, education level; Model 3: age, gender, employment status, education level, family involvement and duration of untreated psychosis

~P=0.1; *p≤0.05; †p≤0.01

9.5 Summary

To summarise, the results from both AESOP and present study data suggest that there have been some changes in the pathways to care and compulsory admission during first episode psychosis in the intervening 15 or so years. It is intriguing to speculate that this may be due to the introduction of EI services. At the same time, it could be due to other factors. In contrast to AESOP findings, individuals who received EIS in the present study were to some degree less likely to experience crisis pathways to care. For example, there were no ethnic differences observed in GP, CJA/police and A&E referral among those who received EIS. It was observed that Black Caribbean patients in the EIS group also differ from those in the AESOP study for compulsory admission as there were no differences between them and White British patients in the present study. However, patients of the Black African ethnic group remain more likely to be compulsorily detained during their first contact for psychosis despite accessing the early intervention services.

Considering those who did not receive EIS in the CRIS-FEP sample, the results point to a mixed outcome. While there were no increased odds of compulsory admission among the minority ethnic groups, individuals of the Black Caribbean ethnic group were less likely to be referred by their GP, although this finding did not hold in the fully adjusted analysis. Another key shift since the AESOP study appears to be that ethnic minority patients not in contact with EIS were more likely to come into contact with mental health services via the A&E department (these groups are Black African, Black Caribbean and White Other), a finding not seen in the AESOP sample.

9.6 Limitations

The limitations and how they were mitigated, discussed in Chapter 8, also apply in this chapter. However, specific issues related to the findings in this chapter are discussed.

The cross-sectional nature of our data means that the differences in associations between ethnicity and pathways to care in the AESOP and CRIS-FEP samples may not be explained by the introduction of early intervention services alone; it could be due to other factors. While we adjusted for demographic, socioeconomic variables and pathways to care variables, the results here may still be confounded by unmeasured variables. Further, the loss of power in the adjusted analyses means that the observed positive associations may be due to chance. For example, the small sample size in the non-EIS group and wide confidence interval around the elevated odds ratios for minority ethnic status and accident and emergency referral are interpreted tentatively.

10 Chapter 10: Results of Associations between Ethnicity and Service Use Outcomes at Follow-up

10.1 Synopsis

The results presented in Chapters 7, 8 and 9 were related to the cross-sectional data collected at first contact for psychosis (i.e. sociodemographic, socioeconomic, pathways to care, and duration of untreated psychosis). In this chapter, data collected longitudinally across the follow-up period are analysed and reported. These include data on service use outcomes, i.e. number of compulsory detentions, number of hospital admissions, total number of days in hospital and diagnosis. Subsequently, this chapter addresses the following aims:

5. To estimate rates and rate ratios of hospital admission and compulsory detention during the two-year follow-up by ethnic group.
6. To estimate differences in length of hospital stay by ethnic group during the two-year follow-up.

This chapter tests the hypothesis that:

Over the two-year follow-up period, worse service use outcomes (characterised by increased rates of hospital admissions, compulsory admission and longer duration of hospital stay) will be observed among those of Black Caribbean and Black African ethnicity compared with White British patients.

Analysis

As mentioned previously in Chapter 6, the analysis set out in this chapter forms the basis for detailed enquiry of the potential factors associated with patterns of service use. The scope of data collected for this stage, and the analytic methods used, are designed to move beyond previous research. The collection of data relating to different outcomes on service use (i.e. hospital admission, compulsory detention, length of hospital stay) over the follow-

up period allows for each of these outcomes and factors associated with them to be examined. A number of previous studies have investigated these outcomes but most considered them as static model of service use, e.g. using cross-sectional data (see Chapters 3 and 4). When considered as a process, earlier outcomes and experiences become important in understanding subsequent service use and engagement. Therefore, this stage of the study attempts to construct the service use process by focussing on both point of first contact with services for psychosis and subsequent outcomes, such as number of compulsory detentions, number of hospitalisations and total length of stay in hospital over the course of the follow-up period.

This chapter now describes service use outcomes at follow-up, and then a comparison of the outcomes between ethnic groups is presented (section 10.3). Secondly, rates of hospital admission and compulsory detention per year during the follow-up period are presented in sections 10.4 and 10.5. Thirdly, univariable and multivariable rate ratios were estimated for number of hospital admissions and number of compulsory admissions using negative binomial regression to assess differences by ethnic groups (sections 10.6 and 10.7). Finally, unadjusted and adjusted analyses of associations between total number of days spent in hospital during the follow-up period and ethnicity are discussed in Section 10.8.

10.2 Sample characteristics at follow-up

Table 10.1: Service Use and Clinical characteristics during the follow up period

Characteristics	**Cases n=558 (%)**
Overall length of follow up	
Mean (SD) years	1.84 (1.14)
Median (IQR) years	2.07 (0.75 – 2.72)
Hospital admission at first contact	
Yes	238 (42.6)
No	320 (57.4)
Hospital admission at follow up	
Yes	145 (26.0)
No	413 (74.0)
Hospital admission, ever	
Once or more	357 (64.0)
None	201 (36.0)
Total number of days hospitalised	

Mean (SD) days	56.82 (124.06)
Median (IQR) days	12 (0 - 68)
Compulsory admission at first contact	
Yes	135 (24.2)
No	423 (75.8)
Compulsory admission at follow up	
Yes	81 (14.5)
No	477 (85.5)
Compulsory admission, ever	
Once or more	268 (48.0)
None	290 (52.0)
OPCRIT ICD10- diagnosis (n=267)	
Non-affective psychosis	119 (44.6)
Affective psychosis	15 (5.6)
Other (Psychosis NOS)	133 (49.8)
ICD-10 Clinical Diagnosis[1]	
Non-affective psychosis	269 (48.7)
Affective psychosis	135 (24.5)
Other (Psychosis NOS)	148 (26.8)
Type of service use[2]	
Early intervention service	222 (39.9)
CMHT	81 (14.6)
Assessment & Treatment	126 (22.7)
Specialist	56 (10.1)
Forensic	7 (1.3)
Other	64 (11.5)
Outcomes	
Active patient in SLaM	222 (39.8)
Discharged to GP	232 (41.7)
Moved out of area/Transferred to other MH provider	93 (16.7)
Moved abroad	7 (1.2)
Prison	2 (0.3)
Died	2 (0.3)

Missing data

1 (5 missing values)

2 (2 missing values)

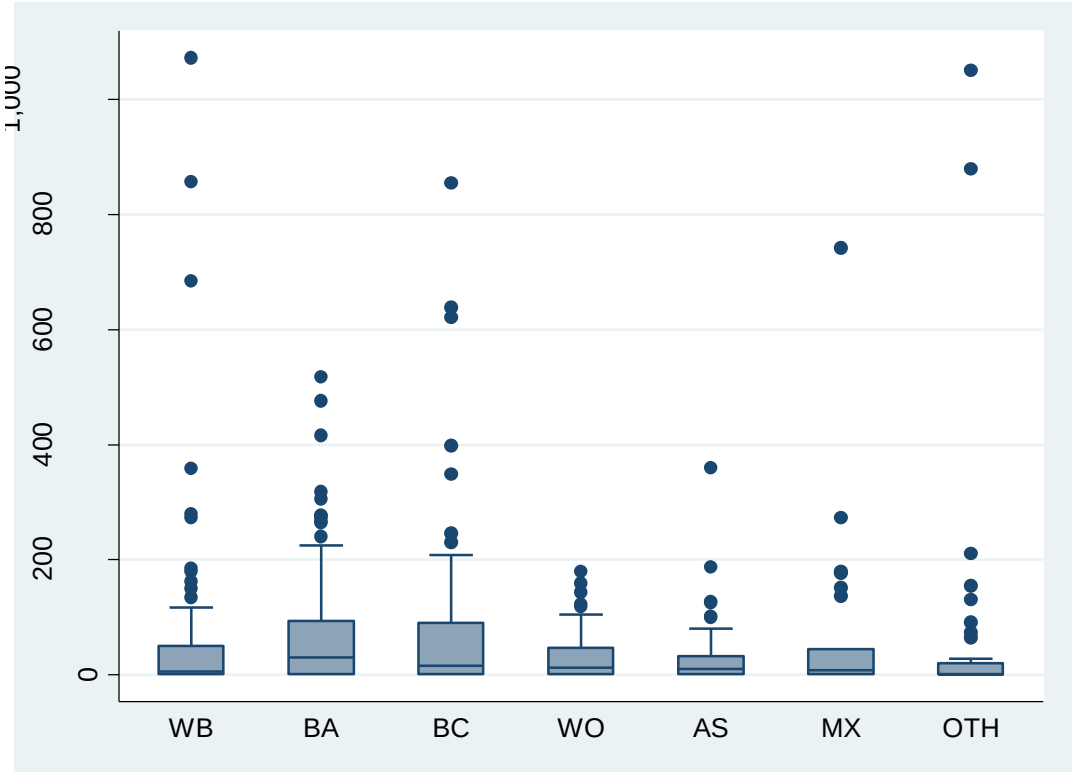
Table 10.1 shows that during the follow-up period, individuals included in the study were followed up for an average of two years (sd = 1.14) and median 2.07 years (IQR = 0.75 – 2.72). At first contact 238 (42.6%) patients were admitted to hospital. By the end of the study, 357 (64%) patients experienced at least one hospital admission. The median length of hospital stay was 12 days, interquartile range 0–68. At first contact, 135 (24.2%) patients were compulsorily detained. The number of patients ever compulsorily admitted had doubled during the course of the study from 24.2% to 48%. However, at follow-up, 145 patients were readmitted, of whom 56% were compulsorily detained. In terms of service use, around 40% of the sample entered into contact with early intervention service, followed by 22.7% receiving assessment and treatment service (A&T), 14.6% seeing community mental health teams (CMHT), 10.1% were seen in specialist teams (such as perinatal, HIV, social inclusion or culture-specific), 11.5% were seen in other services (e.g. outpatients, supported housing, psychology and rehabilitation) and only seven patients (1.3%) were with forensic services. Clinical diagnosis were categorised as follows: 48.7% non-affective (F10-19; F20-29), 24.5% affective (F30-33) and 26.8% other/Psychosis-NOS (Z71, F99). OPCRIT ICD-10 diagnosis data were available for 267 of the 588 sample and showed that the proportion of patients with non-affective psychosis (44.6%) was similar to those that were clinically recorded. There were differences in the two diagnostic groups for affective and psychosis NOS (Table 10.1). It is noteworthy that OPCRIT data were collected on cases identified during the first year of case screening, but not the second year, hence around half of the sample had data on this variable. By the end of the study (30 April 2014), only 40% remained active patients of SLaM. Around 42% were discharged to their GP and 17% either moved out of area or transferred to other mental health service providers. Seven individuals moved abroad, two were sentenced to prison and two died. There was a total 1030 persons-years at risk during the follow-up period.

10.3 Comparison between ethnic groups and clinical characteristics at follow-up

Table 10.2 presents comparisons between follow-up service use characteristics and ethnicity. Chi-square, ANOVA and Kruskal Wallis analyses showed that there was strong evidence of differences between ethnicity and five main variables (i.e. age, total number of days in hospital, compulsory admission and hospital admission and diagnosis). Individuals of

the ‘Mixed’ ethnic group were more likely to be younger (29.7, sd = 9.6 years, p = 0.05) compared with other ethnic groups.

Length of hospital stay was not normally distributed, with some individuals experiencing extremely long hospital stay as illustrated in Figure 10.1; therefore median and interquartile ranges have been used to describe the data. Kruskal Wallis tests showed that during the study period, in total Black African (median = 30; IQR = 0 – 94) and Black Caribbean (median = 16; IQR = 0 – 90) patients spent longer days in hospital during the follow-up period compared with any other ethnic group (Table 10.2).



WB, White British, BA, Black African, BC, Black Caribbean, WO, White Other, AS, Asian, MX, Mixed, OTH, Other

Figure 10.1: Length of hospital stay by ethnicity

Across each of the service use outcome indicators, i.e. ever compulsorily admitted, follow-up hospital admission and number of days spent in hospital, the Black African ethnic group had the poorest outcome (Table 10.2).

In terms of clinical diagnosis, there was strong evidence of ethnic differences ($X^2 = 24.7$, df = 12, p = 0.01). Non-affective psychosis was common among all minority ethnic group patients compared with White British, while a higher proportion of White British and ‘Other’ patients

were diagnosed with psychosis NOS (not otherwise stated). Affective psychosis was less common among 'Mixed' ethnic group patients (Table 10.2). There were no ethnic differences in community service use.

By the end of the study, there was weak evidence that people who had left the study were more likely to have been discharged to GP (White Other = 48%; Other = 58.5%) or moved out of area (White Other =24%; White British = 19.5%). Of those who moved abroad , three were Black African (2%) and White Other (4%), $X^2 = 40.9$, df = 30, p = 0.08. There were no differences observed in ethnicity and DUP, and length of follow-up. This may suggest that some of this study sample may be transient population.

Table 10.2: Comparisons between clinical and service use characteristics at follow up and ethnic groups

	White British n= 133 (%)	**Black African n=147 (%)**	**Black Caribbean n = 91 (%)**	**Other White n =75 (%)**	**Asian n= 44 (%)**	**Mixed n= 27 (%)**	**Other n= 41 (%)**	**ANOVA/ Kruskal-Wallis X^2 test**	**df**	**p**
Mean Age at FEP *in years (SD)*	34.5 (12.5)	32.4 (9.9)	33.4 (10.6)	34.9 (9.6)	32.4 (10.3)	29.7 (9.6)	31.9 (9.1)	**12.56**	**6**	**0.05**
Mean follow up time (SD) years	2.02 (1.2)	1.98 (1.1)	2.22 (1.2)	1.65 (1.0)	1.75 (1.1)	1.96 (1.2)	1.67 (1.2)	3.90	6	0.68
Median DUP in days (IQR)	105 (22 - 514)	88 (17 - 447)	126 (28 - 449)	86 (14 - 408)	76.5 (8.5 - 243)	92 (23 - 361)	60 (12 - 560)	2.40	6	0.87
Median LOS (IQR) days- total number of days hospitalised during follow up period	6 (0 - 50)	30 (0 - 94)	16 (0-90)	13 (0 - 47)	10 (0 – 32.5)	8 (0 - 45)	0 (0 - 21)	**13.47**	**6**	**0.03**
								Chi-sq (exact) test	**df**	**p**
Hospital admission at follow up										
No	99 (74.4)	95 (64.6)	67 (73.6)	59 (78.7)	38 (86.4)	18 (66.7)	37 (90.2)	**17.46**	**6**	**0.008**
Yes	34 (25.6)	52 (35.4)	24 (26.4)	16 (21.3)	6 (13.6)	9 (33.3)	4 (9.8)			
Hospital admission, ever										
None	47 (35.3)	49 (33.3)	35 (38.5)	27 (36.0)	12 (27.3)	8 (29.6)	23 (56.1)	9.83	12	0.13
Once or more	86 (64.7)	98 (66.7)	56 (61.5)	48 (64.0)	32 (72.7)	19 (70.4)	18 (43.9)			
Compulsory admission at follow										

up										
No	119 (89.5)	111 (75.5)	74 (81.3)	67 (89.3)	42 (95.4)	24 (88.9)	40 (97.6)	**24.25**	**6**	**<0.001**
Yes	14 (10.5)	36 (24.5)	17 (18.7)	8 (10.7)	2 (4.6)	3 (11.1)	1 (2.4)			
Compulsory, ever										
None	79 (59.4)	59 (40.1)	47 (51.6)	40 (23.3)	24 (54.6)	13 (48.1)	28 (68.3)	**15.89**	**6**	**0.01**
Once or more	54 (40.6)	88 (59.9)	44 (48.4)	35 (46.7)	20 (45.4)	14 (51.9)	13 (31.7)			
ICD-10 Clinical Diagnosis										
Non-affective psychosis	46 (34.6)	80 (54.8)	45 (50.0)	45 (60.8)	22 (52.4)	16 (59.3)	15 (37.5)	**24.78**	**12**	**0.01**
Affective psychosis	36 (27.1)	37 (25.3)	21 (23.3)	16 (21.6)	9 (21.4)	5 (18.5)	11 (27.5)			
Other (Psychosis NOS)	51 (38.3)	29 (19.9)	29 (26.7)	13 (17.6)	11 (26.2)	6 (22.2)	14 (35.0)			
Type of service use										
Early intervention service	55 (41.3)	70 (47.6)	35 (38.9)	24 (32.0)	14 (32.6)	12 (44.4)	12 (29.3)	35.64	30	0.22
CMHT	15 (11.3)	24 (16.3)	17 (18.9)	13 (17.3)	6 (13.9)	0	6 (14.6)			
Assessment & Treatment	32 (24.1)	25 (17.0)	20 (22.2)	18 (24.0)	7 (16.3)	9 (33.3)	15 (36.6)			
Specialist	17 (12.8)	11 (7.5)	8 (8.9)	8 (10.7)	7 (16.3)	1 (3.7)	4 (9.8)			
Forensic	1 (0.7)	2 (1.4)	2 (2.2)	0	0	1 (3.7)	1 (2.4)			
Other	13 (9.8)	15 (10.2)	8 (8.9)	12 (16.0)	9 (20.9)	4 (4.9)	3 (7.3)			
Administrative outcomes										
Active patient in SLaM	54 (40.6)	63 (42.9)	45 (49.5)	17 (22.7)	18 (40.9)	14 (51.8)	11 (26.8)	40.99	30	0.08
Discharged to GP	51 (38.3)	54 (36.7)	38 (41.8)	36 (48.0)	18 (40.9)	11 (40.7)	24 (58.5)			
Moved out of area/Transferred to other MH provider	26 (19.5)	27 (18.4)	7 (7.7)	18 (24.0)	7 (15.9)	2 (7.4)	6 (14.6)			

Moved abroad	0	3 (2.0)	0	3 (4.0)	1 (2.3)	0	0			
Prison	1 (0.8)	0	1 (1.1)	0	0	0	0			
Died	1 (0.8)	0	0	1 (1.3)	0	0	0			

10.4 Rate of hospital admission per year by ethnic group during the follow-up period

In order to address the objective of estimating rates of hospital admission within the follow-up period by ethnic groups, Poisson regression analysis was employed using the option ***exposure (follow-up time)***. It was important to include and specify the time at risk (follow-up time) using the 'exposure' option since the Poisson command assumes all participants had the same time at risk.

Time at risk was defined as: exit date minus entry date.

Entry date = date of contact with mental health services for FEP or date of discharge for first admission, whichever happened first.

Exit date = study end date (30 April 2014) or date the patient left the study (i.e. discharge from SLaM services) whichever happened first.

Table 10.3: shows the rate of hospital admissions per year with 95% confidence intervals by ethnic groups. From the table, the following observations were made: the rate of admission was highest among Black African patients (0.43 per year or once every two years), followed by the 'Mixed', White British and Black Caribbean ethnic groups (0.34, 0.31 and 0.29 per year or once every three years respectively). The remaining ethnic groups had an admission around once every five years (0.12 to 0.23 per year).

Table 10.3: Rate of hospital admission per year with 95% confidence intervals by ethnic group during the follow up period

Ethnicity	Number in sample (%)	Rate of admission	95% confidence interval (CI)
White British	133 (23.8)	0.31	0.25 – 0.39
Black African	147 (26.3)	0.43	0.35 – 0.51
Black Caribbean	91 (13.4)	0.29	0.22 – 0.38
White Other	75 (13.4)	0.23	0.16 - 0.34
Asian	44 (7.9)	0.19	0.11 -0.32
Mixed	27 (4.8)	0.34	0.21- 0.54
Other	41 (7.3)	0.12	0.06 -0.24

10.5 Rate of compulsory admission per year by ethnic group during the follow-up period

In this section, I have used the same statistical approach described in section 10.4 to estimate the rate of compulsory admission. Table 10.4 presents the rate of compulsory admission per year with 95% confidence intervals by ethnicity. From the table, a markedly elevated rate of compulsory admissions was observed among patients of Black African ethnicity (0.27 per year or once every three years), and the Black Caribbean group were compulsorily admitted once every five years (0.18 per year). White British, White Other and 'Mixed' ethnic groups experienced compulsory admissions around once every ten years. Patients of Asian and 'Other' ethnicity experienced lower rates of compulsory admissions.

Table 10.4: Rate of compulsory admission per year with 95% confidence intervals by ethnic group during the follow up period

Ethnicity	Number in sample (%)	Rate of admission per year	95% confidence interval (CI)
White British	133 (23.8)	0.11	0.06 -0.14
Black African	147 (26.3)	0.27	0.22 -0.34
Black Caribbean	91 (13.4)	0.18	0.13 -0.25
White Other	75 (13.4)	0.10	0.05 -0.16
Asian	44 (7.9)	0.03	0.01 -0.11
Mixed	27 (4.8)	0.10	0.03 -0.22
Other	41 (7.3)	0.03	0.01 -0.12

10.6 Associations between ethnicity and number of hospital admissions during the follow-up

In exploring the relationship between ethnicity and numbers of hospital admissions during the follow-up period, Poisson regression analysis was initially employed to estimate the rate ratios of hospital admission, as it is count data. This was followed by a test of fit using the goodness of fit test which revealed that over dispersion of zero was present and not normally distributed (Pearson goodness-of-fit $X^2 = 3331.6$, df = 550, $p<0.001$). Therefore negative binomial regression was employed for the analysis, whilst taking into account the follow-up period using the ***exposure*** option in Stata. The decision to use negative binomial regression was based on the distribution of the data as shown in the test statistic and histogram displayed in Figure 10.2 (UCLA: Statistical Consulting Group, 2016).

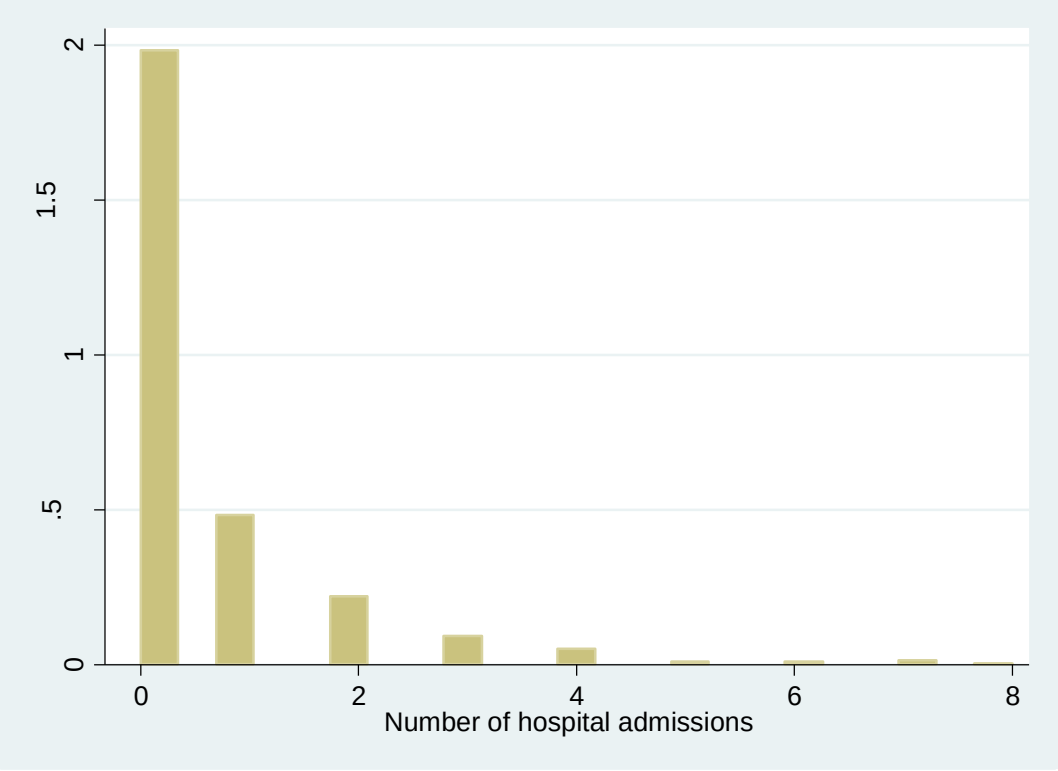


Figure 10.2: Histogram of number of hospital admissions

Unadjusted and multivariable regression analyses were fitted as below. Potential confounders were controlled for as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender

Model 3 – adjusted for age, gender, level of education and employment status

Model 4 – adjusted for age, gender, level of education, employment status and diagnosis

A final regression model was fitted, extending the analyses to adjust for baseline hospital admission (i.e. model 4 plus baseline hospital admission). This was to test whether baseline hospital admission predicts subsequent hospital admissions. The results are reported in the text.

All analyses in the unadjusted and adjusted models here were carried out using complete case sample, i.e. only 367 for whom data were complete for each of the confounding variables. This will allow comparison of associations across the models.

Table 10.5 displays results of univariable and adjusted association between number of hospital admissions along with 95% CI and ethnicity. From this table, strong evidence can be seen that Black African patients had higher rates of hospital admission over the follow-up period and this was independent of all potential confounders. Despite the small attenuation in the effect size when age and gender were controlled for (i.e. from IRR = 1.98 to 1.81), the strength of association remained robust and became stronger in subsequent models when socioeconomic status and diagnosis were adjusted for. There was no evidence of associations between increased number of admissions and any other ethnic groups.

In the final analyses while adjusting for the *a priori* confounders in model 4 as well as baseline hospital admission, differences in hospital admission at follow-up held, with rate ratios of almost two for Black African patients. The rate ratios along with 95% CI by ethnic group are reported in text, below Table 10.5.

Table 10.5: Adjusted rate ratios of associations between ethnicity and number of hospital admissions during the follow up period (n=367)

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**1.98**	**1.14 – 3.44 (0.01)**	**1.81**	**1.05 – 3.13 (0.03)**	**2.12**	**1.21 – 3.68 (<0.01)**	**1.98**	**1.12 – 3.48 (0.01)**
Black Caribbean	1.35	0.72 – 2.54 (0.34)	1.37	0.74 – 2.56 (0.31)	1.25	0.66 – 2.36 (0.48)	1.13	0.58 – 2.19 (0.71)
White Other	1.26	0.62 – 2.55 (0.50)	1.22	0.60 – 2.46 (0.56)	1.23	0.60 – 2.50 (0.56)	1.23	0.60 – 2.49 (0.56)
Asian	0.93	0.36 – 2.38 (0.89)	0.93	0.37 – 2.33 (0.88)	0.96	0.38 – 2.43 (0.94)	0.93	0.36 – 2.40 (0.88)
Mixed	2.00	0.82 – 4.86 (0.12)	1.91	0.79 – 4.58 (0.14)	1.89	0.77 – 4.58 (0.15)	1.83	0.76 – 4.41 (0.17)
Other	0.68	0.24 – 1.97 (0.48)	0.64	0.22 – 1.85 (0.41)	0.65	0.22 – 1.89 (0.43)	0.61	0.21 – 1.78 (0.37)

Model 1- unadjusted; Model 2- adjusted for age, gender; Model 3- adjusted for age, gender, level of education and employment status; Model 4 - adjusted for age, gender, level of education, employment status, diagnosis

Final Model: adjusting for model 4 plus baseline hospital admission

White British: Reference group

Black African: adj. IRR = 1.71; 95% CI 0.98 – 2.99 (p = 0.05)

Black Caribbean: adj. IRR = 1.07; 95% CI 0.55 – 2.07 (p = 0.83)

White Other: adj. IRR = 1.04; 95% CI 0.51 – 2.11 (p = 0.89)

Asian: adj. IRR = 0.91; 95% CI 0.33 – 2.34 (p = 0.85)

Mixed: adj. IRR = 1.54; 95% CI 0.65 – 3.64 (p = 0.31)

Other: adj. IRR = 0.63; 95% CI 0.22 –1.81 (p = 0.40)

10.7 Associations between ethnicity and the number of compulsory admissions during the follow-up period

Figure 10.3 displays the distribution of number of compulsory admissions showing the over dispersion of zero. Therefore, the same statistical method (i.e. negative binomial) used in section 10.6 above was employed to explore the relationship between ethnicity and the number of compulsory admissions.

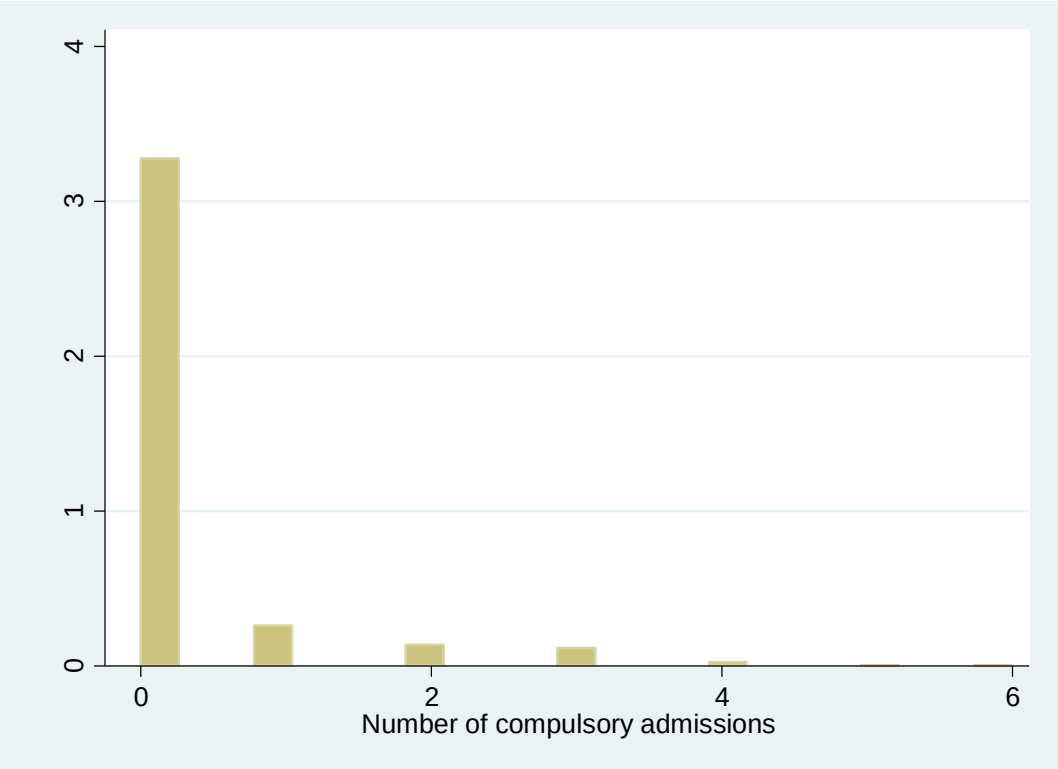


Figure 10.3: Histogram of number of compulsory admissions

Adjustments for the *a priori* confounders were undertaken. Therefore, four regression models were fitted as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender

Model 3 – adjusted for age, gender, level of education and employment status

Model 4 – adjusted for age, gender, level of education, employment status and diagnosis

Again here, a final regression model was fitted, extending the analyses to adjust for baseline compulsory admission (i.e. model 4 plus baseline compulsory admission). This was to test whether baseline compulsory admission predicts subsequent compulsory admissions. The results are reported in the text below.

Table 10.6 shows results of rate ratios of number of compulsory admissions. From this table, there was strong evidence of three-fold elevated rate of compulsory admissions among people of Black African ethnicity throughout the unadjusted and adjusted models. In the unadjusted model, there was also evidence that patients of Black Caribbean ethnic group were more likely to experience an increased rate of compulsory admission (IRR = 2.46; 95% CI 1.03 – 6.01, p = 0.04). This association was attenuated in the fully adjusted models. However, the evidence of associations in models 2 and 3 for the Black Caribbean ethnic group (albeit weak) may suggest that socioeconomic position may play an important role in the relationship between compulsory admission and ethnicity. There were no cases from the 'Other' ethnic group in the multivariable analysis.

In the repeated analyses while adjusting for the *a priori* confounders in model 4 as well as baseline compulsory admission, differences in compulsory admission at follow-up held, with rate ratios of around two and a half for Black Africans. However, the observed associations for the Black Caribbean group did not hold and showed no difference compared with the White British ethnic group. The rate ratios along with 95% CI by ethnic group are reported in text, below Table 10.6.

Table 10.6: Adjusted rate ratios of associations between ethnicity and number of compulsory admissions during the follow up period (n=367)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	**3.50**	**1.59 -7.71 (<0.01)**	**3.09**	**1.39 -6.88 (<0.01)**	**3.46**	**1.52 -7.83 (<0.01)**	**3.01**	**1.33 -6.80 (<0.01)**
Black Caribbean	**2.46**	**1.03 -6.01 (0.04)**	2.27	0.93 -5.51 (0.07)	2.17	0.89 -5.26 (0.08)	1.62	0.65 -4.03 (0.29)
White Other	1.93	0.47 -4.09 (0.54)	1.28	0.43 -3.73 (0.65)	1.52	0.51 -4.51 (0.44)	1.38	0.46 -4.07 (0.55)
Asian	0.54	0.10 -2.88 (0.47)	0.52	0.09 -2.79 (0.45)	0.56	0.10 -3.01 (0.50)	0.43	0.08 -2.36 (0.33)
Mixed	1.51	0.39 – 5.86 (0.54)	1.54	0.40 -5.91 (0.52)	1.30	0.32 -5.18 (0.70)	1.25	033 -4.77 (0.73)
Other	-	No cases	-	No cases	-	No cases	-	No cases

Model 1- unadjusted; Model 2- adjusted for age, gender; Model 3- adjusted for age, gender, level of education and employment status; Model 4 - adjusted for age, gender, level of education, employment status, diagnosis

White British: Reference group

Black African: **adj. IRR = 2.58; 95% CI 1.15** – **5.79 (p = 0.02)**

Black Caribbean: adj. IRR = 1.49; 95% CI 0.61 – 3.68 (p = 0.37)

White Other: adj. IRR = 1.35; 95% CI 0.47 – 3.88 (p = 0.57)

Asian: adj. IRR = 0.42; 95% CI 0.07 – 2.29 (p = 0.32)

Mixed: adj. IRR = 0.98; 95% CI 0.25 – 3.74 (p = 0.98)

Other: No cases

10.8 Associations between length of hospital stay and ethnicity during the follow-up period

Figure 10.4 displays the distribution of length of hospital stay, indicating over dispersion of zero. Therefore, in keeping with the analyses carried out in Sections 10.6 and 10.7, negative binomial regression was employed here to estimate the rate ratios for length of hospital stay by ethnic group.

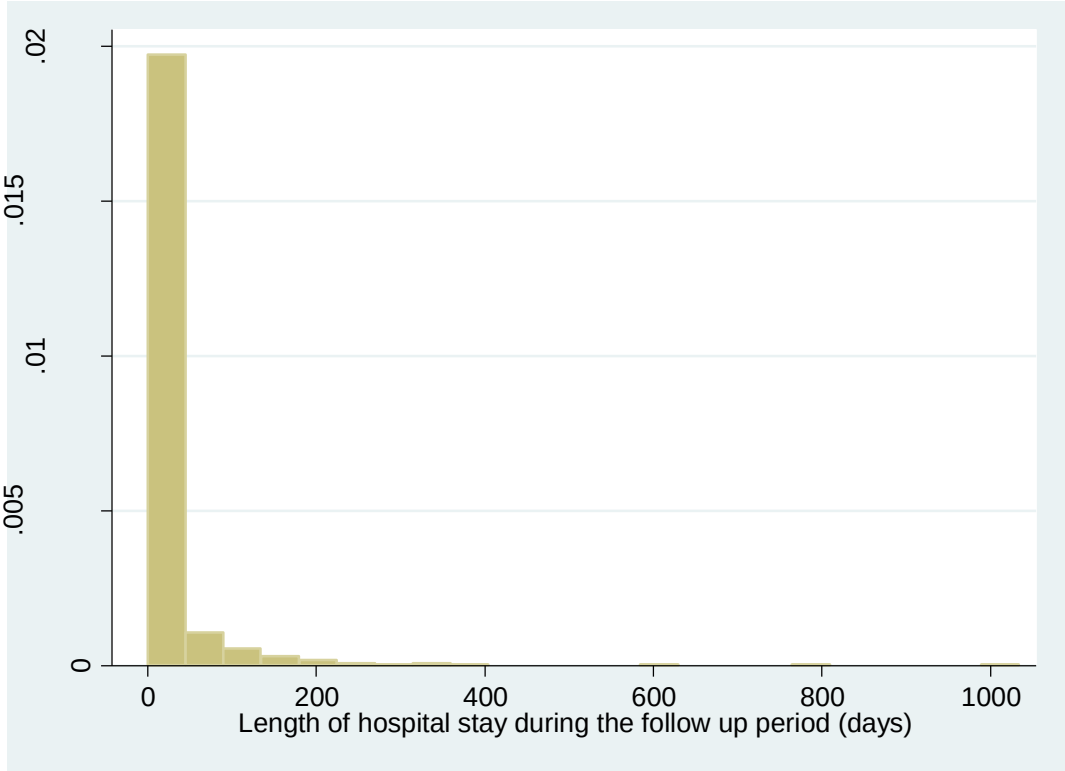


Figure 10.4: Histogram of length of hospital stay

Table 10.7 shows results of unadjusted and adjusted regression analyses along with 95% confidence intervals. It can be seen from this table that there was strong evidence that compared with White British patients, Asian patients were more likely to spend fewer days in hospital, and the strength of association was independent of all potential confounders. There were no further differences observed in the length of hospital stay by ethnic group.

Table 10.7: Adjusted rate ratios of associations between ethnicity and length of hospital stay during the follow up period (n=367)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
Ethnicity								
White British	1.00		1.00		1.00		1.00	
Black African	1.82	0.41 -8.02 (0.43)	1.88	0.42 -8.42 (0.40)	2.17	0.42 -11.28 (0.35)	1.67	0.29 -9.52 (0.56)
Black Caribbean	0.93	0.16 -5.13 (0.93)	1.18	0.20 -6.67 (0.85)	1.08	0.16 -7.06 (0.93)	0.49	0.04 -4.98 (0.54)
White Other	0.33	0.05 -1.96 (0.22)	0.35	0.06 -2.06 (0.24)	0.39	0.05 -2.90 (0.36)	0.36	0.04 -2.82 (0.33)
Asian	**0.10**	**0.01 -0.97 (0.04)**	**0.08**	**0.01 -0.79 (0.03)**	**0.05**	**0.0 -0.86 (0.03)**	**0.02**	**0.01 -0.62 (0.02)**
Mixed	4.49	0.30 -65.65 (0.27)	4.50	0.34 -58.68 (0.25)	6.96	0.43 -110.57 (0.16)	4.69	0.30 (71.61)0.26
Other	0.50	0.05 -4.86 (0.55)	0.69	0.07 -6.84 (0.75)	0.67	0.04 -9.53 (0.77)	0.36	0.02 -5.62 (0.47)

Model 1- unadjusted; Model 2- adjusted for age, gender; Model 3- adjusted for age, gender, level of education and employment status; Model 4 - adjusted for age, gender, level of education, employment status, diagnosis

10.9 Summary

To summarise, the majority of the sample experienced at least one hospital admission and one compulsory admission during the follow-up period, but the rate of hospital admissions and compulsory detentions was markedly higher among patients of Black African ethnicity.

There was some evidence suggestive of some associations between compulsory admission and the Black Caribbean ethnic group but this only went as far as adjusting for socioeconomic status.

In exploring the associations between length of hospital stay and ethnicity, the results suggest that there was strong evidence that only patients of the Asian ethnic group were more likely to spend fewer days in hospital over the follow-up period compared with White British patients. There were no differences in the other ethnic groups.

To conclude, in support of the hypothesis set out in this chapter, Black African patients experienced worse service use outcomes. However, the results did not support the hypothesis for the Black Caribbean group, who did not show any significant difference compared with White British patients. The implications and possible interpretation of these findings will be addressed in detail in the Discussion chapter (Chapter 12).

10.10 Limitations

In addition to the methodological limitations discussed in the preceding chapters, fundamental to longitudinal studies is the issue of attrition. This is reflected in the findings here, as around sixty per cent of the participants had left SLaM services by the end of the study. However, a key advantage of using a case register (CRIS) for this study is the ability to determine date of discharge for each individual and therefore the amount of data each participant contributed to the follow-up period were included in the analyses. Further, the longitudinal analyses were based on the assumption that participants left the study at random (Susser et al., 2006). For example, there were no statistical significant differences in the administrative outcomes (Table 10.3) by ethnic groups, so the impact of attrition on the findings here were minimal.

11 Chapter 11: Results: Ethnicity and Service Use Outcomes by Early Intervention Service Status during the Follow-up Period

11.1 Synopsis

In Chapter 10, data analyses that addressed the relationships between service use outcomes and ethnicity were presented and the results indicated that there were some ethnic variations in the outcomes that were considered. This chapter expands on the work in Chapter 10, by examining whether the differences observed in the service use outcomes may be explained by early intervention service status. Using in part the same statistical approach described in Chapter 10, and non-parametric tests, the following aims and hypothesis were addressed:

7. To compare clinical and service use outcomes (hospital admission, compulsory admission and length of hospital stay) between those using early intervention services (EIS) and non-EIS users and non-eligible patients.
8. To determine whether there are ethnic differences in clinical and service use outcomes at the two-year follow-up in relation to early intervention service use status.

This chapter tests the hypothesis that:

Over the two-year follow-up period, poorer clinical and service use outcomes will be associated with non-EIS use compared with EIS status and these will vary by ethnic groups.

As described in Chapter 9, before assessing associations between clinical and service use outcomes and early intervention service use (EIS), it was important to arrange the total sample according to EIS eligibility. With this in mind, since the age eligibility for EIS at the time of this study was 18–35 years, the sample was re-categorised according to patients' age and whether they received EIS or not as follows:

18–35 years – eligible and received (EIS group)

18–35 years – eligible but did not receive (non-EIS group)

36 and above – not eligible (non-eligible group)

From this, comparisons of sociodemographic factors and clinical outcomes by EIS use are described in section 11.1. Next, unadjusted and multivariable regression analyses were fitted to assess association between EIS status and number of hospital admissions, compulsory admissions and length of hospital stay, presented in sections 11.2, 11.3 and 11.4. Subsequently, the associations between ethnicity and service use outcomes by EIS status are described and reported in sections 11.5 to 11.8.

11.2 Comparisons between EIS use, sociodemographic and follow-up clinical characteristics

In Table 11.1, test statistics i.e. Chi-square, ANOVA and Krusal Wallis analyses were employed to explore differences in EIS use by sociodemographic, pathways to care and clinical characteristics during follow-up.

11.2.1 EIS eligible versus Non-eligible comparisons

As shown in Table 11.1, those not eligible for early intervention services are by definition, older than those eligible for EIS. Perhaps reflecting their older age, far fewer were still in education, were less likely to be single and more likely to be separated or divorced, living alone and women (56.3%). Further, the older age of the non-eligible patients for EIS may also explain the higher proportion of this group to receive a diagnosis of affective psychosis (34.1%). In terms of pathways to care, patients who were non-eligible for EIS were more likely to experience an insidious onset of psychosis, less likely to have family involvement in help-seeking and were more likely to be discharged to GP compared with those who received EIS.

11.2.2 EIS versus non-EIS comparisons

Table 11.1 also displays comparisons between the EIS and non-EIS groups. As can be seen from the table, patients in the non-EIS group appear to differ from their EIS counterparts on characteristics that indicate social isolation and crisis pathways to care. For example, the non-EIS patients were more likely to be unemployed, living alone, have housing tenure such

as 'Other' (hostel), make contact with service out of hours and less likely to have family involvement in help-seeking. For service use outcomes, non-EIS patients more likely to have frequent hospital admissions, to receive a diagnosis of Psychosis not otherwise stated, to use specialists (such as perinatal, HIV, social inclusion or culture-specific) and to move out of study area.

Table 11.1: Comparisons between baseline socio-demographic, pathways to care and follow up clinical characteristics by EIS status

	EIS n= 222 (%)	**Non-EIS n=119 (%)**	**Non-eligible n = 215 (%)**	**ANOVA/ Kruskal-Wallis X^2 test**	**df**	**p**
Mean follow up time (SD) years	2.10 (1.06)	1.69 (1.24)	1.92 (1.21)	5.09	2	0.07
Median DUP in days (IQR)	91.5 (10-447)	82 (17 - 360)	107 (22 - 482)	2.63	2	0.26
Median LOS (IQR) days- total number of days hospitalised during follow up period	22 (0 - 77)	9 (0 - 66)	6 (0 - 50)	5.39	2	0.06
Socio-demographic variables	**EIS n= 222 (%)**	**Non-EIS n=119 (%)**	**Non-eligible n = 215 (%)**	**X^2 test**	**df**	**p**
Gender						
Male	137 (61.7)	59 (49.6)	94 (43.7)	**14.57**	**2**	**0.001**
Female	85 (38.3)	60 (50.4)	121 (56.3)			
Ethnicity						
White British	55 (24.8)	23 (19.3)	55 (25.6)	**20.86**	**12**	**0.05**
Black African	70 (31.5)	25 (21.0)	52 (24.2)			
Black Caribbean	35 (15.8)	17 (14.3)	38 (17.7)			
Other White	24 (10.8)	16 (13.5)	35 (16.3)			
Asian	14 (6.3)	15 (12.6)	14 (6.5)			
Mixed	12 (5.4)	8 (6.7)	7 (3.2)			
Other	12 (5.4)	15 (12.6)	14 (6.5)			
Employment						
Unemployed	121 (58.8)	81 (71.7)	143 (77.3)	**41.27**	**4**	**<0.001**
Student	45 (21.8)	13 (11.5)	2 (1.1)			
Employed	40 (19.4)	19 (16.8)	40 (21.6)			
Education						
School, no GCSE	34 (19.6)	30 (32.6)	34 (27.0)	7.05	6	0.31

School with GCSE	32 (18.4)	14 (15.2)	26 (20.6)			
A level/ Further education	54 (31.0)	25 (27.2)	35 (27.8)			
University	54 (31.0)	23 (25.0)	31 (24.6)			
Relationship status						
Single	151 (70.2)	78 (70.2)	100 (49.0)	**37.12**	**4**	**<0.001**
Married / Steady relationship	46 (21.4)	27 (24.3)	54 (26.5)			
Divorced/Separated	18 (8.4)	6 (5.4)	50 (24.5)			
Living circumstances						
Alone	42 (19.3)	32 (27.8)	86 (41.5)	**30.78**	**4**	**<0.001**
Family/relatives	151 (69.3)	65 (56.5)	109 (52.7)			
Other	25 (11.4)	18 (15.7)	12 (5.8)			
Housing Tenure						
Privately owned	32 (23.7)	11 (12.9)	25 (19.2)	**9.53**	**4**	**0.04**
Rented	80 (59.2)	52 (61.2)	89 (68.5)			
Other	23 (17.0)	22 (25.9)	16 (12.3)			
Pathways to care variables						
Source of referral						
GP/Primary care	75 (33.8)	32 (26.9)	88 (40.9)	7.58	6	0.27
A&E	90 (40.5)	52 (43.7)	75 (34.9)			
Police / Criminal Justice agency	32 (14.4)	17 (14.3)	27 (12.6)			
Other	25 (11.3)	18 (15.1)	25 (11.6)			
Mode of onset						
Acute (within a week)	59 (26.6)	24 (20.2)	33 (15.3)	**14.04**	**6**	**0.02**
Moderate (within a month)	32 (14.4)	29 (24.4)	50 (23.3)			
Gradual (up to 6months)	52 (23.4)	25 (21.0)	44 (20.5)			
Insidious (more than 6 months)	79 (35.6)	41 (34.4)	88 (40.9)			
Time of FEP contact						
Office hours	141 (63.5)	69 (58.0)	151 (70.2)	5.37	2	0.06
Out of hours	81 (36.5)	50 (42.0)	64 (29.8)			
Family involvement						
No	125 (56.3)	82 (68.9)	153 (71.2)	**11.70**	**2**	**0.003**
Yes	97 (43.7)	37 (31.1)	62 (28.8)			
Mode of contact						
Non-compulsory	164 (43.9)	88 (73.9)	169 (78.6)	1.58	2	0.45
compulsory	58 (26.1)	31 (26.1)	46 (21.4)			
Follow up clinical						

variables						
Any hospital admission						
No	74 (33.3)	38 (31.9)	88 (40.9)	3.80	2	0.14
Yes	148 (66.7)	81 (68.1)	127 (59.1)			
Number of hospital admission						
No admission	74 (33.3)	38 (31.9)	88 (40.9)	**9.32**	**4**	**0.05**
1-2	177 (52.7)	58 (48.7)	108 (50.2)			
≥3	31 (14.0)	23 (19.3)	19 (8.9)			
Number of MHA						
No MHA	107 (48.2)	60 (50.4)	122 (56.7)	7.11	4	0.13
1-2	64 (28.8)	41 (34.4)	60 (27.9)			
≥3	51 (23.0)	18 (15.1)	33 (15.4)			
ICD-10 Clinical Diagnosis						
Non-affective psychosis	135 (61.6)	47 (39.5)	87 (40.6)	**35.10**	**4**	**<0.001**
Affective psychosis	28 (12.8)	34 (28.6)	73 (34.1)			
Other (Psychosis NOS)	56 (25.6)	38 (31.9)	54 (25.2)			
Type of service use				**26.20**	**4**	**<0.001**
CMHT	0	16 (13.5)	65 (30.2)			
Assessment & Treatment	0	39 (32.8)	87 (40.5)			
Specialist	0	27 (22.7)	29 (13.5)			
Forensic	0	6 (5.0)	1 (0.5)			
Other	0	31 (26.0)	33 (15.3)			
Administrative outcomes						
Active patient in SLaM	102 (45.9)	37 (31.1)	81 (37.7)	16.22	10	0.09
Discharged to GP	77 (34.7)	56 (47.1)	99 (46.1)			
Moved out of area/Transferred to other MH provider	38 (17.1)	24 (20.2)	31 (14.4)			
Moved abroad	4 (1.8)	1 (0.8)	2 (0.9)			
Prison	1 (0.5)	1 (0.8)	0			
Died	0	0	2 (0.9)			

11.3 Associations between EIS status and number of hospital admissions during follow-up

At this stage of the analysis, I have used the same statistical procedures employed in Chapter 10, section 10.6 (i.e. negative binomial regression) to assess the association between number of hospital admissions and early intervention service use. Unadjusted and adjusted negative binomial regression and potential confounders were adjusted for as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender and ethnicity

Model 3 – adjusted for age, gender, ethnicity, level of education and employment status

Model 4 – adjusted for age, gender, ethnicity, level of education, employment status, and diagnosis

All analyses in the unadjusted and adjusted models here were carried out using complete case sample, i.e. only 366 (66% of whole sample) for whom data were complete for the main exposure variable and each of the confounding variables (e.g. information on education level and employment status was missing for 191 patients and information on EIS was not available for one patient). This will allow comparison of associations across the models.

From Table 11.2, strong and increasing associations between number of hospital admissions and patients in the non-EIS group were observed. Unadjusted analysis showed that the non-EIS group (IRR = 2.35; 95% CI 1.47 – 3.73) experienced more hospital admissions compared with patients who received EIS. This evidence remained robust and became stronger when age, gender and ethnicity were controlled for in model 2 (adj. IRR = 3.32; 95% CI 2.05 – 5.37). The effect size attenuated slightly in models 3 and 4 but remained strong and robust (Table 11.2). However, there was no evidence of associations between number of hospital admissions and being non-eligible for EIS in models 1–3, but a weak evidence of association

emerged when demographic, socioeconomic status and diagnosis were controlled for in model 4 (adj. IRR = 2.09; 95% CI 0.87 – 5.04, p = 0.09).

Table 11.2: Unadjusted and adjusted rate ratios for number of hospital admission and EIS use (n=366)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
EIS use								
EIS	1.00		1.00		1.00		1.00	
Non-EIS	**2.35**	**1.47 – 3.73 (<0.01)**	**3.32**	**2.05 – 5.37 (<0.01)**	**3.04**	**1.85 – 4.99 (<0.01)**	**3.30**	**1.98 – 5.49 (<0.01)**
Non-eligible	0.69	0.42 – 1.13 (0.14)	1.96	0.83 – 4.61 (0.12)	1.77	0.75 – 4.20 (0.19)	2.09	0.87 – 5.04 (0.09)

Model 1 – unadjusted; Model 2- adjusted for ethnicity, age, gender; Model 3- adjusted for ethnicity, age, gender, level of education and employment status; Model 4- adjusted for ethnicity, age, gender, level of education, employment status and diagnosis

11.4 Associations between number of compulsory admissions and EIS use during follow-up

In examining associations between number of compulsory admissions and early intervention service use, negative binomial regression analysis was performed. Univariate and adjustment for potential confounders were carried out as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender and ethnicity

Model 3 – adjusted for age, gender, ethnicity, level of education and employment status

Model 4 – adjusted for age, gender, ethnicity, level of education, employment status and diagnosis

Table 11.3 shows the results for each model. In the univariable model, there was a weak evidence of association with increased compulsory admission and the non-EIS group. However, in the subsequent multivariable models, compared with those who received EIS, there was strong evidence of associations between number of compulsory admissions and individuals in the non-EIS group with increasing effect size particularly from (adj. IRR = 1.87; 95% CI 1.02 – 3.44) in model 3 to (adj. IRR = 2.22; 95% CI 1.18 – 4.18) in model 4. There was no evidence of association between compulsory admission and individuals who were not eligible for EIS.

Table 11.3: Unadjusted and adjusted rate ratios for number of compulsory admission and EIS use (n=366)

	Model 1	**95% confidence interval (p-value)**	**Model 2**	**95% confidence interval (p-value)**	**Model 3**	**95% confidence interval (p-value)**	**Model 4**	**95% confidence interval (p-value)**
EIS use								
EIS	1.00		1.00		1.00		1.00	
Non-EIS	1.75	0.94 -3.26 (0.07)	**1.89**	**1.04 – 3.44 (0.03)**	**1.87**	**1.02 – 3.44 (0.04)**	**2.22**	**1.18 – 4.18 (0.01)**
Non-eligible	0.93	0.51 – 1.69 (0.81)	1.12	0.40 – 3.11 (0.82)	1.08	0.39 – 2.93 (0.87)	1.23	0.44 – 3.76 (0.68)

Model 1- unadjusted; Model 2- adjusted for ethnicity, age, gender; Model 3- adjusted for ethnicity, age, gender, level of education and employment status; Model 4- adjusted for ethnicity, age, gender, level of education, employment status and diagnosis

11.5 Associations between length of hospital stay and EIS use during follow-up

The next stage of analysis sought to assess whether the use of an early intervention service was independently associated with length of hospital stay after controlling for potential confounders. In keeping with the analytical methods used in section 10.8 (chapter 10), negative binomial regression was employed here to estimate the rate ratios for length of hospital stay by EIS status.

Four unadjusted and adjusted regression models were fitted as follows:

Model 1 – unadjusted

Model 2 – adjusted for age, gender and ethnicity

Model 3 – adjusted for age, gender, ethnicity, level of education and employment status

Model 4 – adjusted for age, gender, ethnicity, level of education, employment status, and diagnosis

In Table 11.4, both the univariable and multivariable analyses showed that there were no associations between length of hospital stay and non-EIS nor non-eligible groups compared with those who used early intervention service (EIS group).

Table 11.4: Unadjusted and adjusted rate ratios of length of stay during hospital admission and EIS use (n=366)

	Model 1	95% confidence interval (p-value)	Model 2	95% confidence interval (p-value)	Model 3	95% confidence interval (p-value)	Model 4	95% confidence interval (p-value)
EIS use								
EIS	1.00		1.00		1.00		1.00	
Non-EIS	1.37	0.44 – 4.19 (0.57)	1.59	0.53 – 4.72 (0.25)	1.56	0.52 – 4.65 (0.41)	1.66	0.61 – 4.48 (0.31)
Non-eligible	0.50	0.24 – 1.05 (0.07)	0.38	0.05 – 2.68 (0.33)	0.28	0.02 – 2.69 (0.27)	0.31	0.03 – 2.64 (0.28)

Model 1 – unadjusted; Model 2- adjusted for ethnicity, age, gender; Model 3- adjusted for ethnicity, age, gender, level of education and employment status; Model 4- adjusted for ethnicity, age, gender, level of education, employment status and diagnosis

11.6 Associations between ethnicity and service use outcomes by early intervention service status

This stage of the analyses addressed the objective of whether there are ethnic differences in service use outcomes at follow-up in relation to early intervention service use status. Up until this stage, the data have been stretched and manipulated to consider predictors of outcomes and in particular factors contributing to ethnic differences in all the outcomes considered thus far. As the number of statistical tests increases, the possibility of observing associations that are due to chance also increases. This caveat is already apparent in relation to the analysis of factors associated with ethnic variations in the pathways to care stratified by early intervention service use status (Chapter 9). On the basis of this limitation, the analyses for this final stage employ a straightforward test of association between ethnicity and service use outcomes by EIS status using Kruskal Wallis tests of association. The intention is to explore whether and where there are ethnic differences in the three sub-groups of EIS status.

11.7 Associations between ethnicity and number of hospital admissions by early intervention service status

Table 11.5 shows there was strong evidence that in the EIS group, Black African and 'Mixed' ethnic group patients were more likely to experience multiple hospitalisations, compared with White British patients (IQR (0-2); (0-1.5) and (0-1) respectively $X^2 = 13.71$, df = 6, p = 0.03). However, Asian patients were less likely to experience hospital admission in the EIS group. In the non-eligible group, there was weak evidence of more hospital admissions among White British and 'Mixed' ethnic group patients and no hospital admissions among the 'Other' ethnic group (Table 11.5). Meanwhile, ethnic variations for hospital admissions were not evident in the non-EIS group.

Table 11.5: Associations between ethnicity and number of hospital admissions by use of EI services

	Non- ELIGIBLE N=215			Non- EIS N= 119			EIS N=222		
	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)
White British	55 (25.6)	0 (0 -1)	10.7; 6 (0.09)	23 (19.3)	0 (0 -1)	7.22; 6 (0.30)	55 (24.8)	0 (0 -1)	**13.71; 6 (0.03**)
Black African	52 (24.2)	0 (0)		25 (21.0)	0 (0 -2)		70 (31.5)	**0 (0 -2)**	
Black Caribbean	38 (17.7)	0 (0)		17 (14.3)	0 (0 -1)		35 (15.8)	0 (0 -1)	
White Other	35 (16.3)	0 (0)		16 (13.4)	0 (0-1)		24 (10.8)	0 (0 -0.5)	
Asian	14 (6.5)	0 (0)		15 (12.6)	0 (0 -1)		14 (6.3)	0 (0-0)	
Mixed	7 (3.3)	0 (0 -1)		8 (6.7)	1 (0 -1)		12 (5.4)	**0 (0 -1.5)**	
Other	14 (6.5)	0 (0)		15 (12.6)	0 (0)		12 (5.4)	0 (0 -0.5)	

11.8 Associations between ethnicity and number of compulsory admissions by early intervention service status

Table 11.6 presents associations between ethnicity and number of compulsory admissions by EIS status. There was strong evidence that elevated risk of compulsory admissions was present for Black African patients compared with White British patients in the EIS group (IQR (0 -3) vs. (0 -1), $X^2 = 15.03$ df = 6 p = 0.01). Asian patients in the EIS group were less likely to be compulsorily detained. In the non-EIS group, the evidence (although weak) also suggests that Black African patients were more likely to experience multiple compulsory admissions compared with White British patients (IQR (0-4) vs. (0-1) $X^2 = 11.50$, df = 6 p = 0.07). Meanwhile, 'Other' ethnic group patients in the non-EIS group did not experience compulsory admission. There was no evidence of ethnic differences for compulsory admission among patients in the non-eligible group.

Table 11.6: Associations between ethnicity and number of compulsory admissions by use of EI services

	Non- ELIGIBLE N=215			Non- EIS N= 119			EIS N= 222		
	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)
White British	55 (25.6)	0 (0 -1)	1.79; 6 (0.93)	23 (19.3)	0 (0 -1)	11.50; 6 (0.07)	55 (24.8)	0 (0 -1)	**15.30; 6 (0.01)**
Black African	52 (24.2)	0 (0 -1)		25 (21.0)	1 (0 -4)		70 (31.5)	**1 (0 -3)**	
Black Caribbean	38 (17.7)	0 (0- 2)		17 (14.3)	0 (0 -1)		35 (15.8)	0 (0 -2)	
White Other	35 (16.3)	0 (0 -1)		16 (13.4)	0 (0 -1.5)		24 (10.8)	0 (0 -2)	
Asian	14 (6.5)	0 (0 -1)		15 (12.6)	0 (0 -1)		14 (6.3)	0 (0)	
Mixed	7 (3.3)	0 (0 -1)		8 (6.7)	0 (0 -2)		12 (5.4)	0.5 (0 -1.5)	
Other	14 (6.5)	0 (0)		15 (12.6)	0 (0)		12 (5.4)	0 (0- 1.5)	

11.9 Associations between ethnicity and length of hospital stay by early intervention service status

Table 11.7 shows the associations between ethnicity and length of hospital stay by EIS status. In the EIS group, there was strong evidence that compared with White British, Black African and Black Caribbean patients experienced longer duration of hospital stay (IQR (0 - 14) vs. (1 -97), (0 -98) respectively, $X^2 = 17.83$ df = 6 $p<0.01$). In both non-EIS and non-eligible groups, ethnic differences in length of hospital stay were not evident (Table 11.7).

Table 11.7: Associations between ethnicity and length of hospital stay by use of EI services

	Non- ELIGIBLE N=215			Non- EIS N= 119			EIS N= 222		
	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)	Number in sample (%)	Median (IQR)	Kruskal Wallis test; df (p-value)
White British	55 (25.6)	5 (0 -50)	6.82; 6 (0.33)	23 (19.3)	7 (0 -60)	4.48; 6 (0.59)	55 (24.8)	14 (0-14)	**17.83; 6 (<0.01)**
Black African	52 (24.2)	2 (0 -53.5)		25 (21.0)	29 (2 -157)		70 (31.5)	**46.5 (1 -97)**	
Black Caribbean	38 (17.7)	0 (0 -50)		17 (14.3)	29 (0 -106)		35 (15.8)	**28 (0-98)**	
White Other	35 (16.3)	15 (0 -32)		16 (13.4)	7 (0-51.5)		24 (10.8)	8.5 (0 -38.5)	
Asian	14 (6.5)	24 (1 -63)		15 (12.6)	12 (2 -29)		14 (6.3)	4 (0 -22)	
Mixed	7 (3.3)	19 (0-137)		8 (6.7)	17.5 (3-39.5)		12 (5.4)	6 (0 -95)	
Other	14 (6.5)	0 (0-11)		15 (12.6)	8 (0 -28)		12 (5.4)	0 (0 -38.5)	

11.10 Summary

In summary, the analyses carried out in the first part of this chapter revealed that independent of potential confounders, patients who were eligible for EI services but who did not access them (non-EIS), were at increased risk of multiple hospital admissions and compulsory detentions compared with the EIS group. There were no differences in length of hospital stay by EIS status.

The stratified analysis by EIS status for ethnic differences shed some light on where associations between ethnicity and service use outcomes lie within the EIS strata. Compared with White British patients, Black African patients who accessed EI services experienced poor outcomes in the three domains examined (hospital admission, compulsory admission and length of stay). There was also strong evidence that Black Caribbean patients in the EIS group experienced longer duration of hospital stay. Meanwhile, 'Mixed' ethnic group patients were also more likely to be compulsorily detained in the EIS group.

Interestingly, ethnic differences for service use outcomes were not evident in the non-EIS users or among those who were not eligible for EIS.

In conclusion, the evidence shown in this chapter partly supports the hypothesis that patients in the non-EIS group would have poorer service use outcome. There was also a robust evidence of ethnic variations in the service use outcomes for the EIS group, which appears to suggest that EIS may actually not have influenced patient outcomes by ethnicity. The implications of these findings will be discussed in more detail in Chapter 12.

11.11 Limitations

As well as the issue of attrition, another key limitation of the follow up results is multiple testing. As discussed in section 11.6, increasing numbers of statistical tests increase the likelihood of finding a statistically significant difference due to chance. Within this chapter, multiple tests were conducted to assess associations between service outcomes and EIS membership, but a simple descriptive analysis was employed to explore the ethnic differences in service use outcomes. This means that only the p value threshold was used to assess likelihood of associations between the outcomes and ethnicity. Therefore, firm conclusions cannot be drawn from the findings without formally testing the hypothesis that outcome would differ by ethnic group and by EIS membership.

12 Chapter 12: General Discussion and Methodological Consideration

12.1 Synopsis

In this chapter, after summarising the key findings in relation to the hypotheses that were set out in Chapter 1, I will address the methodological strengths and limitations of the study. This will be followed by methodological considerations put in place to mitigate potential shortcomings. I will then attempt to infer possible explanations, draw together the key findings and offer a broad interpretation of the results in relation to previous studies. Finally, a discussion of some possible implications and future research on ethnicity, service use, course and outcome and psychosis will follow.

12.2 Summary of findings

This thesis tested a number of hypotheses about the incidence of psychosis, pathways to care, service use outcome and the role of early intervention services and association with ethnicity. The following hypotheses were supported by the results:

Incidence of psychosis

- Incidence of psychosis was higher among Black African Africans (SIR = 120.8 per 100,000 PPY) and Black Caribbean (SIR = 93.6 per 100,000 PPY) ethnic groups compared with the White British (SIR = 39.4 per 100,000 PPY) population.
- The magnitude of risk of psychosis was lower for Black Caribbeans (adj. IRR = 2.81; 95% CI 2.15 – 3.63) than those reported in the AESOP study (adj. IRR = 6.7; 95% CI 5.4 – 8.3), but little or no change for the Black African population (adj. IRR = 3.59; 95% CI 2.80 – 4.55) compared with the AESOP study (adj. IRR = 4.1; 95% CI 3.2 – 5.3).

Pathways to care characteristics at first contact for psychosis

- Increased risk of hospital admission at first contact for psychosis was associated with Black African ethnicity (adj. OR = 2.38; 95% CI 1.27 – 4.42).
- Increased risk of compulsory admission at first contact for psychosis was associated with Black African ethnicity (adj. OR = 3.23; 95% CI 1.57 – 6.63).

- Ethnic differences in GP referral were smaller for Black African (non-EIS users: adj. OR = 0.37; 95% CI 0.07 – 2.00; EIS users: adj. OR = 0.57; 95% CI 0.20 – 1.62) and Black Caribbean (non-EIS users: adj. OR = 0.18; 95% CI 0.01 – 2.47; EIS users: adj. OR = 1.20; 95% CI 0.37 – 3.87) ethnic groups compared with findings from 15 years ago (the AESOP study).
- Ethnic differences in criminal justice referral were smaller for Black African (non-EIS users: adj. OR = 0.26; 95% CI 0.01 – 4.09; EIS users: adj. OR = 1.35; 95% CI 0.35 – 5.20) and Black Caribbean (non-EIS users: no cases; EIS users: adj. OR = 1.06; 95% CI 0.16 – 7.01) ethnic groups compared with findings from 15 years ago (the AESOP study).

Service use outcomes at two-year follow-up

- Higher rates of hospital admission were associated with Black African (adj. IRR = 1.98; 95% CI1.12 – 3.48) ethnicity compared with White British at the two-year follow-up.
- Higher rates of compulsory admission were associated with Black African (adj. IRR = 2.27; 95% CI 1.18 – 4.34) ethnicity compared with White British at the two-year follow-up.
- Worse service use outcomes were associated with non-EIS status, hospital admission (adj. IRR = 3.30; 95% CI 1.98 – 5.49) and compulsory admission (adj. IRR = 2.22; 95% CI 1.18 – 4.18) compared with the EIS group at the two-year follow-up.

The following hypotheses were not supported by the results:

- Increased risk of hospital admission at first contact for psychosis was not associated with Black Caribbean ethnicity (adj. OR = 1.20; 95% CI 0.57 – 2.49).
- Increased risk of compulsory admission at first contact for psychosis was not associated with Black Caribbean ethnicity (adj. OR = 1.78; 95% CI 0.75 – 4.24).
- Increased risk of police/criminal justice referral was not associated with Black African (adj. OR = 1.05; 95% CI 0.43 – 2.57) or Black Caribbean (adj. OR = 1.28; 95% CI 0.43 – 3.77) ethnicity.

- Reduced likelihood of GP referral was not associated with Black African (adj. OR = 0.63; 95% CI 0.33 – 1.19) or Black Caribbean (adj. OR = 0.54; 95% CI 0.35 – 1.15) ethnicity.
- Ethnic differences in accident and emergency referral were actually evident and larger for Black African (adj. OR = 7.34; 95% CI 1.15 – 46.74) and Black Caribbean (adj. OR = 48.89; 95% CI 3.49 – 684.71) ethnic groups compared with findings from 15 years ago (the AESOP study).
- Higher rates of hospital admission at follow-up were not associated with Black Caribbean (adj. IRR = 1.13; 95% CI 0.58 – 2.19) ethnicity compared with White British ethnicity.
- Higher rates of compulsory admission at follow-up were not associated with Black Caribbean (adj. IRR = 1.27; 95% CI 0.59 – 2.74) ethnicity compared with White British ethnicity.
- Longer length of hospital stay at follow-up was not associated with Black African (adj. IRR = 1.67; 95% CI 0.29 – 9.52) or Black Caribbean (adj. IRR = 0.0.49; 95% CI 0.04 – 4.98) ethnicity.

12.3 Methodological Strengths and Limitations

12.3.1 Strengths

In identifying first episode psychosis cases using the Clinical Record Interactive Search database (CRIS) and collecting a wide range of data relating to risk factors for psychosis and service use, a range of important research questions were addressed. Since the completion of the AESOP study, this study (CRIS-FEP) is one of the largest studies of first episode psychosis.

The key strengths of this study are its large sample size, comprehensive case identification strategy, the involvement of clinicians in screening clinical records using a standardised screening schedule (PSS, Jablensky et al. 1992), inter-rater reliability tests across the measurements and ‘real time’ information from the case register. Each of these will be discussed in more detail below. Furthermore, the availability of AESOP data on pathways to care allowed for comparison of two datasets collected in the same study area at different

time points to assess change over time in pathways to care and service use characteristics by ethnic groups.

- **Comprehensive case identification**

To our best knowledge, this is one of few studies to manually screen clinical records for symptoms of psychosis, carefully elicit date of onset and match cases' resident address to the study catchment area. The three-stage screening and monthly consensus meetings with the principal investigator ensured that only cases that met the inclusion and exclusion criteria were included in the sample. In this study, more people with clear psychotic symptoms were identified; we found a higher incidence rate of psychosis compared with two previous studies that have estimated incidence of psychosis among ethnic minority groups (Fearon et al., 2006a, Coid et al., 2008b). Importantly, this thesis presents a marked improvement on other case ascertainment, e.g. face-to-face first contact methods as used in previous studies (Coid et al., 2008b, Cheng et al., 2011b).

- **Large sample size**

This study was conducted using the same inclusion/exclusion criteria and within the same catchment area of south London as the AESOP study over a decade ago. We had a large sample that is representative of the catchment area population of patients that present to mainstream mental health services. Data on the 18 ethnic group categories of the 2011 Census were collapsed into seven groups for clarity of presentation. Doing so provides an improvement on previous studies which tend to merge ethnic groups crudely, e.g. Black, White, Asian etc. The size of the sample in this study enabled a more fine-grain classification of ethnic groups, e.g. separating out Black African and Black Caribbean. In addition, White British instead of an all-White group was used as the reference group in the multivariable analysis. By using the 2011 Census data, which was closer to the time of this study and which accounted for under-enumeration in certain minority ethnic groups, it is believed that the most accurate denominator was used, particularly in estimating the incidence rates of psychosis.

- **Human resources and hours spent by experts in identifying first episode psychosis cases**

In order to undertake an endeavour such as screening clinical records to identify patients with psychotic features who met the well-defined inclusion criteria in this study, some clinical expertise is required for accuracy. The screening exercise was undertaken by clinically trained personnel: me – a psychiatric nurse, another PhD candidate – a psychiatrist, a foundation medical doctor, an experienced clinical researcher and the principal investigator. In total, four and a half years were spent screening, extracting and validating demographic, socioeconomic, pathways to care, service use and clinical data. While this is a resource-intensive and time-consuming approach, it offers confidence in data validity and integrity as will be discussed next. In addition, the manual annotation approach in this thesis is an improvement on other case register studies that tend to rely on clinically recorded diagnoses or other clinical features which may vary according who is doing the recording and may not be recorded at all.

- **Reliability scores**

Researchers undertaking the screening exercise in this study received training on all the screening and data collection measures. Inter-rater reliability was tested between researchers at each stage of the data collection and high reliability scores were achieved as discussed and shown in section 6.5.4.

- **Real-time information**

Since the CRIS database pulls data daily and directly from the SLaM electronic health record, it provides valuable real-time information on routine mental healthcare. This automatically generates and accumulates large volumes of data ready for research interrogation.

12.3.2 Overall limitations

As discussed in section 7.6, inaccurate ethnic classification will lead to inaccurate findings. The current ethnic classification is based on an imperfect categorisation that combines people who may have very different cultural backgrounds (e.g 'black Africans come from several African countries and indeed, tribes within countries each with different social and

cultural traditions). This inevitably can only lead to imperfect findings but is an issue of the wider society in general, not just a concern of this thesis.

Specific to the incidence investigation, is an issue surrounding diagnostic accuracy, particularly within a case register. Several studies have used case registers to estimate the incidence of psychosis, but many have done so based on the recorded clinical diagnosis with no attempt to check the likely accuracy of the diagnosis in terms of a detailed examination of the constituent symptoms and signs in the case notes (Smith et al., 2006, Kennedy et al., 2004, Boydell et al., 2012). In the present study, diagnosis was based on manually screening the detailed clinical records for symptoms of psychosis, carefully eliciting the date of onset and matching each case's resident address to the study catchment area. Of course even this is not perfect as the symptoms and signs of illness that go to make up the diagnosis are not assessed using standardised rating instruments as used in epidemiological surveys, but are instead based on the appraisal of different clinicians of varying levels of expertise. Further, if information is not recorded, it is not known whether the symptoms was genuinely absent or was missed by the clinician.

Despite the large sample size and denominator of 852,920 person-years at risk, the high rate ratios observed in some smaller ethnic groups may be due to chance, given the small sample size and wide confidence intervals in those groups. This also applies to the associations seen in these groups and pathways to care and service use outcomes.

In addition, in spite of the comprehensive case finding in this study, it is possible that some cases may be missed as we have only included people who sought help from publicly funded mental health services within the catchment area and have not accounted for those who may have accessed privately funded services. It is also possible that our search criteria were not exhaustive and the screening was not 100% watertight. However, the possibility of missing cases owing to our inception cohort design was minimal because people presenting with major mental health issues such as psychosis tend to present to statutory specialist mental health services directly or are referred by their general practitioners or emergency departments to specialist mental health services. This means that although we did not identify cases through other sources, we are much more confident about the quality of our inclusion since SLaM is the only mental healthcare provider for our study catchment area

and CRIS holds multi-disciplinary clinical information for services both in the community and hospitals (Perera et al., 2016).

As with pathways to care and compulsory admission investigation, the analyses were based on cross-sectional data, therefore direction of causality cannot be inferred. Further within the pathways to care investigation, crude dichotomies have been used in some variables to simplify analyses. These include criminal justice agency (yes) – 'police/courts/prisons' versus none. These dichotomies are likely to over simplify the true nature of criminal justice involvement in care pathway by ethnicity. However, simplifications at this stage are likely to clarify the areas on which future research are focussed.

Specific to the outcomes investigation, is an issue surrounding attrition. Within this thesis a sizeable number of participants had left SLaM services by the end of the study. Had this study been a face-to-face survey, where participants had to be re-contacted for follow up data, the impact of the attrition would have been greater in this study. However, owing to the ability to take full advantage of the clinical records (Morrison et al., 1997), particularly information on dates of discharge for each participant, the whole sample was included in the analyses.

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12.4 Methodological considerations

In all research studies inference is a key activity, which is a process of passing from observations to generalisations (Prince et al., 2003). In epidemiology, an observed association between an exposure and outcome does not mean one caused the other. However, before the direction of causality can be considered the role of bias, chance and confounding must be assessed. Each will be considered in turn below in relation to this study.

12.4.1 The role of bias

In order to ensure a sample is representative, it is important the selection process is random, so that the sample does not encounter systematic errors that vary between exposure and outcome variables. Selection bias (occurring at study design phase) and information bias (occurring at data collection phase) are the two main sources of non-random bias.

12.4.2 Selection bias

Selection bias occurs when a sample includes or excludes certain people systematically and the differences in the characteristics of those selected are related to the exposure and outcome of interest (Susser et al., 2006).

In this study, efforts were made to reduce selection bias by using the Clinical Record Interactive Search (CRIS) system, which allowed us to comprehensively interrogate clinical records to screen and identify first episode psychosis cases presenting to any adult mental health service both in hospital inpatients and community-based services, including those presenting to psychiatric liaison services in accident and emergency departments. Our included cases had to exhibit evidence of psychotic symptoms, and scored at least 2 or more for psychotic symptoms as assessed by the Psychosis Screening Schedule (Jablensky et al., 1992a). The screening procedure was conducted on a weekly basis which provides a prospective observation of point of contact of new episode of psychosis cases. This also reduces the possibility of missing cases or of differences between ethnic groups occurring since our screening procedures were based on psychopathology over the course of the study period; therefore, it is unlikely that clear psychotic symptoms in any ethnic group would not have been recorded or missed in our search strategy. Further, our screening approach ensured that all psychosis diagnostic spectrums were included rather than focussing on specific diagnoses since there is evidence that psychiatric diagnoses are unstable over time (Heslin et al., 2015). Another form of selection bias is attrition. The completeness of data is important to the success of a cohort study, but inherent in any kind of cohort study is some degree of attrition of participants. In this study, around 60% of the sample had left by the end of the study. However, we were able to determine date of discharge for each individual and therefore the amount of data each participant contributed to the follow-up period were included in the analyses.

12.4.3 Information bias (observer)

In cohort studies information bias may arise due to random error in information. To reduce information bias 'blind' ratings are considered most desirable (Lee et al., 2007). However, this is not a plausible method for examining the influence of ethnicity on the risk of psychosis, pathways to care and outcome using clinical records. Careful considerations were

taken in this study to ensure misclassification of exposure and outcome were kept to a minimum. To minimise misclassification in the outcome data, researchers underwent intensive training for screening manually for psychosis as well as other data collection schedule at the outset of the study. A three-stage manual screening procedure was employed in identifying first episode psychosis cases as described in Chapter 6 (section 6.5.2). Further, to reduce information bias in the exposure data, careful steps were taken to ensure consistency in the ascription of ethnic groups as discussed in the Methods chapter 6 (section 6.5.4).

12.4.4 Chance

In this thesis, despite the relatively large sample size of 558 patients but given the multiple testing of associations between ethnicity and a number of outcomes (i.e. incidence of psychosis, compulsory admissions at first episode, as well as clinical and service use outcome hospital admission, length of stay), it is still possible that some positive associations ($p<0.05$) observed may have arisen due to chance. For instance, in estimating the age-specific incidence rate ratios by ethnic groups, the small numbers of patient of Asian, Mixed and Other ethnic groups may have influenced the observed elevated risk as the range of confidence intervals were very wide for these groups. However, evidence of elevated risk of psychosis among Black African and Black Caribbean is less likely to be due to chance given the narrow confidence intervals. Further, some findings in this study are consistent with the wider literature. However, some of the associations observed may be due to chance. For example, data was complete for 367 patients, therefore for some analyses statistical power was slightly reduced and raises the question of biases in the estimates of associations. However, where necessary, data were analysed in two ways a) on the whole sample and b) on the 367 people for whom data on all variables were complete. This helped in assessing the impact missing data may or may not have on the observed associations. The associations we observed between female patients of Asian and 'Mixed' ethnic groups and compulsory admissions at FEP were imprecise due to the small sample size in these groups. Therefore, only tentative conclusions can be drawn from the results for these groups. More research with larger sample sizes particularly for Asian, Mixed and Other ethnic group is needed for replication of these results.

12.4.5 Confounding

A-priori sociodemographic and socioeconomic confounders (age, gender, and employment status and education level) were adjusted for in this study with the exception of incidence of psychosis in which only age and gender were controlled for. In line with previous studies, associations between ethnicity, incidence of psychosis, compulsory admission, hospital admission and length of hospital stay were investigated with and without adjustment for the *a priori* confounders. Furthermore, other variables identified in the literature as potential confounders in relationship between ethnicity and outcomes of interest namely, diagnosis, previous service use and duration of untreated psychosis were selected in this study as potential confounders

Meanwhile it is possible that we did not identify or measure other potential confounders in this study which may distort the validity of positive associations observed. For example, a key limitation of the incidence analysis was in the lack of data on socioeconomic status for our denominator sample and therefore did not adjust for them (such as employment status, education level, income level etc.) which may possibly explain differences in incidence rates. Previously, where investigators have adjusted for socioeconomic factors, this made little difference to the estimates. For example in the East London First Episode study, the authors adjusted for socioeconomic variables but these did not explain the elevated rate of psychosis observed in the minority ethnic group patients (Kirkbride et al., 2008). Similarly in a Swedish study of all persons admitted for schizophrenia, where socioeconomic status was controlled for, the elevated risk of schizophrenia remained significant among immigrants (Hjern et al., 2004).

12.5 Explaining the findings and relationship with previous studies

The results from this thesis suggest that changes have occurred in the last two decades in the relationship between first episode psychosis and minority ethnic status, albeit for one group in particular – Black Caribbean. Evidence from the incidence of psychosis estimates in this study appears to suggest that while rates of psychosis were high among Black Africans, a notable reduction in magnitude of risk (rate ratios) than has previously been reported was

observed among Black Caribbeans. The remainder of the results consistently show that only the Black African group were more likely to be detained compulsorily at first contact for psychosis and were more likely to have poorer outcomes at follow-up, i.e. higher numbers of hospital admissions and compulsory admissions, and they were also more likely to experience these poor outcomes despite the use of early intervention services compared with White British patients.

However, the findings from this study highlight the complexities around ethnicity and mental disorder. In interpreting the findings, the scope and depth devoted to explaining differences in the ethnic groups is uneven. This is because, although this thesis has included and reported on all ethnic groups, it is concerned with the outcomes of three key ethnic groups, i.e. White British, Black African and Black Caribbean. Therefore, it seems important to give much more in-depth explanations to these ethnic groups and so the discussion surrounding the findings is guided by the hypotheses under investigation and each will be addressed in turn.

12.5.1 Interpreting the Incidence findings and relationship to previous studies

Main findings

The findings of higher incidence of first episode psychosis among Black African and Black Caribbean populations are consistent with a number of previous research studies. In this study, standardised incidence rates (SIR) of 120.8/100,000 and 93.6/100,000 persons-years (PPY) were observed among the Black African and Black Caribbean ethnic groups compared with White British (39.4/100,000). This is comparable with the incidence rates of FEP found by Coid et al. (2008) (Black Caribbean: 90.8/100,000). But in contrast to findings by both (Fearon et al., 2006a, Coid et al., 2008b), incidence rates of psychosis seem to have increased for the Black African ethnic group in this study (80.6 PPY and 73.6 PPY vs. 120.8 PPY respectively).

However there was evidence in this study that the risk of psychosis has attenuated among Black Caribbean groups but there is little or no change in the Black African groups compared with 15 years ago – but the difference was more striking for the Black Caribbean group. For example, in contrast to the AESOP and other previous studies, this study showed a lower differential rate ratio for psychosis (adj. IRR = 2.81; 95% CI 2.15 – 3.68) for the Black

Caribbean ethnic group compared with the rate ratio of (adj. IRR = 4.2; 95% CI 3.0 – 5.8) reported by (Coid et al., 2008b); and (adj. IRR = 6.7; 95% CI 5.7 – 8.3) reported by (Fearon et al., 2006a).

Among the other ethnic minority groups included in this study, the Asian ethnic group had a modest rate of psychosis (51.9 PPY) and incidence rate ratio of 1.5. This is slightly different from two previous studies that investigated this group; Bhugra et al. (1997) reported (IR = 37.0 and IRR = 1.38 95% CI 0.81 – 2.33) and Coid and colleagues who found (IR = 37.1 and IRR = 1.7 95% CI 1.2 – 2.3). However, the findings are similar to that reported by (Fearon et al., 2006a) (IRR = 1.5; 95% CI 0.9 – 2.4).

The 'Other' ethnic group also showed elevated rates of psychosis (126.4 PPY) compared with the White British population. Whilst this is higher than those reported in previous studies (Fearon et al. 2006), the estimate needs to be considered with caution. This is because the 'Other' group in this study comprised of any other ethnic group and some newly added ethnic groups in the 2011 Census, e.g. Arab, and so it is possible that the denominator data may not be accurate; therefore this finding may be artificially inflated if under enumeration is present in the denominator population.

Regarding age and gender, the present findings were consistent with previous studies (Cheng et al., 2011b, Coid et al., 2008b). It was observed that rates were at their peak among men between the ages 18–35 years which is in keeping with findings by (Fearon et al., 2006a, Kirkbride et al., 2009). Elevated rates were also observed among women over the age of 35 years, and late onset of psychosis has been widely reported among females, particularly those of Asian ethnic group (Bhugra et al., 1997).

Explaining the difference in incidence rates: Acculturation, generational status and ethnic density

The reduced discrepancies between Black Caribbean and White British ethnic groups may be explained by possible post-migration experiences and material position among the Black Caribbean group, e.g. acculturation, support networks, aspiration and achievement. In this study, data on sociodemographic factors showed that there were no differences between Black Caribbean and White British patients on relationship status, housing tenure, living

arrangements and social isolation variables. Several studies have shown that social networks and ethnic density are important factors in understanding elevated rates of psychosis (Boydell et al., 2001, Mallett et al., 2002). While unemployment was ubiquitous in this thesis sample, which is consistent with previous studies, it is possible that other social disadvantages experienced by minority ethnic groups (e.g. living alone, poor housing, poor education and social isolation), particularly in the post-migration phase, may have improved for the Black Caribbean population. For example, given that this study was conducted in the same catchment area as the AESOP London site, comparing sociodemographic characteristics between this study and those reported for the AESOP London site (Morgan et al. 2006) would shed some light on the changes that may have occurred. First, the proportion of Black Caribbean patients living alone have reduced from (AESOP: 56.3% to CRIS-FEP: 35.2%); being educated to a higher level have improved (AESOP: 4.9% vs CRIS-FEP: 14.7%) and being in a stable relationship also showed some improvement (AESOP: 19.4% vs. CRIS-FEP: 22.1%). In addition, there is a stream of evidence that suggests in areas where Black and minority populations make up a greater proportion of the population, their risk of psychosis was no greater than that of the majority population (Schofield et al., 2011, Das-Munshi et al., 2012, Veling et al., 2008). As previously described (Chapter 5), the Black Caribbean ethnic group (15.2%) was one of the larger groups of the minority ethnic population in Lambeth and Southwark. Therefore, it is also plausible that the Black Caribbean group may have developed community social networks that encourage mutual support, a sense of belonging and enriched social relationships through social capital and acculturation (Sharpley et al., 2001, Bhugra and Becker, 2005). The argument of acculturation, defined as 'a phenomena which results when groups of individuals from different cultures come into continuous first hand contact with subsequent changes in the original culture pattern of either one or both groups' (Bhugra 2004; Berry 1976), seems quite relevant to the Black Caribbean sample in this study. For instance, in addition to the sociodemographic changes described above, generational acculturation may have occurred in the Black Caribbean group. The data in this study showed that the majority of the Black Caribbean group were born in the UK (64.2%). Therefore, although this was not measured specifically here, it is possible that there are up to second or third generations of the Black Caribbean group in the study population and the wider UK, since migration into the UK

among the Black Caribbean population was highest post-World War II, mostly from the 1950s onwards (Coid et al., 2008b, Chamberlain, 2002).

Inversely, the above argument could not be said for the Black African ethnic group in this study. A higher rate of psychosis was found among the Black African group (SIR = 120/100,000) than was reported in some recent previous studies, such as SIR = 80.6/100,000 (Fearon et al., 2006a) and SIR = 73.6/100,000(Fearon et al., 2006a, Coid et al., 2008b). There may be three possible explanations for this. First, it is possible that the increased rates among Black African ethnic groups may be attributable to stressors related to migration. According to the Office of National Statistics (2005), there has been an increase of 2.4% in the denominator population for Black African ethnic groups since the 2001 census (ONS, 2011a). This is an indication that a proportion of these groups may be recent migrants, and this was also reflected in this study sample, as the majority of the Black African (83.8%) group were non-UK born.

Second, indicators of social disadvantages and post-migration stresses which are associated with psychosis and commonly reported among migrant cases of psychosis may be important in understanding the elevated incidence of psychosis among the Black African ethnic group (Reininghaus et al., 2010a, Tarricone et al., 2015). Previous research suggests that recent migrants may experience more social disadvantage on arrival in the new environment since there may be tension with regard to cultural bereavement and culture shock, i.e. a discrepancy between expectations and achievement in the host country (Bhugra et al., 2011b). For instance, in this study a sizable proportion of Black African patients were educated to higher (university) level (27.1%) or had student status (14.7%), which indicates a sense of aspiration, yet the level of unemployment was high for this group (65.1%) as it was for other minority groups. This suggests a high level of underemployment and possible status loss. In addition, the gap between aspiration and achievement is further widened when the high expectations about life in the UK are not met given the limited opportunities for social participation. It is also possible that disadvantage and psychosis are symbiotic, such that disadvantage exacerbates symptoms and vice versa in a vicious cycle, the consequence of which for many Black African patients, is deep-seated psychosis and enduring social exclusion.

Third, it is possible that perhaps the level of integration into the UK culture among the Black African group is not the same as the Black Caribbean group, since there is continuous flow of migration within the Black African group, particularly to the London boroughs of Lambeth and Southwark. So this group may occupy the position of an outsider compared with the Black Caribbean group, who seem to be more established for many generations. In a study of a prospective multi-ethnic cohort of adolescents in east London, Bhui et al. (2012) suggested that cultural integration (defined by friendship with own or other ethnic groups) was associated with better mental health. Furthermore, the four-fold increase of psychosis among Black Africans in this study may be explained by their greater differences in physical or behavioural characteristics. These visible differences in the Black African ethnic group may make them more vulnerable to feeling different or excluded in the host society (Cantor-Graae and Pedersen, 2007). This argument was also demonstrated in a systematic review by (Bourque et al., 2011), which showed a higher relative risk of 4.8 of schizophrenia among migrants from countries where the majority is Black compared with the reference population.

Interestingly, an almost double rate of psychosis was observed among White British (37.8 PPY) than that reported in the AESOP study (20.2 PPY). This may be due to methodological issues in relations to accessibility to patients during the case identification for the AESOP study. For example, it may be possible that cases were more accessible in crisis or acute services than via the community services. In the AESOP study, the Black African and Black Caribbean experience included shorter duration of untreated psychosis and these patients tended to experience acute onset of psychotic episodes, hence they were often admitted to hospital or crisis resolution services compared to White British patients (Morgan et al., 2006, Ghali et al., 2012). Therefore, the number of cases identified among the White British group in the AESOP study may have been underestimated. By contrast, the case identification employed in this study points to a more comprehensive search for psychosis cases since by screening the multidisciplinary healthcare professional documented clinical records we were able to identify more persons with clear psychotic symptoms within the study catchment area.

12.5.2 Interpreting the Pathways to care characteristics at first contact for psychosis and relationship to previous studies

Main findings

Findings on pathways to care at first contact for psychosis (using the whole sample) in this study showed that independent of confounders, Black African patients were two times more likely to be hospitalised and three times more likely to be compulsorily detained. Further, the increased risk of compulsory admission was present in both men and women of Black African ethnicity. Meanwhile, early intervention-specific ethnic differences in pathways to care at first contact showed that Black African patients in the EIS group were more likely to be compulsorily admitted (adj. OR = 2.25; 95% CI 1.01 – 5.01). These findings are consistent with previous studies. For example, Mann and colleagues (2014) found that in an early intervention sample of FEP, Black Africans had a five-fold increased risk of compulsory admission and four-fold risk of hospital admission at first contact. Other studies that have used broadly defined Black ethnic groups also showed increased risk of compulsory admission with effect size ranging from OR = 1.35; 95% CI 1.13 – 1.62 (Singh et al., 2014b) to OR = 4.31; 95% CI 3.33 – 5.58 (Reininghaus et al., 2010b). Evidence from the rest of Europe also suggests a similar trend. For example, in a Dutch study Van der Post et al. (2012), having adjusted for a number of confounders, also replicated UK findings that sub-Saharan African patients are more likely to be detained compulsorily (adj. OR = 3.0; 95% CI 1.4 – 6.4) (van der Post et al., 2012).

Meanwhile, in contrast to previous studies (Morgan et al., 2005a, Lawlor et al., 2012, Corrigall and Bhugra, 2013), this study did not find associations between Black Caribbean ethnicity and compulsory admission.

The results also indicated that among other minority ethnic groups, the Mixed ethnic group were also at increased risk of hospital admission (adj. OR = 2.65; 95% CI 0.99 – 7.09) and compulsory admission (adj. OR = 3.20; 95% CI 1.10 – 9.26) at first contact for psychosis. Meanwhile, gender specific ethnic differences in compulsory admission showed that Asian (adj. OR = 4.18; 95% CI 1.02 – 17.15) and 'Mixed' (adj. OR = 8.36; 95% CI 1.67 – 41.85) women were particularly at risk of detention at first contact.

12.5.2.1 Expression of distress and help-seeking – ethnic and cultural differences

To begin with, the cultural difference in relation to the experience of mental disorder and the way in which distress is expressed varies across different cultures and ethnic groups. A vast body of literature exists on the cross-cultural theory of the conception of mental illness, particularly from the anthropological perspective. For example, in some African societies, it has been reported that people believed that illness could be caused either by disease-bearing spirits that struck suddenly and independent of an individual's behaviour or as a result of external forces entering the body, e.g. spirit, germ or disease-carrying object (Lewis, 1971). Furthermore, a review of 11 sub-Saharan African countries showed cross-cultural similarities, particularly in relation to the universal belief in supernatural forces as the primary cause of mental illness (Patel, 1995). Patel's (1995) review also highlights the types of experiences and behaviours believed to characterise madness across African societies, centred on outward disturbed behaviour and on difficulty in social relationships rather than on the inner psychological and emotional dysfunction as is the case in psychiatric classifications. For the Caribbean societies, literature around beliefs about mental illness reflects African traditions as well as religious influence. For example, the African-Caribbean folk beliefs were highlighted by (Laguerre, 1987), who documented that individuals with supernatural powers (e.g. voodoo men, obeah men) are believed to be capable of working magic to cause and cure illness, including mental illness.

Kleinman (1980) proposed that taken together, illness-related beliefs form culturally influenced 'explanatory models' and that help-seeking behaviours logically follow (e.g. a person's deep sense of disturbance is interpreted as a sign of spiritual crisis, in response to which he or she prays and consults a respected religious figure). So it would seem reasonable to acknowledge that pathways to care and help-seeking behaviour are influenced by an individual's cultural appropriateness, previous experiences and attitudes towards services. Although this study did not explore the expression of distress specifically, there is substantial evidence that the process of help-seeking and pathways to care is influenced by the patient and their relatives/friends and how the illness is conceptualised (Bhui and Bhugra, 2002, Anderson et al., 2015). In this study sample, more than a third of the Black African patients were detained compulsorily at first contact for psychosis. It would appear that their model and expression of mental (psychotic) illness differ on a number of

counts. Firstly, it is possible that some behaviours and symptoms are perceived as normal or as having spiritual meanings, more than in other ethnic groups. Evidence from work carried out on mental health, culture and beliefs suggest that ethnic minority group patients were more likely to report supernatural attributes and seek help from spiritual healers (Singh et al., 2015b, Leff, 1988). This 'spiritual' perception of abnormal behaviour is likely to contribute to the delay in medical help-seeking, and it is also likely that a religious and spiritual understanding of the patient's symptoms is being sought in the intervening period until the behaviour becomes unmanageable and urgent help is required. The urgency of help required highlights the crisis state of the illness and health services are more likely to respond with coercive intervention as a way of upholding safety and offering effective treatment. Both patient and relative may become resentful of this experience and therefore this may affect future engagement with mental health services. This possibility appears to be confirmed in the follow-up findings in this study where Black African patients consistently experienced more compulsory admissions during the follow-up period of the study.

12.5.2.2 The pathways to care

In this study, data on source of referral and pathways to care suggest that the way people make contact with and seek help from mental health services may have changed compared with some previous studies. Most previous studies have reported that Black African and Black Caribbean patients were more likely to come in contact with services via the criminal justice system (Ghali et al., 2012, Mann et al., 2014b) and were less likely to be referred by their GP (Anderson et al. 2015; Ghali et al. 2014). This study is one of the few to find no ethnic differences in the criminal justice agency referral or GP referral at first contact with mental health services (Burnett et al., 1999). When the data was stratified by early intervention use, in both EIS and non-EIS groups the proportion of Black Caribbean (14.3% and 11.7% respectively) and Black African (18.6% and 12.0% respectively) patients referred via the criminal justice system were similar to those for White British (14.5% and 17.4% respectively). These proportions are much lower than those we found in the AESOP sample here, and even lower than those reported in previous studies. Evidence of lower levels of GP involvement among the Black Caribbean group was partly consistent with previous research (Bhui and Bhugra, 2002, Anderson et al., 2015). There were no associations between ethnic minority status and accident and emergency referral among the AESOP sample. However,

the findings of increased risk for criminal justice agency referral among Black African and Black Caribbean patients in the AESOP sample analysed in this thesis are consistent with other studies (Mann et al., 2014b, Singh and Grange, 2006), and so is the finding of reduced likelihood of GP referral among the same ethnic groups (Ghali et al., 2012). The findings on accident and emergency referral that showed Black African and Black Caribbean patients were more likely to be referred to mental health services via the emergency route are also consistent with previous research (Mulder et al., 2006, Anderson et al., 2010).

Interestingly, socioeconomic position and involvement of family in pathways to care appear to play a key role in explaining the increased likelihood of minority ethnic group and accident and emergency referral. Several authors have argued that careful consideration must be given to socioeconomic status in studies investigating the relationship between ethnicity and mental health (Das-Munshi et al., 2016, Nazroo, 1997, Kirkbride et al., 2008). Considering the non-EIS group in this study, unemployment and poor education were higher compared with EIS users and AESOP sample. It is possible that the previously suggested explanation of poor understanding of help-seeking among minority ethnic groups may also explain this difference (Anderson et al., 2014a, Bhui et al., 2003, Sass et al., 2009). But this may be difficult to disentangle since psychosis is linked to behavioural problems and affects relationships, and executive functioning may possibly precede unemployment or lack of education qualification, and indeed vice versa.

The widely reported reduced likelihood of GP involvement in pathway to care for Black African and Black Caribbean patients was not evident in this study either in the analyses that considered the whole sample (n = 558) or in the EIS-stratified data (n = 201). The evidence here suggests that both Black Caribbean and Black African patients are now comparable to White British patients in the involvement of their general practitioner on the pathway to care. Two explanations may be possible. First, compared with fifteen years ago, there were no early intervention services in SLaM. The introduction of EIS was anticipated to make a significant contribution to earlier, less coercive care and so improve outcomes. This is demonstrated in an RCT study by Power and colleagues (2007) in which they rolled out a GP education programme and direct access to an early intervention team (the Lambeth Early

Onset Crisis Assessment Team) versus usual care. They found that GPs in the intervention group were more likely to refer patients directly to mental health services and fewer patients experienced long delays in receiving treatment. A number of other endeavours have also been implemented in raising awareness, knowledge and attitudes about mental health problems in the wider community for both medical and mon-medical professionals as part of early detection and intervention (Lloyd et al. 2015). Second, as noted before, some social changes have occurred within the population under investigation in this study and therefore some of the documented factors associated with lower levels of GP involvement in pathways to care for minority ethnic groups – e.g. lack of family involvement in help-seeking or lack of GP knowledge to recognise early psychosis (Ghali et al. 2012) – may no longer be relevant in explaining the difference in pathways to care by ethnic group.

A key source of concern is the fact that 119 patients (21.3%) in this study who were eligible for EIS did not receive it. This violates the National Institute for Clinical Excellence (NICE) (2014) recommendation that adults with a first episode of psychosis (FEP) start treatment in early intervention in psychosis (EIS) services within two weeks of referral. A key consideration is the difference in the proportions of patients with duration of untreated psychosis of more than a year, particularly among the non-EIS group, which may shed some light on possible explanations for this group not reaching early intervention services. In comparison to the AESOP sample, a long DUP in our non-EIS group was evident for 25% compared with 18%. In addition, data on type of service use for the non-EIS group showed that the majority of patients were receiving care from specialist mental health services (i.e. perinatal, mother and baby unit). This may suggest that these patients may have experienced other disorders prior to the manifestation of psychosis and therefore these services continue to treat them for initial presenting disorder as well as psychosis. This is a plausible explanation since there are mostly women in our non-EIS group. However, delays in reaching early intervention services have been previously reported. Birchwood and colleagues (Birchwood et al., 2013) in a cross-sectional study of DUP and care pathways sought to investigate DUP and their link with delays in accessing specialist EIS. In a sample of 343 patients recruited from an EIS, they found an overall mean DUP of 260 days. However, a third of the sample had a DUP greater than six months; these were patients whose first

contact with mental health services was generic care, e.g. a community mental health team. They found that delay in reaching EIS was strongly correlated with longer DUP.

12.5.2.3 Compulsory admission

Ethnicity was associated with compulsory admission both during first episode psychosis and at follow-up, independent of age, gender, education and employment status. This was partly consistent with previous research as only the Black African ethnicity was consistently associated with this outcome (Anderson et al., 2015, Bhui and Bhugra, 2002, Morgan et al., 2005a, Burnett et al., 1999). Further, the evidence in this study showed that regardless of early intervention service use, Black African ethnic group patients remained at increased risk of compulsory admissions at first contact.

It is noteworthy that the data here suggest that the disparity between White British and Black Caribbean patients seems to be narrowing as the proportions of compulsory detention between the two groups are now relatively similar (20.5% vs. 24.5% respectively). This may suggest that the factors that contributed to differences in previously reported findings such as lack of understanding of health services, distrust in mental health services and reduced family involvement may no longer be relevant to the Black Caribbean groups. For example, it is possible that Black Caribbean patients have better understanding and trust for the healthcare professionals and services and so may be persuaded to come in voluntarily. Inversely, given that the majority of Black African patients in this study sample were born outside of the UK, it could be argued that perhaps they perceive seeking help from mental health services stigmatising, unfair and discriminatory (Anderson et al., 2013a, Henderson et al., 2015, Gabbidon et al., 2014) and so they may be reluctant to come in voluntarily. .

12.5.2.4 Social isolation / clinical presentation

Findings here showed that shorter DUPs go along with acute onset of psychosis, crisis source of referral and out of hours contact. In turn, this is associated with greater likelihood that the person will be detained compulsorily and in this case it is the Black African ethnic group that were more likely to be compulsorily admitted to hospital. This supports the argument about cultural beliefs about mental illness and expression of distress discussed above, indicating that Black African held beliefs differ markedly from those rooted in mental

health services. That is to say that transition from folk culture into the professional health sector may be challenging for Black Africans. On the other hand, a longer duration of untreated psychosis is a reflection of an onset that goes unnoticed because the person has a limited social network.

12.5.3 Interpreting the Service Use Outcomes at follow-up and relationship to previous studies

Main findings

Findings from the second stage of this study suggest that the course of first episode psychosis is characterised for Black African patients by higher rates of admissions (adj. IRR = 1.98; 95% CI 1.12 – 3.48) involving detention (adj. IRR = 2.27; 95% CI 1.18 – 4.34). This is in keeping with previous research that specifically considered Black African and Black Caribbean as separate groups (Morgan, in press) and those that crudely defined a Black group (Commander et al., 1999, Maden et al., 1999, Goater et al., 1999). By contrast, the evidence in this thesis suggests that service use outcomes for Black Caribbean patients were more benign, which goes against the original hypothesis that higher rates of hospital admissions and compulsory admission would be associated with Black Caribbean ethnicity, a hypothesis supported by only a few previous studies (McKenzie and et al., 2001, Walsh et al., 2002, Harrison et al., 1999). In addition, the hypothesis that over the two-year follow-up period, poorer clinical and service use outcomes would be associated with non-EIS (compulsory admission: adj. IRR = 2.22; 95% CI 1.18 – 4.18 and hospital admission: adj. IRR = 3.30; 95% CI 1.98 – 5.49) compared with EIS status and these will vary by ethnic groups was supported. This is also in keeping with previous studies that showed the effectiveness of EI services compared with treatment as usual (Craig et al., 2004a, Bertelsen et al., 2008a). Meanwhile, the EI-specific analysis of service use outcomes by ethnic group also revealed that for Black Africans, worse outcomes persisted, as they were more likely to have higher rates of hospital admissions (interquartile range = 0–2), compulsory admission (interquartile range = 0–3) and longer stay in hospital (median = 46.5; interquartile range =1–97) compared with White British patients (Tables 11.7 to 11.9). For the Black Caribbean group, the findings only point to the evidence that they were more likely to have a longer hospital stay compared with White British patients.

12.5.3.1 Explaining the difference in service use outcomes: social disadvantages and changes in mental health services.

Making sense of the striking differences in the course and outcomes of psychotic disorder by ethnicity in this study may be considered in two ways. First, over a few decades, the way UK mental health services are structured and provided has changed considerably. Hospital beds have been reduced significantly and there has been a shift towards community-based treatment (Johnson et al., 2001, Tyrer, 2011, Priebe et al., 2008). A number of community-based crisis resolution initiatives such as Home Treatment and Outreach services were introduced in the early 2000s with a view of seeing patients that would normally require acute hospital admission (Johnson et al., 2001). These services are responsible for assessing, treating and supporting people in psychiatric emergencies in their own homes and the services are available 24 hours a day. Consequently, there is focus on hospital admission prevention and speedy discharge. What this means is that for a patient to be admitted to hospital, they have to be extremely unwell, possibly posing danger to themselves and others, and therefore requiring compulsory admission. In addition, the findings in this study are consistent with findings of wider inequalities in many marginalised and disadvantage groups (Marmot, 2005). This draws attention to the social structures and processes, including institutional discrimination that shape access to material resources and health services, which in turn contribute to health outcomes. Further, the findings here on the persistent use of compulsion in Black African patients highlight the disparities in outcomes; health systems as well as social policy can play a vital role in reducing these disparities. Second, the social circumstances surrounding the individual's admission is noteworthy. As has been alluded to in the preceding sections, social network, significant others and accommodation are important in the mental health of an individual. In this study, the Black African patients (16.1%) were among those with high proportion of living circumstances that involved homeless/refuge hostel. Such accommodation can be precarious as places may be given to someone else while the patient is in hospital. In addition, reports of social isolation were common among Black African patients (53.2%). Taken together, this means that patients may spend longer in hospital while accommodation and community support are being sought.

12.6 Alternative explanations

There are further nuances in this thesis that are noteworthy. First, the reduction in the incidence rate and incidence rate ratios for the Black Caribbean ethnic group in this study (IR= 93.6 (74.0 – 113.2); IRR=2.81 (2.15 – 3.68)) compared with those reported in previous studies e.g. AESOP (IR=140.8 (114.4 – 167.2); IRR=6.7 (5.4 – 8.3)) could be explained by considering other factors pertinent to minority groups. For example, cumulative social disadvantage are reported to be associated with increased risk of risk of psychosis for both White British and ethnic minority groups but the impact of such events appears to be more pervasive among some minority groups (Morgan et al., 2008, Morgan et al., 2007). If as speculated previously that the Black Caribbean group may now have multiple generations in the UK, it is possible that, in addition to acculturation, social disadvantage may have attenuated in this group. For example, fifty-five percent of the Black Caribbean patients in this study lived with family/relatives, and living alone is one of the domains of social disadvantage (Morgan et al., 2008).

Further, data in this study suggest that there were no differences between the Black Caribbean ethnic group compared with the White British group on socio-environmental exposures (e.g. social isolation, p=0.37). This could potentially explain the attenuation in elevated incidence rates as well as better pathways to care and outcomes at follow up. For instance, it is plausible that the Black Caribbean group may have developed social networks that encourage a sense of belonging and enriched social relationships through social capital and acculturation (Sharpley et al.2001). This in turn could mean that some of the previously reported beliefs and attitudes about mental illness that are divergent from those held by professionals in mental health services (Morgan et al 2005) may actually be diminishing. This means that, within the Black Caribbean community, there may be more acceptance and recognition of mental illness as a clinical issue that need to be treated medically. Therefore, the initial engagement with mental health services may be seen as a collaboration with healthcare professionals, which then informs subsequent service engagements.

Second, the contrast in the incidence rates in the White British group IR= 39.4 (95% CI=32.2 – 46.6) compared with the earlier studies e.g. AESOP, IR= 20.2 (95% CI=17.8 – 22.7) may be explained by methodological issues regarding the case identification. Given the evidence from previous studies which suggest that compared with White British, Black patients are over-represented in psychiatric inpatients units (Tolmac and Hodes, 2004, Koffman et al., 1997) and are more likely to experience short onset of illness and in turn more likely to present to emergency room or crisis services (McKenzie et al., 2001, Morgan et al., 2006), it can be argued that relying on sampling patients from service contact alone may overestimate the incidence rate in the Black ethnic groups. Further, researchers conducting surveys (in both inpatient and community settings) rely on the goodwill of clinicians to help identify new patients presenting to services for psychosis, which inevitably influences accurate sampling and indeed estimation of incidence rate ratios. Therefore, studies relying on these methods may have inadvertently underestimated the incidence rate of psychosis in the White British group, given they are less represented in inpatient units, where such method is often used (Tolmac and Hodes, 2004). If true, this means that being the reference group, a rise or drop in the rate of incidence for the White British groups will affect the incidence rate ratios in the other ethnic groups. Also if the white group have been under identified in earlier research this could partially account for the attenuated ethnic differences in this study because of the more comprehensive case identification. There is some evidence that this might be the case. A recent study illuminated this issue, where the incidence of psychosis was estimated using data of people aged 16-35 years presenting to six early intervention services based in rural and urban areas of East Anglia, UK (Kirkbride et al., 2017). They reported an incidence rate of psychosis among White British population in urban area as 38.4 (95% CI= 32.8–44.9). This is consistent with the findings in this thesis where the White British group had an incidence rate of 39.4 (95% CI= 32.2 – 46.6).

Third, migration is arguably the single defining marker of health inequalities (Kirkbride, 2017) in epidemiological studies. Despite not controlling for migration status in this thesis, the findings highlight the vulnerability of migrants from sub-Saharan Africa, for instance they perhaps face more stressful psychosocial adversities before emigration compared with those from other regions, irrespective of refugee status (Hollander et al., 2016). Added to

this, negative post migratory experiences such as chronic social defeat and poor quality of life (Karlsen and Nazroo, 2002, Bhui et al., 2003) would also increase the risk of developing psychosis. For example, interpersonal and institutional racism experienced by migrants is deleterious to health outcomes, and previous studies have shown the interconnectedness between racism, discrimination and health inequalities (Karlsen and Nazroo, 2002, Morgan and Fearon, 2007, Chakraborty et al., 2009). Although, more research is needed on this issue. The findings here showed that the majority of Black African patients and Asian women were born outside of the UK and it is within these ethnic groups that the rates of psychosis were highest. So it is intriguing to speculate that the implication of risk factors from migration itself, such as leaving a native country and family or resettlement-related stress (Tarricone et al., 2014, Reininghaus et al., 2008, Bhugra, 2002) may be operating in these groups. Further, the higher incidence rates observed among women is consistent with previous studies (Kirkbride et al., 2016) where the median age at onset typically occurs a few years later for women as a result of a secondary peak of psychosis close to the time of menopause (Grigoriadis and Seeman, 2002). In addition, the increased risk of psychosis among the Asian women in this study could be due to some other social difficulties that have been highlighted as pertinent to this population. These include social isolation, quality of relationship with male partner and lack of English language proficiency (Talbani and Hasanali, 2000, Nilaweera et al., 2014).

Fourth, we found no evidence of an association between compulsory admissions and White Other patients in both AESOP and CRIS-FEP samples. While this finding is consistent with previous studies (Mann et al., 2014, de Wit et al., 2012, van der Post et al., 2012), it is intriguing, given the arrival of a large number of White migrants from Eastern Europe into the UK since the expansion of the EU in 2004. During the same periods Black African people were also arriving in the UK, resulting to around 2.4% increase in the Black African population in London (ONS, 2011). Yet, we found the most striking odds of being compulsorily detained in the Black African ethnic group. This is important, Black African patients may perceive seeking help from mental health services stigmatising, unfair and discriminatory as has been reported in previous studies (Anderson et al., 2013, Gabbidon et al., 2014, Henderson et al., 2015) and so they may be reluctant to come in voluntarily.

However, the association of compulsory admission with Black African ethnicity also draws attention to the social structures and processes, including institutional discrimination that shape access to material resources and health services, which in turn contribute to differences in health outcomes. Our findings of involuntary admission among Black African patients are consistent with findings of wider inequalities in many marginalised and disadvantage groups (Marmot, 2005).

Fifth, the finding that increased odds of compulsory admission were present in those accessing early intervention service suggests that unmet needs still remain in the delivery of service. In principle, early intervention service would take referrals from GPs and also reach out to groups of patients known to have difficulty accessing services, perhaps outreaching to emergency rooms in major hospitals or developing contacts with criminal justice agencies including prison services to detect and divert patients at an early stage of disorder (Jarrett et al., 2012, Fusar-Poli et al., 2013). In addition, some EIS specifically targeted the ethnic minority groups, for example one of the Lambeth Early Onset project's objectives was to reduce levels of disengagement and relapse rates among young black African and Caribbean patients (Craig et al., 2004). It is worth noting that many of these services which started as part of research projects became embedded in the wider health system and hence work-pressure and number of patients on caseloads increased. Therefore, some of the initial gains in terms of improved sensitivity to the needs of ethnic minorities may have been lost. This is reflected in the results of this study where some but not all ethnic minority groups experienced compulsory pathways to care.

Although, there was insufficient evidence of ethnic differences by DUP for the sample overall or when stratified by GP and A&E referral, people who were referred by the GP had longer DUPs, but those seeking help via A&E had shorter DUP and they were more likely to be students and employed. There are a number of possible explanations for this observation. First, it reflects the long wait to see a GP in London that is resulting in higher consultations in A&E for all conditions (Kaffash, 2017). People who are working may well choose the local A&E rather than wait for a GP appointment. An A&E consultation is also the

chosen route taken by many students. The findings might also reflect choice of recent migrants to the UK. Finally it also possibly reflects acuity itself so that those with abrupt onset and/or with socially disruptive behaviours are taken to A&E by alarmed family members.

In addition, the implication of the GP waiting times in recent years, means that the duration of untreated psychosis becomes prolonged. As has been shown previous studies, longer DUP is associated with poorer outcomes (Drake et al, 2000; Bhui et al. 2014; Addington et al. 2015). Data in this thesis supports this argument where we observed that long DUP (OR=2.60; 95%CI=1.34-5.05) was associated with compulsory admission, even among those accessing early intervention services (EIS). However, it is important to note that the majority of the non-EIS patients were already receiving care from specialist mental health services (i.e. perinatal, mother and baby unit), as shown in Chapter 11 (section 11.2.2). This suggest that by virtue of being within the mental health system, these patients will receive treatment for psychosis as soon as symptoms emerge.

Finally, as mentioned in section 10.1, earlier experiences become important in understanding subsequent service use and engagement. This is reflected in the findings for the Black African patients, whose experience of compulsory admission at first contact was sustained two years later. Some of the social factors discussed above could also explain the poor follow up outcomes in this ethnic group.

12.7 Implications for research, policy and clinical agenda

The complexity of the questions that this thesis has attempted to address and the methodology that was employed means that the work has raised many questions to be answered. However, important matters for both the development of future research and policy arise from the work.

One of the most surprising findings in this thesis related to the Black Caribbean ethnic group. First, contrary to previous research on rates of psychosis, the magnitude of risk of

psychosis among the Black Caribbean ethnic group were attenuated than previously reported (Coid et al., 2008b, Fearon et al., 2006a). Second, there was no evidence of association for problematic pathways to care at first contact and poor service use outcome at follow-up for the Black Caribbean group. This raises a concern to explore whether these findings were genuine or were as a consequence of methodological artefact. The similarities in the inclusion/exclusion criteria, ethnicity classification between this study and the AESOP study as well as the inter-rater reliability checks for ethnicity in this study (Kappa score of 0.87, $p<0.001$) would suggest that the finding is genuine. The next concern is to explore the reasons for over-representation of Black Caribbean patients in previous studies. One possibility is that this is a consequence of case identification (i.e. face-to-face vs. case register), which has already been discussed in section 12.5.1. A second possibility is that perhaps the sociodemographic and socioeconomic factors (such as support network, relationship, education attainment, employment opportunity) that influenced the discrepancies in pathways to care and follow-up outcomes between Black Caribbean and White British may be improving as highlighted in section 12.5.1 above.

Another set of findings in this study that were striking was the consistent poor outcome for the Black African ethnic group patients from first contact for psychosis through to two-year service use outcomes. When considered as a process, the evidence showed that experiences and outcomes at earlier stages on the pathway to care influenced outcomes at later stages. So, crisis services involvement (e.g. police /criminal justice involvement, A&E referral), acute onset of psychosis, shorter DUP as well as the presence of social isolation increase the risk of compulsory admission. The second stage of this study, in focussing on pattern of service use following first episode psychosis revealed that Black African patients often followed pathways into and through care that at each point increased the likelihood that hospital admission and compulsory admission would be necessary and that length of hospital stay would be longer.

Some changes in incidence rates may be expected at different time points due to changes in methodological approaches, healthcare delivery and population. The fact that there is evidence suggestive that incidence rates have changed across ethnic groups indicates that change may have also occurred in the association between ethnicity and the associated risks of psychosis. This raises the question about what socio-environmental exposures may have

contributed to the observed differences between Black African patients and their Black Caribbean counterparts.

Furthermore, the shifting socio-political landscape may have consequences for the health inequalities in migrant and minority ethnic groups. For example, as (Bhui, 2016) highlighted, the recent referendum election in which the UK voted to leave the European Union appears to have contributed to an increase in discrimination, prejudice and stigma with some overt expressions of hostility toward migrants and ethnic minority groups. Such experiences are well-known contributors to poor mental health.

12.8 Future research

Further research is needed to explore and examine at community level the extent of mental health awareness and what happens when seeking help. The research would need to consider the potential facilitators and barriers to social capital and cohesion, since it is at the community level that prevention of psychosis and problematic pathways to care may be avoided. Such research needs to reach out beyond the clinic to tackle fears and stigma of minority groups. For example, working with police, prisons, social and primary care sectors to shorten pathways to care and provide social engagement opportunities for families and communities is crucial.

Furthermore, the UK government has pledged to reform and improve mental health care by investing an extra £1 billion per year to put mental and physical health on equal footing, including: helping people with mental health issues stay in work, reducing mortality, enhancing quality of life, monitoring the Mental Health Act etc. These areas of reform will require continuous monitoring to assess the impact and effectiveness of the policies as well as investigate inequalities in outcomes.

The recent advancement within the CRIS database such as data linkage and natural language processing provide opportunities to harness these types of research. This would make it possible to link the cohort of individuals in this study sample to other large databases and infrastructure such as those available from the UK Data Service (UK Data Service, 2017) to investigate social outcomes. Another pioneering work that is ongoing in SLaM and linked to the CRIS system is the Consent for Contact programme (C4C). C4C was developed to facilitate recruitment of patients into mental health research studies (Callard et al., 2014,

Patel et al., 2017). Through this mechanism, it would be possible to identify and invite a proportion of this study cohort to conduct face-to-face interviews for the proposed studies.

The following areas form the possible avenues for future research:

1. Social outcomes: a future study could explore whether there have been improvements in the social and economic position of this study sample, e.g. change in employment, marital status, housing/living circumstances and education.
2. Clinical outcomes: the poor outcomes observed in Black Africans in this study may be a consequence of poor availability of services. It is possible that social factors such as poor housing, social isolation, unemployment, racism and discrimination may well continue to affect outcomes. It is also possible that poor access to treatments such as psychological intervention may also contribute to continuous poor outcomes. Therefore, it is important to continuously monitor the course and outcomes of psychotic disorders, particularly examining ethnic differences in access to and the uptake of therapeutic services, e.g. psychological interventions and service engagement.
3. Physical health outcomes: a future study could investigate the effect of psychosis on physical health (e.g. diabetes, heart disease, cancers) risk factors, looking at the role of psychotropic medication and variations by ethnic group. The linkage between CRIS and the Hospital Episode Statistics (HES) will provide robust data to attempt to address this question.
4. A mixed methods study could be used to describe the views and experiences of people of ethnic minority group and their families in attempting to obtain assistance or treatment for psychosis symptoms. Such study could also explore patients' and families' perception of their community using social capital measures such as trust, attachment, reliance, membership of organisations and volunteering. Such study may also explore the affected individuals' and their families' experience and beliefs about mental illness and expression of distress.
5. Neighbourhood effects on outcomes: evidence has accumulated that implicates socio-environmental risk factors such as ethnic density, isolation and deprivation at neighbourhood level in the aetiology of psychosis and service engagement (Kirkbride et al., 2016, Omer et al., 2016, Schofield et al., 2017, Stain et al., 2017). However,

these studies tend to be cross-sectional in nature; therefore longer-term socio-environmental impact is lacking. Further research is needed to explore the socio-environmental predictors of the course and outcomes of psychosis. Large-scale longitudinal follow up studies can describe service utilisation and the influence of socio-environmental factors both overall and in specific subgroups of FEP populations. They can be used to establish effectiveness of mental health policy in at least two ways: first, by demonstrating increased delivery of evidence-based intervention, and second, by demonstrating whether this results in measurable health gain.

6.

12.9 Conclusions

This thesis was able to confirm that incidence rates of first episode psychosis in the Black African and Black Caribbean populations in two catchment areas in south London are higher than those of the White British population. It also confirms previously reported findings of increased risk of compulsory admission during first contact and poor follow-up outcomes for psychosis among the Black African ethnic group. The risk of psychosis was attenuated for the Black Caribbean group compared with that reported in previous research. This is one of very few studies to have sufficient sample to investigate outcomes in these two Black ethnic groups separately.

There were some interesting similarities and differences that emerged across the three ethnic groups under investigation. More similarities were seen between White British and Black Caribbean groups in the pathways to care and service use outcomes. The main difference for the Black Caribbean group was that they were more likely to have a longer duration of hospital stay, particularly for those accessing the early intervention service. By and large, there were more differences for the Black African group, from inception through to two-year follow-up outcomes in the three key outcome domains that were investigated. The risk of psychosis, hospitalisation/compulsory admission and longer duration of hospital stay were shown to be higher among the Black Africans.

The high incidence rates in the Black Caribbean group cannot be wholly explained by migration, as a majority in this group were born in the UK, although the Black African group were more likely to have been born outside the UK. It is therefore plausible that the Black African group are perhaps subject to risk-increasing factors in the socio-environment of the host country (UK) which may be less common in their home country. So factors like social isolation, unemployment and poor housing become important possible contributory factors in the aetiology of psychosis.

It is clear from this study that ethnic minority groups as well as the majority population are heterogeneous. As Morgan & Hutchinson (2009,) asserted, 'the problem is not "in" migrant populations, it is not "in" psychiatry. The problem is "in" society.' The findings in this thesis have to a great extent supported and demonstrated this statement. It is therefore imperative that the place of social factors should be at the heart of healthcare, whether considered as contributing to aetiology and therefore a target for prevention, as indicators of population health inequalities or as healthcare themselves missing out on key outcomes for treatment.

Whilst the UK society is generally tolerant and welcoming of migrants (Holmes, 2015), some migrant groups experience social difficulties more than others, which in turn have significant impact on their mental wellbeing. Concerted efforts are needed to ameliorate health outcomes for our minority populations. The recent humanitarian crisis in Europe, the Middle East, African and parts of Asia which have contributed to an increase in the number of displaced people, asylum seekers (United Nations High Commissioner for Refugees (UNHCR), 2015), as well as the potential consequences of Brexit (Bhui, 2016) could only herald public mental health issues, which will require urgent attention. Healthcare providers need to move beyond generic health education programmes but work closely with community groups to improve pathways to care for ethnic minority patients. There are opportunities to engage with community leaders and religious groups, who have been found to be significant in how people from some minority ethnic groups seek help for mental health distress (Singh et al., 2015a). Public health programmes that raise public awareness specifically on ethnic minority issues need to be developed and evaluated empirically. We also need to harness opportunities of cross-disciplines to explore the implications of migratory adversities associated with psychosis. For example, integration of

observational data with sociological and ethnographic research would be useful to shed light on the possible pre-and-post-migratory factors that increase psychosis risk among minority ethnic populations.

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APPENDIX 1: FEP Screening Search Commands

```
select d.*,Gender_ID,ethnicitycleaned,Marital_Status_ID from

(

select brcid, start_date as date, comments as notes, Location_udf_6

from event

where contains (comments, '"psychosis*" or "delusion" or "hallucinat*" or "voices" or "psychotic"') and event_category='ward progress note'

union all

 select brcid, start_date as date, comments as notes, Location_udf_6

from event


where contains (comments, '"psychosis*" or "delusion" or "hallucinat*" or "voices" or "psychotic"') and event_category='event'

) d

left join dbo.EPR_Form p on d.BrcId=p.BrcId

where

[date] between '24-Jul-2010' and '30-jul-2010'

and

location_udf_6 like 'lambeth'

and

d.BrcId not in

(Select Diagnosis.BrcId from Diagnosis where

(Primary_Diag like 'F2%'

or Primary_Diag like 'F30.2%'

or Primary_Diag like 'F31.2%'

or Primary_Diag like 'F31.5%'

or Primary_Diag like 'F32.3%'

or Primary_Diag like 'F33.3%')
```

```
and Diagnosis_Date < '01-May-2010')
and
d.brcid not in
(Select brcid from SQLCrisImport.dbo.FEP_Exclude_IDs$)
```

APPENDIX 2: Psychosis Screening Schedule

If the answer to any of the following questions is 'yes' (***must be at least one yes on section A or two on section B***), the patient is considered to screen positive for psychotic symptoms and therefore, is potentially eligible for inclusion.

Section A

Has the patient ever presented any of the following (circle Y or N):

1)	Hallucinations or pseudo-hallucinations in any modality	Y	N
2)	Delusions	Y	N
3)	Marked thought and speech disorder (e.g. incoherence, irrelevance, thought blocking, neologisms, incomprehensibility of speech) other than simple retardation or acceleration	Y	N
4)	Marked psychomotor disorder (e.g. negativism, mutism or stupor, catatonic excitement, constrained attitudes or unnatural posture maintained for long periods) other than simple retardation or acceleration	Y	N
5)	Emergence of marked exacerbation of bizarre and grossly inappropriate behaviour (e.g. talking or giggling to self, acts incomprehensible to others, loss of social constraints etc.)	Y	N

Section B

Has the patient ever presented a definite <u>change</u> in personality and behaviour manifested in any of the following (circle Y or N):

1)	Marked reduction or loss of interests, initiative and drive, leading to a serious deterioration of the performance of usual activities and tasks	Y	N
2)	Emergence or marked exacerbation of social withdrawal (active avoidance of communication with others)	Y	N
3)	Severe excitement, purposeless destructiveness or aggression	Y	N
4)	Episodic or persistent states of overwhelming fear or severe anxiety	Y	N
5)	Gross and persistent self-neglect	Y	N

APPENDIX 3: Data Collection Booklet

Subject number: **2EU02. |__|__|__|__|** **Date of Birth** |__|__|-|_|_|-|
1 | **9** |__|_ |

Date |__|__|-|_|_|-|

2 | **0** |__|_ |

Social (1) Sociodemographics (at first contact)

1. **Gender** **[**O -77 Not Recorded] O1 Male O2 Female
2. **Age** **[**O -77 Not Recorded] |__|__|
3. **Postcode** **[**O -77 Not Recorded] |__|__|__|__|-|__|__|__|__|
4. **Ethnicity** **[**O -77 Not Recorded]

O11White British	O12 White Irish	O13 White gypsy, traveller	O14 Other White
O15 Mixed (w, bc)	O16 Mixed (w, ba)	O17 Mixed (w, as)	O18 Other Mixed
O19 Indian	O20 Pakistani	O21 Bangladeshi	O22 Chinese
O23 Other Asian	O24 Black African	O25 Black Caribbean	O26 Other Black
O27 Arab	O28 Other, specify: _____		

5. **Place of Birth** **[**O -77 Not Recorded]

O1 Austria	O2 Belgium	O3 France	O4 Germany
O5 Ireland	O6 Italy	O7 Spain	O8 Switzerland
O9 The Netherlands	O10 Turkey	O11 United Kingdom	O12 Brazil
O13 Australia	O14 other, specify: _____		

6. **Age of migration (if applicable)** **[**O -77 Not Recorded] |__|__|
7. **Ever employed (paid work)** **[**O -77 Not Recorded] O0 No
   O1 Yes

8. Registered with a GP **[**O -77 Not Recorded] O0 No
O1 Yes

9. Lives with

Alone	Alone, with children	Partner, Spouse	Partner, Spouse, with children	Parents	Other family	Friends	Other: specify (e.g. hostel, halls of residence)	Not Recorded
O1	O2	O3	O4	O5	O6	O7	O8_____	O -77

10. Housing tenure

Privately owned (self)	Privately owned (family)	Rented (Private)	Rented (government)	Other, specify:	Not Recorded
O1	O2	O3	O4	O5_____	O -77

11. Ever had a long-term relationship (one year or more) **[**O -77 Not Recorded] O0 No
O1 Yes

12. Number of children ...? **[**O -77 Not Recorded]
|__|__|

13. Relationship status …?

Single	Married, living with someone	In a steady relationship	Divorced, separated	Widowed	Not Recorded
O1	O2	O3	O4	O5	O -77

14. Highest level of education achieved ...? **[**O -77 Not Recorded]

O1	School, no qualifications	(to end of compulsory education; passed no exams, tests, etc.)
O2	School, with qualifications	(to end of compulsory education; passed one or more exams, tests, etc.)
O3	Tertiary, Further	(first level of non-compulsory education; e.g. A-levels, Baccalaureate)
O4	Vocational	(job related education, e.g. teacher training, plumber, electrician, etc.)
O5	Higher (undergraduate)	(University; first degree)
O6	Higher (postgraduate)	(University: higher than first degree level, e.g. Masters, PhD)

15. Employment status …?

Unemployed	Economically inactive (i.e. house person, physical illness/disability, carer, retired)	Student	Part-time employee	Full-time employee	Self-employed	Not Recorded
O1	O2	O3	O4	O5	O6	O -77

16. Weekly + contact with family **[**O -77 Not Recorded] O0 No
O1 Yes

17. Weekly + contact with friends **[**O -77 Not Recorded] O0 No
O1 Yes

18. Any report of social isolation **[**O -77 Not Recorded] O0 No
O1 Yes

Social (2) Childhood

1. One or both of your biological parents died, before age 17?

1.a. Mother died [O -77 Not Recorded] O0 No O1 Yes

1.b. Father died [O -77 Not Recorded] O0 No O1 Yes

2. Separated from a biological parent (longer than 6 months), before age 17?

2.a. Separated from mother [O -77 Not Recorded] O0 No O1 Yes

2.b. Separated from father [O -77 Not Recorded] O0 No O1 Yes

2.e. What was the main reason for the separation? [O -77 Not Recorded]

O1 Parental Illness | O2 Divorce, Separation | O3 Work | O4 Never knew parent | O5 Own illness | O6 Boarding school | O7 Migration | O8 Other

2.g. Specify other: ……..

	Age					
Before the age of 17 years …	**0-11**			**12-16**		
3. Ever change schools? (other than change to secondary)	O-77 NR	O0 No	O1 Yes	O-77 NR	O0 No	O1 Yes

Notes

	Age					
Before the age of 17 years …	**0-11**			**12-16**		
4. Ever hit/slapped on number of occasions, enough to cause harm?	O-77 NR	O0 No	O1 Yes	O-77 NR	O0 No	O1 Yes
5. Ever sexually abused?	O-77 NR	O0 No	O1 Yes	O-77 NR	O0 No	O1 Yes

If **yes to Q7:**

(1) Perpetrator	(2) Age started	(3) Age ended	(4) Duration yrs	(4) Duration mths	(5) Frequency	(6) Severity	(8) Official contact
☐	_____	_____	☐	☐	☐	☐	☐

If **yes to Q 8:**

(1) Perpetrator	(2) Age started	(3) Age ended	(4) Duration yrs	(4) Duration mths	(5) Frequency	(6) Severity	(8) Official contact
☐	_____	_____	☐	☐	☐	☐	☐

RATINGS		
Perpetrator **1 Both parents; 2 Mother; 3 Father; 4 Sibling; 5 Other relative; 6 Family friend; 7 Other person in household; 8 Other person outside of household**		
Frequency **0 Never; 1 Rarely (once/twice); 2 Occasionally (less than monthly); 3Frequently (monthly+); 4 Very frequently (weekly+)**		
Severity	**Physical**	**Sexual**
0 None	No abuse; Object used without possibility of causing	No abuse; Flashed by stranger; Willing sexual contact

	injury; Pushed, grabbed or shoved	with someone the same age
1 Some	Hit with open hand; Single incidents of being slapped around head or face; Hit hard or repeatedly around body, hard enough to cause injury	Single incidents of non-intercourse abuse; Forced to watch pornography/masturbation; Verbal solicitations by relative/authority figure
2 Moderate	Punched, kicked, bitten, burnt; Implement or object used that could have caused injury	Repeated non-intercourse abuse (touching of own or others' private parts)
3 Marked	Life threatened (e.g. gun or knife); Severe/multiple injuries likely; Abuse intense and frequent	Repeated sexual abuse that involved intercourse (vaginal or anal)
Official contact **0 None; 1 Social services; 2 GP; 3 Police; 4 Other (specify)**		

Notes

DUP

Please note the most accurate date!

- In case only information about the *year of onset* is available, please note the 1st of July of that year as date of onset
- In case only information about the *month of onset* is available, please note the 15th of that month as date of onset

Date of onset psychosis:

First day of onset of psychotic symptoms

Onset of psychotic symptoms is defined as: Clear evidence of delusions, hallucinations, first rank symptoms, catatonic symptoms (i.e. A score of 2 for a psychotic symptom in Part II of the SCAN OR a score ≥ 4 on PANSS items P1, 'delusions', P3 'hallucinatory behaviour', P5 'Grandiosity', P6 'Suspiciousness' or A9 'Unusual thought content').

Date of contact with mental health services (for FEP)

(day/month/year): **[**O -77 Not Recorded] ☐☐ – ☐☐ – ☐☐☐☐

Date of onset psychosis: **[**O -77 Not Recorded] ☐☐ ☐☐ ☐☐☐☐

Mode of Onset

O1 Abrupt onset definable to within hours or days

O2 Acute onset definable to within 1 week

O3 Moderately acute onset definable within 1 month

O4 Gradual onset over period up to 6 months

O5 Insidious onset over period greater than 6 months

Pathway to Care

1 Mode of Contact

(Secondary Mental Health Service)

0 = Community; 1 = Home treatment; 2 = In-patient (voluntary);

3 = In-patient (compulsory); -77 = Not recorded

2 MHA Section (if applicable)

1 = Section 2

2 = Section 3

3 = Section 4

4 = Section 5(2)

5 = Section 5(4)

6 = Section 37

7 = Section 37/41

8 = Section 47

9 = Section 48

-77 = Not recorded

2a. MHA Sec 136/135

0= No 1= Yes -77= Not recorded

3 Source of Referral

1 = General practitioner; 2 = Nurse, other health worker, or social worker;

3 = Accident and Emergency; 4 = Police; 5 = Courts; 6 = Prison;

7 = Other, specify; -77 = Not recorded

4 Contact out of hours

0 = No 1 = Yes -77 = Not recorded

5 Family Involvement

0 = No 1 = Yes -77 = Not recorded

6 Police or CJA Involvement

0 = No 1 = Yes -77 = Not recorded

Family History

[O -77 Not Recorded]

1. Evidence of history of mental illness in first degree relative? O0 No O1 Probable O2 Defini

If probable or definite, complete following for each affected relative:

No.	Relative (1 Father; 2 Mother; 3 Sibling; 4 Child)	Age	Treatment (1 GP; 2 Social worker; 3 Other)	Treatment setting (1 Inpatient; 2 Outpatient; 3 Medication only)	Reliability of information (1 Good; 2 Fair; 3 Poor)	Type of Disorder
1.						
2.						
3.						
4.						
5.						

Substance Use

1 Ever smoked/used cannabis?	[O -77 Not Recorded]	O1 Yes	O0 No

APPENDIX 4: Follow-up Data Extraction

Outcome data on hospital admission, service use, compulsory admission, length of stay and diagnosis.

```
SELECT [brcid]
  ,[gender]
  ,[postcode]
  ,[ethnicity]
  ,[employment_status]
  ,[age]
  ,[higehesteducationlevel]
  ,[registeredwithgp]
  ,[hospitaladmissions]
  ,[Firstadmission]
  ,[noofadmissions]
  ,[Psychosocial_intervention]
  ,[Currentcontactwithpsychiatricservices]
  ,[CurrentTeamorward]
  ,[dischargedfromslamservices]
  ,[referraldischargedate]
  ,[referraldischargedestination]
  ,[CAT_Therapies]
  ,[CBT]
```

```
  ,[Counselling]
  ,[Eclectic_Approcahes]
  ,[Family_Therapies]
  ,[Group_therapy]
  ,[Mentalisation_therapy]
  ,[No_Therapy_Offered]
  ,[Other_therapy]
  ,[play_therapy]
  ,[Therapy_Offered]
 FROM [SQLCrisImport].[dbo].[vw_sho_cohort_base]
GO
```

Appendix 4a, Data on hospital admission pattern

```
SELECT [BrcId]
  ,[dateofadmission]
  ,[dateofdischarge]
  ,[mhastatusonadmission]
  ,[wardtype]
  ,[admissionsource]
  ,[mhastatusduringadmission]
  ,[Police_or_CJA_involvement]
  ,[Adult_Acute_inpatient_wards]
```

```
  ,[Forensic_Acute_inpatient]
  ,[PICU136_Suite]
  ,[Rehab_wards]
  ,[Triage_Wards]
 FROM [SQLCrisImport].[dbo].[vw_sho_cohort_admissions]
GO
```

Appendix 4b, Data on compulsory admission pattern

```
SELECT [BrcId]
  ,[dateofadmission]
  ,[dateofdischarge]
  ,[mha_section_start_date]
  ,[mha_section]
 FROM [SQLCrisImport].[dbo].[vw_sho_cohort_mhasection]
GO
```

Appendix 4c, Data on community service use pattern

```
SELECT [BrcId]
  ,[episodestartdate]
  ,[episodeenddate]
  ,[locationname]
  ,[group]
  ,[Referralsource]
  ,[Assessment_and_Treatment]
  ,[CMHTs]
  ,[Early_intervention]
  ,[Forensic_community_teams]
```

```
  ,[Home_Treatment_Crisis_Resolution]
  ,[Outpatients_Day_services]
  ,[Psych_Liaison_A_and_E]
  ,[Psychology_team]
  ,[Rehab]
  ,[Specialist_teams]
  ,[Supported_Housing]
  ,[Grp_136Suite]
 FROM [SQLCrisImport].[dbo].[vw_sho_cohort_team_episode]
GO
```

Appendix 4d, Data on clinical course and diagnosis

```
SELECT [brcid]
  ,[cn_doc_id]
  ,[source_table]
  ,[diagnosis_date]
  ,[primary_diagnosis]
  ,[Secondary_Diag_1]
  ,[Secondary_Diag_2]
  ,[Secondary_Diag_3]
  ,[Secondary_Diag_4]
  ,[Secondary_Diag_5]
  ,[Secondary_Diag_6]
 FROM [SQLCrisImport].[dbo].[vw_sho_cohort_diagnosis_structured]
GO
```